FAMILY MATTERS

The rise of the Dutch family movement in mental health care 1960 - 2000

irene geerts

Family matters

The rise of the Dutch family movement in mental health care 1960-2000

PROEFSCHRIFT

ter verkrijging van de graad van doctor
aan de Open Universiteit
op gezag van de rector magnificus
prof. dr. Th.J. Bastiaens
ten overstaan van een door het
College voor Promoties ingestelde commissie
in het openbaar te verdedigen

op vrijdag 25 oktober 2024 te Heerlen
om 16.00 uur precies

door
Irene Maria Anna Elisabeth Geerts
geboren op 18 juli 1969 te Etten-Leur

Promotores:
Prof. dr. G. Blok, Open Universiteit
Em. prof. dr. E.M.A. van Boven, Open Universiteit

Leden beoordelingscommissie:
Prof. dr. W.G.J. Duyvendak, Universiteit van Amsterdam
Prof. dr. M.S. Parry, Vrije Universiteit Amsterdam
Em. prof. dr. J. Vijselaar, Universiteit Utrecht
Prof. dr. A.E.R. Bos, Open Universiteit
Dr. J.Th.W. Oosterholt, Open Universiteit

Family matters

The rise of the Dutch family movement in mental health care
1960-2000

Irene Geerts

Voor mijn lieve familieleden en vrienden van wie het leven werd en wordt getekend door de psychische kwetsbaarheden in henzelf of in hun dierbaren.

For my dear family members and friends whose lives were and are determined by the mental vulnerabilities in themselves or in their loved ones.

Family matters. The rise of the Dutch family movement in mental health care 1960-2000

ISBN 978-94-93391-44-4

Copy editing: Kim Hajek, Clear & Correct Editing
Cover design: Willum Geerts
Layout and design: Indah Hijmans, persoonlijkproefschrift.nl
Printed by Proefschriftspecialist | proefschriftspecialist.nl

Editing and printing of this dissertation was financially made possible by the Open Universiteit and José Vissers.

Table of contents

Introduction

“ ‘Maar dokter,’ zei ik kwaad, ‘u kent me niet en u heeft al dadelijk een oordeel over mijn gedrag tegenover Raf klaar. Ik zie u voor het eerst. Ik vind het onaangenaam dat ik steeds een andere psychiater te spreken krijg, die meteen klaar staat met zijn beschuldigingen. Wat weet u eigenlijk over de moeilijkheden thuis? Hele gezinnen gaan kapot, omdat ze met iemand in hun midden moeten leven met wie niet te leven valt. [...] *Daardoor komen er steeds meer overspannen gezinnen en moeten ook daarvan weer mensen worden opgenomen.’*
‘Zo ligt het niet,’ antwoordde hij belerend. ‘Het is het gezin dat het geestelijk zwakke gezinslid kapotmaakt.’”[1]

(“ ‘But, doctor,’ I said angrily, ‘you don’t know me, and you have already made your judgement regarding my behaviour towards Raf. This is the first time I see you. I find it unpleasant that every time, I get to speak to a different psychiatrist, who is ready to confront me with his accusations. What do you really know about the difficulties at home? Entire families are destroyed because they have to live with someone in their midst with whom it is impossible to live. [...] As a result, there are more and more burned-out families, and some of those people have to be admitted as well.’
‘That is not the case,’ he replied pedantically. ‘It is the family that destroys the mentally weak family member.’ ”)

In 1983, Sera Anstadt published her memoir *Al mijn vrienden zijn gek* (All My Friends Are Crazy). It was her personal account of what it was like to deal with severe mental health problems in a close relative, and with the Dutch mental health care system in particular. During the 1970s, psychoses – delusions and hallucinations – had taken over the life of Anstadt’s teenage son Raf. Painful and complicated as that was in itself, Raf’s mental state had also isolated Anstadt from family, friends and neighbours. But what had struck her most, was how she, as the boy’s mother, was treated by the mental health care professionals she encountered. Even though she was her son’s primary caregiver, she was denied even the most basic information about what was wrong with him, and shut out of any consultation with his therapists. And more often than not, in the conversations

---

[1] Sera Anstadt, *Al mijn vrienden zijn gek. De dagen van een schizofrene jongen* (’s-Gravenhage 1983) 60-61. Raf is a pseudonym.

she tried to have with them, she was blamed – either in a veiled and implicit way, or as bluntly as in this quote – for having caused her child's suffering.[2]

It is not incidental that the book was widely read and was reprinted many times.[3] The early 1980s was the time when relations of people with severe mental health issues who, like Anstadt, felt overburdened, blamed and powerless, started to find their voice in protest and to organise. They were dealing, often 24/7, with the consequences of the psychosis, autism, anorexia nervosa, addiction or other serious mental health problem from which their loved one suffered, and shouldering the bulk of their care. Instead of being met with compassion and support, however, these relatives had the experience that they were unseen and unheard by care professionals, left to their own devices, and blamed and stigmatised in mental health care settings as well as in their community and society at large.

Between 1980 and 1985, relatives like Anstadt joined forces in several organisations that laid the groundwork for the Dutch family movement in mental health care: In Perspektief (In Perspective, 1981),[4] Ypsilon (1984), and Labyrint (1985). Widening the definition of mental health care to include addiction care, the Landelijke Stichting Ouders van Drugsverslaafden (LSOVD, National Foundation Parents of Drug Addicts, 1980), can be considered part of the same development. What was new about all of them was that they challenged mental health care policies and practices in the Netherlands from *their* perspective, the perspective of the relations. This book tells the history of the rise of this family movement in Dutch mental health care.

The burden on the family

Severe mental health problems not only touch the life of an individual, but the lives of close family members and friends as well. Many of us sooner or later experience the worries, the confusion, the anxieties, the tensions, the grief, the guilt, the practical and financial consequences and the burden of care that can take over a relative's life. Of course, such problems come in all shapes and sizes, and the corresponding burden on the person who suffers from them, and those close to that person, varies accordingly. But the extent to which relations are willing and able to deal with that burden depends not

---

[2] Anstadt, *Al mijn vrienden zijn gek*.

[3] Esther Hageman, 'Sera Anstadt 1923-2008', *Trouw* 5 November 2008.

[4] In Perspektief was not established as an independent foundation under that name until 1990. The organisation started in 1981 as a working group of the Algemeen Diakonaal Bureau van de Gereformeerde Kerken (ADB, General Diaconal Bureau of the Reformed Churches) and operated under the name In Perspektief from 1988 onwards. For the sake of readability, I will often refer to them as In Perspektief even before 1988.

so much on the character of the problems in themselves, but on how the consequences weigh on them, relative to their capacity to cope.

This model of the balance between burden and coping capacity *(draaglast en draagkracht)*, a concept that is commonly used in mental health care,[5] was introduced to the Dutch historiography of psychiatry by Joost Vijselaar.[6] Vijselaar defined the burden on the family as the severity of the problems that result from the patient's worrisome behaviour, and the coping capacity as the ability to endure such behaviour, put up with it, live with it, and care for the person suffering from it.[7] As long as the 'coping scale' is sufficiently weighted, a family can manage, but if the 'burden scale' tips the balance, relations run the risk of collapsing. I would like to widen the definition of this burden to include the consequences of lack of (professional) support and care, stigma (both the stigma directly targeting the person with the mental health issue and the stigma that affects their relations by association) and other problems linked to, but not caused by the mental health problems themselves. The idea of the critical balance between burden and coping capacity is helpful to understand the experiences of relations in a historical perspective.

Mental health issues have always been a part of the human condition, but how we cope with them, today as well as in the past, is very much defined by how we look at them. How a society deals culturally with mental health problems can add to or lighten the burden: it makes a difference, for example, whether someone in a psychotic state is considered crazy, ill, criminal, possessed or holy. In turn, this interpretation can weaken or strengthen the coping capacity of the relations, as it influences to what extent families dealing with such issues are stigmatised, blamed, or, on the contrary, supported. How a society deals culturally with mental health issues has also varied throughout history, and the experiences of people with mental health problems and their relations have varied accordingly. These variations stem from differing beliefs on what the problem is exactly, what it should be called, and how it should be solved or prevented. Those beliefs have differed through time, influencing the experiences of the people who suffer from them and their relations.[8]

---

[5] See for example P.C. Kuiper's widely used textbook for psychiatrists-in-training *Hoofdsom der psychiatrie* (Utrecht 1973) 187. With thanks to Koen Hilberdink.

[6] Joost Vijselaar, *Het gesticht. Enkele reis of retour* (Amsterdam 2010) 84, 120-122, 326-330. Vijselaar develops his balance concept from psychiatrist Gerbrandus Jelgersma's concept of *sociale onmogelijkheid* (social impossibility) from 1928.

[7] Vijselaar, *Het gesticht*, 121.

[8] Edward Shorter, *A History of Psychiatry: From the Era of the Asylum to the Age of Prozac* (Chichester 1997); Joost Vijselaar & Ruud Abma, 'Psychiatrie in meervoud. De wetenschappelijke oriëntaties van de Nederlandse psychiatrie in het interbellum (1918-1940)', *Studium* 3 (2010) 79-81; Owen Whooley, *On the Heels of Ignorance: Psychiatry and the Politics of Not Knowing* (Chicago, London 2019).

Since the late eighteenth century in the Western world, a specialised branch of medicine has developed to help people with severe mental health problems: what we have come to call psychiatry. Its practitioners optimistically set out to find cures for mental suffering, but to this day, understanding the fundamental causes of severe mental health issues and finding effective cures for them has turned out to be quite elusive. Nonetheless, by the late nineteenth century, psychiatry's institutions overflowed with patients from families where the balance had tipped. As a result, many of these places turned into overcrowded, underequipped depositories rather than places of healing, which widened the gap between promise and practice even further.[9]

Whenever psychiatry has fallen short of people's needs and expectations, those with mental health issues and their relations have challenged the professionals they deemed responsible. In the United Kingdom, Germany and France, this resulted in patient-led mental health movements as early as the mid-nineteenth century. Their criticisms were directed towards poor practices and mistreatment in asylums, but also towards families conspiring with doctors to have their unwanted members locked away.[10] In the Netherlands, in this period, voices were raised in protest too. The best documented case is that of Johanna Stuten-te Gempt, who in the 1890s published three brochures in which she exposed the mistreatment she and her former fellow patients had had to endure in a clinic in The Hague. Locked up in cold, damp, dark and stinking wards, patients were scolded, laughed at and severely physically abused by their caretakers, as well as by the single, omnipotent doctor in the facility. All communication between Stuten-te Gempt and her supportive family was blocked, until her son was able to force her release.[11]

The publication of the brochures led to great public outrage. Fellow ex-patients and their relations confirmed Stuten-te Gempt's experiences with their own. As a consequence of public indignation, the hospital's superintendents and board were fired and improvements were made.[12] In Stuten-te Gempt's view, however, these improvements were only superficial and did not really change the hardships endured by patients. She

---

[9] Vijselaar, *Het gesticht,* 151, 330-331; Andrew Scull, *Madness in Civilization: A Cultural History of Insanity from the Bible to Freud, from the Madhouse to Modern Medicine* (London 2010); Andrew Scull, *Desperate Remedies: Psychiatry's Turbulent Quest to Cure Mental Illness* (London 2022).

[10] Roy Porter, 'Anti-Psychiatry and the Family: Taking the Long View' in: Marijke Gijswijt-Hofstra & Roy Porter, *Cultures of Psychiatry and Mental Health Care in Postwar Britain and the Netherlands* (Clio Medica volume 49; Amsterdam, Atlanta 1998) 257-281, 261-263; Nick Crossley, *Contesting Psychiatry: Social Movements in Mental Health* (London, New York 2006) 53; Alexandra Bacopoulos-Viau & Aude Fauvel, 'The Patient's Turn: Roy Porter and Psychiatry's Tales, Thirty Years on', *Medical History* 60 (2016) 1, 1-16, 13.

[11] Corrie van Eijk-Osterholt & Kurt Bökenkamp, *Wartaal van een gek. Het schokkende verhaal van Johanna Stuten-te Gempt* (Den Haag 1983).

[12] Van Eijk-Osterholt & Bökenkamp, *Wartaal van een gek*, 8-21.

kept insisting on improving care, on involving the family of those who were hospitalised and on putting an end to stigma:

"Nogmaals: geef de patiënt goed voedsel, behandel hem menselijk, ontneem hem zijn vrijheid niet; niemand heeft het morele recht zijn medemens op te sluiten als in een kooi, zolang er nog andere en betere middelen bestaan waardoor hij – als dat nodig is – tijdelijk zichzelf en de maatschappij geen nadeel kan berokkenen. Geef hem ook altijd de toegang tot zijn familie naar wie zijn hart verlangt. Niets is dommer en wreder dan de patiënt te vervreemden van zijn familieleden. Tenslotte zou ik het zeer wenselijk achten dat als een patiënt het gesticht heeft verlaten, hij eens wat meer respect zou mogen ondervinden van zijn medeburgers die hem doorgaans als het ware buitensluiten en door laster en verdachtmaking zijn leven in een hel herscheppen."[13]

("Again: give the patient good food, treat him humanely, do not deprive him of his freedom; no one has the moral right to lock up his fellow man as in a cage, as long as there are other and better means by which – if necessary – temporarily he cannot harm himself and society. Also, always give him access to his family, whom his heart longs for. Nothing is more stupid and cruel than alienating the patient from his family members. Finally, I would consider it very desirable that when a patient has left the asylum, he should be granted a little more respect from his fellow citizens, who usually exclude him, as it were, and make his life hell through slander and suspicion.")

Although Stuten-te Gempt's individual protests gained support from fellow (ex-) patients and relations, this did not lead to collective action, let alone in the setting up of organisations or the birth of a movement. That kind of activism developed in the Netherlands over the course of the second half of the twentieth century. The earliest initiatives organised from below in the Dutch mental health care field were mutual support groups and anti-stigma campaigns that were set up, from the 1960s onwards, in ways that protected the anonymity of all involved. They can hardly be categorised as activism, but they were certainly activities set up and run by people with severe mental health issues and their relations, and directed against isolation and stigmatisation. In the 1970s, the first activists started to chip away at the taboo by speaking out openly about their experiences with mental suffering. Besides stigma and lack of support, they added new issues to the agenda – most importantly, the low quality of care in institutions and

---

[13] Van Eijk-Osterholt & Bökenkamp, *Wartaal van een gek*, 94-95. Stuten-te Gempt's words were rewritten in contemporary Dutch by the book's authors.

the lack of legal rights of patients there. To underline their empowerment, the most vocal members of the new movement rejected the term ‘patient’ and referred to themselves as *cliënten,* clients or consumers of mental health care. In this clients’ movement, people who (had) suffered from mental health problems and their relations advocated together for the interests of all users of mental health services, especially those confined to institutions.[14]

In the early 1980s, however, relations started to present themselves as a party of interest in their own right, and established their own separate organisations. Through these new organisations, they demanded that close relations should be acknowledged as distinct stakeholders in mental health care, on the individual level as well as on the collective level of care practices and policies. In claiming their position at the table, relations and their organisations did not deny that individuals with mental health issues could have good reasons for not wanting their relations involved in their care or therapy, especially when there was a history of neglect or abuse. As Labyrint founder Linda Horn put it, family could be a *“zeer trouwe en onmisbare ondersteuner,* [...] *liefdevolle platdrukker of* [...] *meedogenloze moller of een combinatie van dat al”* (a “very loyal and indispensable supporter, [...] loving squasher or [...] ruthless crusher or a combination of all that”).[15] The point was that when a person got in severe mental trouble, this had serious repercussions for those close to that person too, and these relations also needed and deserved a say and support.

Wondering about the Dutch family movement: research questions

This book uncovers the origins and the establishment of the family organisations of the early 1980s in the Netherlands – organisations that, taken together, I approach as a social movement. It also includes their predecessors: organised family actions and activism in the mental health care field before 1980. These predecessors can be considered a different kind because they did not explicitly represent the relations’ voices – in the 1950s and 60s, the earliest, anonymous initiatives by relatives emerged, while in the 1970s, relations allied with patients and ex-patients to form the first openly activist organisations of

---

[14] A.J. Heerma van Voss, ‘De geschiedenis van de gekkenbeweging. Belangenbehartiging en beeldvorming voor en door psychiatrische patiënten (1965-1978)’, *Maandblad Geestelijke Volksgezondheid* 33 (1978) 6, 398-428; Adrianne Dercksen & Sonja van ’t Hof, *Erkenning gevraagd. Organisaties van patiënten, cliënten en hun familie in de geestelijke volksgezondheid* (Utrecht 1996) Chapter 2; Petra Hunsche, *De strijdbare patiënt. Van gekkenbeweging tot cliëntenbeweging. Portretten 1970-2000* (Haarlem 2008).

[15] Linda Horn, ‘Antwoord’, *Maandblad Geestelijke Volksgezondheid* 42 (1987) 1, 63.

'clients', consumers of mental health care. The main question that guides this history is how the Dutch movement of the relations of people with severe mental health issues arose and took shape over the second half of the twentieth century. Five sub-questions will guide the analysis: Which experiences triggered the mobilisation of relations of people with severe mental health issues? Which socio-cultural factors facilitated their action? What initiatives did relations take and how? How were their organisations received in the mental health care arena? And what were the beliefs underlying their actions and interactions in that arena?

The family movement in mental health care was not exclusively of or for family members – unmarried partners, close friends and neighbours who shared their fate as well as other allies were just as welcome. I therefore use the word 'relation' as a shorthand for all of them. 'Relation' in my eyes comes closest to the Dutch word *naaste*, that includes all close relations of a person and therefore is the term the Dutch family movement prefers. As 'relations' movement' would be a confusing term, I translate *naastenbeweging in de geestelijke gezondheidszorg* as 'family movement in mental health care', but again with the explicit notion that this is the movement of all those who are closely involved in the life of a person with severe mental health problems, whether they are related by blood or marriage or not.

For these relations' loved ones, I use the terms 'patient' and 'client', depending on the historical context, alternating them with a phrase like 'person with mental health issues' when possible. I am aware that the more correct English equivalent of the term *cliënt* in this context would be consumer or user (of mental health care services), but I prefer to stay closer to the terminology that the Dutch movement chose back then and is still using today. In the 1960s, 70s and 80s, people with an intellectual disability were most commonly referred to in the Netherlands as *geestelijk gehandicapten* (mentally handicapped people).[16] To avoid anachronism, that is the term that I will use in the historical context too.

A first sketch of the Dutch family movement

What I term the Dutch family movement in mental health care of the early 1980s, was in fact a handful of independent organisations that each advocated on behalf of their own particular constituencies, in their own way. To members of the organisations themselves, during the first fifteen to twenty years of their existence at least, it did not

---

[16] Aartjan Ter Haar, Sander R. Hilberink & Alice Schippers, 'Shifting terminology and confusing representations. An examination of intellectual disability terminology in Dutch newspapers from 1950 to 2020', *Alter* 17 (2023) 4, 31-52, 35.

feel like they belonged together. Some were very aware of each other, others less so. Sometimes organisations first tried to collaborate, then soon after rejected each other forcefully, such that the idea that they formed a movement would have been far from their minds.[17] Despite that, as sociologist Nick Crossley has argued, organisations like these can nonetheless be defined as a movement. In his study of the British movement in mental health care, Crossley used sociological concepts to define social movements, as "emergent discourses within a society or subsection of society which constitute or connect to a political demand". These movements are not considered as actors, however – it is the organisations in them that are. Crossley defines these "social movement organisations" as "any group, network, organisation or collective project which has a discrete identity within a field of contention; that is, a collective formation that either thinks of itself as distinct or is recognised and known as such in the field".[18]

Disagreement and even conflict between social movement organisations is not only common, it is also vital in how they develop their ideas and identities. In their interactions, social movement organisations circulate ideas and in doing so develop their own norms, narratives, discourses and identities.[19] These norms, narratives, discourses and identities are based on common points of reference that allow organisations to agree on what they disagree about. That is how a movement develops a culture of contention, according to Crossley, "a sense of being a social world in its own right".[20]

But viewed from the retrospective and birds-eye viewpoint of the historical researcher, social movement organisations can share more than that. Although it may have been largely overshadowed by their mutual disagreements, when the Dutch family organisations emerged, they most certainly had a common cause: that the suffering of relations of people with severe mental health issues should be recognised, that relations should be supported in dealing with their difficult situation, and that they should have a say in mental health care matters. That common cause justifies examining them in conjunction and calling them a movement. Which does not mean they were all the same – on the contrary.

When talking about family organisations in mental health care in the Netherlands, the first and often only name that comes up is Ypsilon, the association set up by and for relations of people with chronic psychosis in 1984. In a way, that is strange, as Ypsilon's

---

[17] Linda Horn already spoke of a *familieledenbeweging* (family member movement) in 1990, but the term does not seem to have stuck back then. L.M. Horn, 'Met recht betrokken', in: L.M. Horn, O.P.F. Oldenburg & J.H. Scholma-Hofdijk, *Met recht betrokken. Verslag van het eerste lustrumcongres van de Stichting* Labyrint, *gehouden in samenwerking met de sectie gezondheidsrecht van de juridische faculteit van de Vrije Universiteit op woensdag 9 mei 1990* (Utrecht 1991) 55-57.

[18] Crossley, *Contesting Psychiatry,* 4, 14, 19.

[19] Crossley, *Contesting Psychiatry,* 22-23.

[20] Crossley, *Contesting Psychiatry,* 29.

initial focus was not on the empowerment of the relations, but on improving the fate of 'their patients', as they referred to their loved ones – if the patient was doing well, the motto went, so was the family.[21] What made Ypsilon the face of the family movement of the 1980s, seems to have been its strong opposition to the clients' movement of the 1970s. That prominence has also resulted in this organisation being mistakenly seen as standing for the entire family movement in mental health care by many, including historians.[22]

At the same time that Ypsilon appeared in the early 1980s, however, two other family organisations emerged which also mobilised relations to help and educate each other in mutual support groups, advocate for their interests and protest against practices and policies in psychiatry that were detrimental to them. First, the Algemeen Diakonaal Bureau van de Gereformeerde Kerken (ADB, General Diaconal Bureau of the Reformed Churches) started a working group in 1981 that would develop into the independent Christian foundation In Perspektief. Second, in 1985, the anti-stigma organisation Stichting Pandora (Pandora Foundation, Pandora for short) set up Labyrint, a religiously neutral foundation. These two organisations were open to relatives no matter what mental health issue their loved one suffered from, unlike Ypsilon, which exclusively focused on families dealing with chronic psychosis or schizophrenia. Together, these three organisations have formed the heart of the Dutch family movement in mental health care ever since. Ypsilon, In Perspektief and Labyrint still exist, though nowadays In Perspektief and Labyrint comprise one organisation under the name Naasten Centraal (Relations Central).

No matter how broad the definitions of mental health problems that In Perspektief and Labyrint deployed, addiction tended to fall outside their scope. Taking a somewhat wider perspective on mental health issues by including addiction allows us to see that In Perspektief, Ypsilon, and Labyrint were preceded in 1980 by the LSOVD (Landelijke Stichting Ouders van Drugsverslaafden, National Foundation Parents of Drug Addicts), the organisation that I consider the first of the family organisations of the early 1980s. They were all preceded, however, by family members taking initiatives in mental health care that did *not* identify relations as a separate interest group. In the 1960s, spouses organised anonymously in Al-Anon (a branch of the Alcoholics Anonymous) and a 'father-of' founded Pandora, while in the 1970s, parents and (ex-)patients banded together in an unspoken, self-evident bond to set up the Cliëntenbond in de Welzijnszorg (Clients' League in Welfare Care, Cliëntenbond for short), the Nederlandse Vereniging voor Autisme (NVA, Dutch Association for Autism) and the Stichting Anorexia

---

[21] Interview Bas van Raaij 21 June 2018; interview Bert Stavenuiter 27 January 2022.

[22] Gemma Blok, *Baas in eigen brein. 'Antipsychiatrie' in Nederland 1965-1985* (Amsterdam 2004) 187-190; Harry Oosterhuis & Marijke Gijswijt-Hofstra, *Verward van geest en ander ongerief. Psychiatrie en geestelijke gezondheidszorg in Nederland (1870-2005) Band II* (Houten 2008) 927-929.

Nervosa (Anorexia Nervosa Foundation). Including these predecessors in this history of the Dutch family movement in mental health care helps to shed more light on the movement's origins and early development.

Likewise, the Dutch associations that parents of mentally handicapped people set up in the 1950s are a point of reference that also deserves some attention, and the same goes for the Alzheimerstichting (Alzheimer's Foundation), founded in 1984 in support of people caring for a loved one with dementia. These organisations arose outside of the mental health care arena, in the separate care sectors that over the second half of the twentieth century developed for the mentally handicapped and the elderly, respectively.[23] It was not until the 1990s, however, that the separation of these groups in specialised care facilities was completed. Thus, until well into the 1980s, patients of all categories could still be found in the same psychiatric hospitals.[24] And although the categories were considered separate by most professionals even before the Second World War, it took decades for the general public to become acquainted with them. That explains, for example, how the Dennendal affair – the early 1970s conflict over the Dennendal home for mentally handicapped people – was seen by many as exemplary of the entire Dutch mental health care sector.[25] In other words, the mental health care arena into which the family organisations of the early 1980s stepped, was to a significant extent still undifferentiated. That is why I cast the net wide in this book.

Part of the bigger picture is also that I consider the family movement a separate branch of the larger clients' movement – known in Dutch as the *cliëntenbeweging* – that preceded them by a decade. Again, this will be debated: Ypsilon, to give the strongest counter-argument, was and is considered an adversary of the clients' movement of the 1970s, and certainly not an ally. But there was more to the Dutch family movement than that, as this book will show: it was partly *a reaction to* and partly *a product of* the clients' movement. To look at it as a counter-development as well as a continuation will not only allow us to see the family movement in all its facets, but also to understand its complexities and dilemmas.

These may be awkward or even offensive choices for those who were or are active in any of these realms, as they may not feel these organisations belong together in any way. I hope that over the course of reading this book, they will come to appreciate the wider context too, as it may be informative as well as inspiring to discover how relations in situations that may have been of another category, but with important parallels to their own, have dealt with care professionals, scientists, policy makers and politicians, public opinion and each other in the past.

---

[23] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 523-532.

[24] Vijselaar, *Het gesticht,* 328-330.

[25] Blok, *Baas in eigen brein,* 28-29; Evelien Tonkens, *Het zelfontplooiingsregime. De actualiteit van Dennendal en de jaren zestig* (Amsterdam 1999).

The scientific relevance of this history

Defining the Dutch family movement in mental health care is one thing, justifying the value of studying its history is quite another. Are these organisations important enough to make the effort worthwhile? Most people have never heard of them, and neither have historians paid attention to them, even though a lot of the Dutch historiography of the 1960s, 70s and 80s is focused on the protest culture of that era, and the Dutch clients' and family movement in mental health care was very much part of that culture.[26] Especially for the vocal, colourful and influential clients' movement, that is a bewildering observation.

Ignoring more modest social movements like the family movement presents a problem, however. In their focus on the young, hip and free-spirited, these historians have missed the protests of other, older, less fashionable fellow citizens who also found themselves in a marginalised position and decided to confront the establishment. The protests of the family organisations in mental health care may have been less eye-catching, but in challenging issues they were confronted with as a result of changes in mental health care policy and practice, as well as societal phenomena such as stigmatisation and secularisation, their demands and ideals were no less grand. From this point of view, this study has new insights to offer not only to the historiography of psychiatry, but also to the general historiography of the Netherlands: by challenging historians to look beyond the most noticeable protestors and take into account activism of less conspicuous groups in society too.

In addition to how little the Dutch family movement in mental health care is known, its small size could be an argument to dismiss it as a subject deserving of historical research. Despite the ubiquity of mental health problems, the membership of the family movement was and is small in numbers – a fact that has puzzled some of its initiators too.[27] In 1996, when the number of clients' and family organisations in the Netherlands was booming, Adrianne Dercksen and Sonja van 't Hof calculated the membership of all family organisations in mental health care at around twenty-five thousand; a very small number compared to the four hundred thousand people who at that point were institutionalised or in outpatient care.[28]

---

[26] For example Hans Righart, *De eindeloze jaren zestig. Geschiedenis van een generatieconflict* (Amsterdam 1995); James Kennedy, *Nieuw Babylon in aanbouw. Nederland in de jaren zestig* (Amsterdam 1995); *Jouke Turpijn, 80's dilemma. Nederland in de jaren tachtig* (Amsterdam 2011); Duco Hellema, *Nederland en de jaren zeventig* (Amsterdam 2012); Piet de Rooy, *Alles! En wel nu! Een geschiedenis van de jaren zestig* (Amsterdam 2022).

[27] Bob van Amerongen, 'Ouders van drugsverslaafden: van schuld naar verantwoordelijkheid. Een terugblik op tien jaar', *Maandblad Geestelijke Volksgezondheid* 44 (1989) 2, 115-124, 117.

[28] Dercksen & Van 't Hof, *Erkenning gevraagd,* 20.

With such a low representation rate, it could be argued that the Dutch family movement should remain the mere footnote in the history of psychiatry that it has been so far. After all, from these numbers, one could conclude that most people probably did not have issues with mental health care, or did not feel the need for more support. Certainly, not everyone who has suffered from the consequences of a loved one's mental health problems has had life-defining bad experiences, let alone experiences that have made them rise up in protest. Most mental health professionals choose their profession out of a genuine wish to help people who suffer, and many have been able to provide valuable support. But history has also shown us that in an ambitious yet overwhelmed sector such as this one, even good intentions have backfired, and that tunnel-vision instead of a genuine eye for patients and relations can do very serious harm. As Owen Whooley has put it:

> *"Psychiatrists have committed horrifying abuses and then turned a blind eye to these horrors. They have also sat with patients in the throes of delusions and offered an empathetic hearing. They have joined an air of quackery with expressions of genuine sympathy for society's most marginalized. They have been prone to hyperbolic optimism toward the newest fads and then shock when such fads prove empty, or, worse, harm those under their care."*[29]

But in order to explain why the membership of the family organisations was and is relatively small, there are other factors to consider too, as will become clear over the course of this book. First, the burden of care for a person with mental health problems could stand in the way of becoming active in an organisation, or make volunteers disappear whenever the situation at home took a turn for the worse. Second, financial circumstances (often aggravated through loss of income as a consequence of the mental health problem or the burden of care) could make it hard for people to donate or pay membership fees, and although all organisations offered reduced rates and free activities to those who could not afford them, some felt too uncomfortable to participate under those terms. Third, stigma and disinterest by mental health professionals and the media could stand in the way of the organisations becoming known and reaching their target groups. Fourth, and certainly not least, stigma could also be a reason why relations could be afraid to join an organisation – what would the neighbours think if they found out?

The small size of the family organisations limited them in their possibilities to create awareness, attract more volunteers and members, and attract (financial) resources. As a result, they found themselves caught in a vicious circle, staying small or even disappearing when government subsidies were withdrawn. Still, the fact that only a small fraction of all relations of people with severe mental health issues actually joins a family

---

[29] Whooley, *On the Heels of Ignorance,* 6.

organisation justifies us in questioning to what extent the organisations represent these family members. But paradoxically, it is precisely the discrepancy between the potential and actual membership that underlines the movement's significance.

Although only a small proportion of relations organised, what their movement has accomplished has affected all of them. This book does not assess the achievements of the family movement, but the fact is that today the combined clients' and family movement in mental health care is an acknowledged party of interest, taking part in all kinds of consultative bodies, committees and projects in which mental health care policies are made.[30] In fact, as Dercksen and Van 't Hof have argued for the clients' and family movement as a whole, their significance far transcends their arguably small formal constituencies. They offer recognition of peoples' problems, and ways to overcome shame and isolation. They point out the shortcomings of mental health care and contribute to improvements from which all Dutch people can benefit. And they are important in the continued battle against ignorance and stigma associated with mental health problems.[31]

That the Dutch clients' and family movement has successfully claimed its position in the mental health care field is also a source of worry, however, for today's activists: has their movement been swallowed up, become an instrument in the hands of policy makers instead of a critical thorn in their side? In recent years, voices inside the movement have started to appeal to their fellow members to take a more outspoken stand again, to push their own agendas instead of follow those set by others and to draw inspiration from the actions of their predecessors.[32] But in order to be able to draw that inspiration from history at all, the movement needs its history to be uncovered. For the family movement, that starts with the quickly fading history of its origins.

The historiography on families dealing with mental suffering

In the Dutch historiography of psychiatry, the perspective of the relations of people with severe mental health issues has long been largely absent. The last fifteen years, however,

---

[30] Dercksen & Van 't Hof, *Erkenning gevraagd,* 86-87; Trudi Nederland, Jan Willem Duyvendak & Margaret Brugman, *Belangenbehartiging door de patiënten- en cliëntenbeweging. De theorie* (Utrecht 2003); Marian Vink & Daan Stremmelaar, *Krachtige mensen in beweging. Geschiedenis van de patiënten- en cliëntenbeweging in Amsterdam* (Amsterdam 2022).

[31] Dercksen & Van 't Hof, *Erkenning gevraagd,* 86.

[32] Vink & Stremmelaar, *Krachtige mensen in beweging;* 'Perspectiefsessie Crisis in de ggz; Een kans voor de cliëntenbeweging?', https://wijzijnmind.nl/agenda/perspectiefsessie-crisis-in-de-ggz-een-kans-voor-de-clientenbeweging accessed 22 February 2023; 'Historici als activisten in de cliëntenbeweging', http://www.irenegeerts.nl/historici-als-activisten-in-de-clientenbeweging/ accessed 22 February 2023.

have been marked by a modest but significant 'family turn'. Using patient files from three institutions between 1890 and 1950, Joost Vijselaar reconstructed the workings of institutions in his book *Het gesticht* (The Institution, 2010), squeezing as much information as possible out of the dossiers about the lived experiences of patients and their relations.[33] Vijselaar found that the majority of the families in his sample survey tried to manage at home as long as they could, and had their loved one return home as soon as they thought they could manage again. Martje aan de Kerk focused on the early modern period in her dissertation *Madness in the city* (2019), reconstructing from seventeenth- and eighteenth-century notary records the ways families back then dealt with mentally ill loved ones in the cities of Amsterdam, Rotterdam and Utrecht.[34] Even though the urban care system was growing considerably, Aan de Kerk concluded that the family remained pivotal in organising care. Both of these studies present a detailed, empathic view of what families endured and undertook in the face of mental suffering in one of their members.

These researchers highlighted the way most families carried the burden of care for their own for as long as they could, in reaction to how, in the international historiography, families had been presented in a negative light since the 1960s. Before then, they were simply overlooked: just like medical history in general, the history of psychiatry used to be a 'history of doctors'.[35] Reflecting the unquestioned authority of those doctors and the belief in scientific progress that was typical for the age, this history was about asylums, the development of treatments and medication, the lives and works of psychiatrists, and so on.[36] In the Netherlands, this remained the case well into the 1970s.[37] The historiography from this period, as a consequence, reflected only the perspective of the professional, not that of the patient or that of the relations.

The dominance of the perspective of those in authority was paradoxically reinforced when in the 1960s and 70s, thinkers like Erving Goffman and Michel Foucault started using the history of psychiatry, and that of the asylum in particular, as the centrepiece of their social criticism. In their writings, psychiatry was historically portrayed as an instrument of exclusion and control.[38] Deviant people were subjected and disciplined by

---

[33] Vijselaar, *Het gesticht*; see also Joost Vijselaar, 'Out and In: The Family and the Asylum: Patterns of Admission and Discharge in Three Dutch Psychiatric Hospitals 1890-1950', in: Marijke Gijswijt-Hofstra et al. (eds.), *Psychiatric Cultures Compared: Psychiatry and Mental Health Care in the Twentieth Century: Comparisons and Approaches* (Amsterdam 2005) 277-294.

[34] Martje aan de Kerk, *Madness and the city: Interactions between the mad, their families and urban society in Amsterdam, Rotterdam and Utrecht, 1600-1795* (PhD thesis University of Amsterdam 2019).

[35] Roy Porter, 'The Patient's View: Doing Medical History from Below', *Theory and Society* 14 (1985) 2, 175-198, 175.

[36] Alexandre Klein, 'Never far away. Those Close to the Ill: Key Players in the History of Health', *Histoire social/Social History* 54 (2021) 122, 499-506.

[37] J.A. [van] Belzen & J. Vijselaar, 'The historiography of Dutch psychiatry and mental health care', *History of Psychiatry* 2 (1991) 7, 281-288.

[38] Erving Goffman, *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* (New York 1961); Michel Foucault, *Histoire de la folie* (Paris 1961).

isolating them in remote institutions, labelling their behaviour as symptoms of mental illness and subjecting them to medical authorities exercising power over every aspect of their lives.[39] This way of thinking inspired anti-psychiatry, the deluge of criticism that North-American and Western-European clinical psychiatry was confronted with in the 1960s and 70s.[40] Anti-psychiatry rejected the biomedical model: the approach to mental health issues as illnesses, and to people suffering from them as patients. It rejected clinical psychiatry (in general as well as as a tool of social control in particular) and the negative appreciation of insanity in society. Instead, anti-psychiatry proposed a positive approach to mental health issues, regarding them as a healthy response to an unhealthy environment, and an opportunity for personal growth.[41]

These ideas were reflected in the history of psychiatry – by Andrew Scull, for example, one of the most prominent international authors on the subject. In *Museums of Madness* (1979), Scull wrote about family members as people who were 'dumping' their loved ones in asylums, and part of communities that were 'glad to get rid of' those 'inconvenient', 'unwanted' 'wrecks'.[42] Despite the major impact that anti-psychiatry had in the Netherlands as well, this was hardly reflected in the historiography of Dutch psychiatry. Marijke Gijswijt-Hofstra and Harry Oosterhuis have speculated that the reason for this was that the frame of reference generally was that of the sociological theories of Norbert Elias and Abraham de Swaan, who interpreted mental suffering as a consequence of the stress that comes with changing social relations.[43] A notable exception here was the work of Hans Binneveld, who evaluated Scull's reasoning for the Netherlands and some other European countries in *Filantropie, repressie en medische zorg* (Philanthropy, Repression and Medical Care, 1985). Binneveld concluded that the rise of psychiatric institutions in the nineteenth century had lowered the level of tolerance that Dutch families were able to muster, making them increasingly board-out their mentally ill members.[44] No matter their theoretical background, however, Dutch as well as international historians stuck to the perspective of those in power, whether they were doctors or other authorities.

Although Roy Porter had his roots in the same school of thinking, in the early 1980s he took issue with how it depicted patients and their relations as voiceless victims of the system. In his seminal article 'The Patient's View' (1985), he was the first to raise this issue successfully, pleading for a medical history 'from below':

---

[39] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 775-780; Bacopoulos-Viau & Fauvel, 'The Patient's Turn', 5-7; Marijke Gijswijt-Hofstra & Harry Oosterhuis, 'Psychiatrische geschiedenissen', *BMGN – Low Countries Historical Review* 116 (2001) 2, 162-197, 162-163.

[40] Blok, *Baas in eigen brein,* 10.

[41] Kees Trimbos, *Antipsychiatrie. Een overzicht* (Deventer 1975) 53-66.

[42] Andrew Scull, *Museums of the Mad: The Social Organisation of Insanity in Nineteenth-Century England* (London 1979) 250-252.

[43] Gijswijt-Hofstra & Oosterhuis, 'Psychiatrische geschiedenissen', 192-193.

[44] Hans Binneveld, *Filantropie, repressie en medische zorg. Geschiedenis van de inrichtingspsychiatrie* (Deventer 1985) 194-195.

> *"… it takes two to make a medical encounter – the sick person as well as the doctor; and for this reason, one might contend that medical history ought centrally to be about the two-way encounters between doctors and patients. Indeed, it often takes many more than two, because medical events have frequently been complex social rituals involving family and community as well as sufferers and physicians. Moreover, a great deal of healing in the past (as, of course, in the present) has involved professional practitioners only marginally, or not at all, and has been primarily a tale of medical self-help, or community care. In medicine's history, the initiatives have often come from, and power has frequently rested with, the sufferer, or with lay people in general, rather than with the individual physician or the medical profession at large."*[45]

Porter's call inspired historians around the world to take on the challenge of finding sources in order to research the patient's perspective.[46] In the 1990s, boosted by new research funding and inspired by intense collaborations with Porter and colleagues, historians of Dutch psychiatry were able to follow suit. Most of these studies were histories of institutions in which the patient's view was one of the perspectives, while some publications were dedicated to that view almost exclusively.[47] Interestingly, in one of the edited volumes that was the result of the cross-Channel collaboration, Porter entertained the idea that families used nineteenth-century institutions to get rid of aberrant members.[48] By that time, however, the school of Goffman and Foucault had lost its grip on international debate.[49] That did not automatically mean, though, that the negative view of the family also disappeared. Edward Shorter, for example, wrote his international bestseller *A History of Psychiatry* (1997) from an entirely different point of view, but just as obviously painted the lives of people with mental health problems inside the pre-nineteenth-century family home as hell on earth.[50]

Porter's article was not so much outdated, however, as it was a bridge between the historiography on the family of the 1960s and 70s, and that of the 'family turn'. This family turn originated in the United Kingdom and was a reaction to neo-liberal policies

---

[45] Porter, 'The Patient's View', 175.

[46] Bacopoulos-Viau & Fauvel, 'The Patient's Turn', 2-3; Klein, 'Never far away', 499-506.

[47] Gijswijt-Hofstra & Oosterhuis, 'Psychiatrische geschiedenissen', 162-197; Peter van Lieshout, *Symptomen van de tijd. De dossiers van het Amsterdamse Instituut voor Medische Psychotherapie (IMP), 1968-1977* (Nijmegen 1991); Leonie de Goei, Sonja van 't Hof & Giel Hutschemaekers (eds.), *Curium 1955-1995. Bladzijden uit de geschiedenis van de Nederlandse kinder- en jeugdpsychiatrie* (Utrecht 1995); Cees Willemsen, *Van God los. Geschiedenis van de psychiatrische inrichting Sint-Antonius* (Breda 1997); Gemma Blok & Joost Vijselaar, *Terug naar Endegeest. Patiënten en hun behandeling in het psychiatrisch ziekenhuis Endegeest 1897-1997* (Nijmegen 1998); Catharina Th. Bakker, Gemma Blok & Joost Vijselaar, *Delta. Negentig jaar psychiatrie aan de Oude Maas* (Utrecht 1999); see in addition Michiel Louter, *Uit de inrichting. Vertelde verhalen over tachtig jaar inrichtingspsychiatrie in Nederland (1925-2005)* (Amsterdam 2005); Gemma Blok, *Ziek of zwak. Geschiedenis van de verslavingszorg in Nederland* (Amsterdam 2011).

[48] Porter, 'Anti-Psychiatry and the Family', 269-271.

[49] Blok, *Baas in eigen brein,* 207.

[50] Shorter, *A History of Psychiatry,* 1-4.

of the 1990s calling on relations as informal caregivers – policies that were instigated all over the Western world, including in the Netherlands.[51] The moral appeal to the family to 'take back' care tasks that were 'traditionally' theirs was challenged as a thinly veiled way to cut back on care budgets by replacing professional care with care given not only in, but also by the community. For British historians of psychiatry, that political debate was the starting point from which to investigate the historical role of relations as informal caregivers across countries and across the ages.[52]

This approach resulted in an international trend of research from the family perspective.[53] What these studies showed was that 'traditionally', the care for the mentally ill was not the sole responsibility of the family or the community; instead, even before the introduction of psychiatry around 1800, there was cooperation and interaction between the home front and professional caregivers outside. This new focus on how families historically dealt with their loved ones who were suffering mentally, in the international as well as the Dutch literature, was a crucial addition to a history of psychiatry that had not yet looked beyond the perspective of the professional and the patient to include that of the patient's relatives.

The historiography on social movements in mental health

Historians of psychiatry have been resourceful in finding sources and research strategies that can shed light on the patient and family perspective: they have used patient files, legal documents, letters, diaries, newspapers, and, for more recent periods, oral history interviews. Another way to explore the views of patients and their relations is by studying their social movements. Whereas Johanna Stuten-te Gempt was a lone wolf in the late nineteenth century, since the 1950s people like her and her family have joined forces in organisations that together have grown into a widespread movement in mental health

---

[51] Porter, 'Anti-Psychiatry and the Family', 275; Blok, *Baas in eigen brein,* 208, 216.

[52] Klein, 'Never far away', 501; Peregrine Hurdles & Richard Wright, *The Locus of Care: Families, Communities, Institutions, and the Provision of Welfare since Antiquity* (London, New York 1998), [iii].

[53] David Wright, 'Getting out of the Asylum: Understanding the Confinement of the Insane in the Nineteenth Century', *Social History of Medicine* 10 (1997) 1, 137-155; Peter Bartlett & David Wright (eds.), *Outside the Walls of the Asylum: The History of Care in the Community 1750-2000* (London, New Brunswick 1999); Akihito Suzuki, *Madness at Home: The Psychiatrist, the Patient, and the Family in England, 1820-1860* (Berkeley, Los Angeles, London 2006); Catherine Coleborne, *Madness in the Family: Insanity and Institutions in the Australasian Colonial World, 1860-1914* (Basingstoke, New York 2010); Elizabeth Walker Mellyn, *Mad Tuscans and their Families: A History of Mental Disorder in Early Modern Italy* (Philadelphia 2014); 'Thematic section: The Ill and Those Close to Them', *Histoire Social/Social History* 54 (2021) 112, 491-650. Aan de Kerk, *Madness and the city,* and Vijselaar, *Het gesticht*, represent the family turn in Dutch historiography of psychiatry.

care in the Netherlands. The published and unpublished sources of these organisations, combined with media archives and oral history interviews offer a land of plenty when it comes to the perspective of people with mental health issues and their relations.

However, despite its great influence on Dutch mental health care over the past fifty years, historians have paid surprisingly little attention to the clients' and family movement. To begin with, histories of individual organisations in the clients' and family movement are quite scarce. Valuable contributions come from Master's or PhD students: Arend Benner wrote a detailed thesis on the history of the Nederlandse Vereniging voor Autisme, for example, while Henk Beltman's dissertation on the history of the Dutch care sector for mentally handicapped people also offers some background on the associated parents' organisations.[54] Sometimes historical publications issued by the organisations themselves, on occasion of their jubilees, can also be quite detailed.[55]

As a movement, however, the organisations have barely been studied by historians. Thanks to solid historical publications by journalists and activists, some of the origins of the clients' movement have been spared from oblivion. Arend Jan Heerma van Voss already noted the significance of some of the Dutch organisations in forming a movement in a seminal article from 1978.[56] Some activists inside the movement were equally aware of its historical significance, and documented their organisations and actions for posterity in the early 1980s.[57] In spite of the availability of source material, however, the movement's history has for the most part been told in a schematic or fragmented way, as a part of larger historical[58] or sociological studies.[59] Only journalist Petra Hunsche's books *De strijdbare patiënt* (The Combatative Patient, 2008) and *Herstel*

---

[54] Arend G. Benner, *Streven naar limonade. De NVA als partner in een vertoogcoalitie rond autisme, 1973-2003* (Master's thesis Universiteit van Amsterdam 2003); Henk Beltman, *Buigen of barsten. Hoofdstukken uit de geschiedenis van de zorg aan mensen met een verstandelijke handicap in Nederland 1945-2000* (PhD thesis Rijksuniversiteit Groningen 2001).

[55] Reinhilde van der Kroef, *25 jaar en nog steeds geen normaal mens ontmoet. Pandora, psychiatrie en beeldvorming* (Baarn 1990); Jan Lakeman, *Toevlucht en thuisbasis. 15 jaar Alzheimerstichting* ([Bunnik] 1999); Cees Weber, '25 jaar NVA. Enige kanttekeningen en notities', *Wetenschappelijk Tijdschrift Autisme* 2 (2003) 3, 88-95; Daan Heerma van Voss, 'Bloemen van geluk moet je zelf planten', *Vizier* 48 (2018) 3, 24-37; *Canon Autisme*, https://www.canonsociaalwerk.eu/nl_aut/ accessed 2 December 2022.

[56] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 398-428.

[57] Marjon den Ouden, *Een psychiatrische tegenbeweging in Nederland. Een inventarisatie van tien jaar organisatievormen, akties en tegenpraktijken (1970-1980)* (Amsterdam 1981); Rozemarijn Esselink, Projektgroep Psychiatrische Tegenbeweging & Stichting Pandora, *Tien jaar psychiatrische tegenbeweging in Nederland. Een samenvattend verslag van een inventarisatie van organisatievormen, akties en tegenpraktijken in de periode 1970-1980* (Amsterdam 1982); Becky Fox et al., *Psychiatrische tegenbeweging in Nederland* (Amsterdam 1983).

[58] Dercksen & Van 't Hof, *Erkenning gevraagd*; Blok, *Baas in eigen brein,* Chapter 6; Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 928-929.

[59] Vink & Stremmelaar, *Krachtige mensen in beweging;* Nederland, Duyvendak & Brugman, *Belangenbehartiging door de patiënten- en cliëntenbeweging*; Trudi Nederland & Jan Willem Duyvendak, *De kunst van effectieve belangenbehartiging door de patiënten- en cliëntenbeweging* (Utrecht 2004).

in beweging (Recovery in Movement, 2022) are exclusively dedicated to the history of the Dutch clients' movement.[60]

These authors have also pointed towards the role of the relatives in the clients' movement's origins. In addition, historical studies on other topics have sometimes mentioned the Dutch family movement in passing or dealt with it briefly.[61] The only study that delves deeper, Gemma Blok's dissertation on the history of Dutch anti-psychiatry *Baas in eigen brein* (My Brain, My Choice, 2004), limits itself to the history of one organisation, Ypsilon.[62] In *Verward van geest en ander ongerief* (Confusion of the Mind and Other Discomforts, 2008), Harry Oosterhuis and Marijke Gijswijt-Hofstra mention the fact that more organisations existed, but they mistakenly class the entire movement under the countermovement against anti-psychiatry, in accordance with Blok's writings on Ypsilon.[63] Over the course of this book, however, we will see that the family movement came in more colours than this alone.

International historiography on clients' and family movements in other countries reveal a similar situation. Historians are remarkably absent from the field.[64] Often histories of individual organisations were not written by historians, but by mental health professionals connected to an organisation, such that they have been published in scientific journals for mental health care professionals instead of in the historical realm.[65] In *Die Angehörigengruppen* (The Family Groups, 1984), some early examples of such publications by health professionals across Western Europe were collected.[66] Sociologists have also done important work on the history of the mental health movement in particular countries, like Nicolas Henckes on the French family organisation UNAFAM (short for Union nationale des Familles et Anciens malades mentaux et de leurs associations, National Union of Families and Elders of the Mentally Ill and of Their Organisations).[67] Nick Crossley's *Contested*

---

[60] Hunsche, *De strijdbare patiënt*; Petra Hunsche, *Herstel in beweging. De cliëntenbeweging in de 21ᵉ eeuw* (Amsterdam 2022).

[61] For example, Timo Bolt and Leonie de Goei have wondered why the family movement originated in the 1980s and not ten years earlier, with the onset of the larger mental health movement. Timo Bolt & Leonie de Goei, *Kinderen van hun tijd. Zestig jaar kinder- en jeugdpsychiatrie in Nederland 1948-2008* (Assen 2008) 59.

[62] Blok, *Baas in eigen brein,* 187-190.

[63] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 927-929.

[64] An exception is Jonathan Toms, 'MIND, Anti-Psychiatry, and the Case of the Mental Hygiene Movement's "Discursive Transformation" ', *Social History of Medicine* 33 (2020) 2, 622-640.

[65] E.g. Robert Sommer, 'Family Advocacy and The Mental Health System: The Recent Rise of the Alliance for the Mentally Ill', *Psychiatric Quarterly* 61 (1990) 3, 205-221; Heinz Katschnig, 'Zur Geschichte der Angehörigenbewegung in der Psychiatrie', *Psychiatrische Praxis* 29 (2002) 3, 113-115.

[66] Matthias C. Angermeyer & Asmus Finzen (eds.), *Die Angehörigengruppen. Familien mit psychisch Kranken auf dem Weg zur Selbsthilfe* (Stuttgart 1984).

[67] Nicolas Henckes, *La politique du handicap psychique. Familles, psychiatres et État face à la chronicité des maladies mentales des années 1960 aux années 1970* (s.l. 2011); Nicolas Henckes 'Entre thérapie et oblation. Le discours de l'Unafam sur les familles de malades mentaux (1963-1980)', in: L.

Psychiatry (2006) stands out as a study of an entire social movement in mental health, in this case in Britain, across the spectrum of professional, consumer and family initiatives.[68]

This gap in the historiography may have something to do with doubts as to what extent such organisations can be considered a social movement, a question that Trudi Nederland, Jan Willem Duyvendak and Margaret Brugman have considered.[69] Following Kriesi et al.,[70] they argue that when a movement uses unconventional means, it is a social movement, but when it doesn't, they rather speak of special interest or lobby groups. Following this definition, the clients' movement in mental health care, with its colourful and disruptive public protests and campaigns, would qualify as a social movement, but the family movement would not.

That focus on unconventional means of protest, however, does not do justice to the fact that social movements can be unconventional and disruptive in other ways. They simply must be, in order to make themselves heard in arenas where they have no voice. That is why I feel James Jasper's definition of social movements as "sustained, intentional efforts to foster or impede broad legal and social changes, primarily outside the normal institutional channels endorsed by authorities" is more appropriate here.[71] Before they started organising in the early 1980s, the relations of people with mental health issues were overlooked by the parties that made up the Dutch mental health care arena: mental health care organisations, the government and even the clients' movement that had emerged in the 1970s. The relations simply had no institutional channels at their disposal, leaving them no choice but to start operating from the outside and try to fight their way in.

Another way to disqualify patient's, clients' and family organisations as social movements is to define them as mere mutual support or self-help groups. But as Nederland, Duyvendak and Brugman have shown, mutual support, advocacy and protest are inextricably linked. Like other social movements in health, the organisations in the early family movement had two wings. One wing was directed inwards, facilitating mutual support groups in which people helped each other cope with their difficult situation and empower themselves. The other wing was directed outwards, dedicated to protest and advocacy for change in mental health care and policy, as well as in society at large. The two directions are inseparably linked: in the support groups, an awareness was created that empowered people not only in their personal situations, but also collectively, in how they related to authorities, regulations and structures in society.[72]

Guignard, H. Guillemain & S. Tison (eds.), *Expériences de la folie. Criminels, soldats, patients en psychiatrie, XIXe-XXe siècles* (Rennes 2013) 313-322.

[68] Crossley, *Contesting Psychiatry.*

[69] Nederland, Duyvendak & Brugman, *Belangenbehartiging door de patiënten- en cliëntenbeweging,* 20.

[70] Hanspeter Kriesi et al., *New Social Movements in Western Europe: A Comparative Analysis* (London, New York 1995).

[71] James M. Jasper, *Protest: A Cultural Introduction to Social Movements* (Cambridge, Malden 2014) 14.

[72] Nederland, Duyvendak & Brugman, *Belangenbehartiging door de patiënten- en cliëntenbeweging,* 16-17.

To gain access to the 'normal institutional channels' at that level, the early family movement did not take to the streets, certainly, but it chose its own action repertoire. By developing their own empowering mutual support methods; by using their life and work skills to argue their case before authorities which had ignored them or held their doors closed to them; by confronting scientists on their own turf, grabbing the microphone at conferences and expertly picking their theories apart. Such means may not have been very unconventional, but it took unconventional courage to apply them in an arena in which the relations had no pre-existing place.

Discovering the Dutch family movement: sources and periodisation

When I first started investigating the history of the Dutch family movement in mental health, I expected this story to start in the early 1980s, when the first family organisations – the LSOVD, In Perspektief, Ypsilon and Labyrint – were set up. Soon, however, I realised that relations had been active in the field of mental health for many years prior to that. However, there was a crucial difference with the family movement of the 1980s: prior to that decade, relations did not take action in their own interests as family members, they did so for the sake of their children, siblings and spouses. Looking for that kind of activism made me discover that parents of autistic children were essentially the founders of the Cliëntenbond, the most high-profile Dutch clients' organisation of the 1970s; that the Pandora anti-stigma foundation was initiated in the 1960s by a 'husband-of' and 'father-of'; while the wives of alcoholics, gathered in Al-Anon (the family branch of the Alcoholics Anonymous), preceded them all with mutual support groups dating from the early 1960s. Although these organisations do not belong to the family movement as I have defined it – as a movement that was explicitly about making the voice of the *relations* heard – as precursors they are important to include in this story, because their existence and significance makes the question even more pressing as to what, in the early 1980s, made new groups of relations organise for themselves.

In most clients' and family organisations today, there is very little awareness of their historical roots. As a consequence of stigma, many members remained anonymous, especially in family organisations in the addiction field, making it harder to remember even key figures after they had left. And as these organisations had a high turnover in volunteers, whose home situation could be volatile, that could lead to people coming and going in a quicker succession than in other protest movements, which is also not conducive to retaining organisational memory. Contacting those family organisations still in existence, I found that only very few of them have kept archives that went back further than the early twenty-first century. The only exception is the earliest records of what would later be called In Perspektief, that have been saved in the archive of the ADB, the church organisation that originally founded it as one of its social activities. That there are not more archives, is not surprising. The organisations in the Dutch clients' and family movement, many of which are heavily dependent on government subsidies, have been on the receiving end of budget cuts for a long time. That has forced them to move to ever smaller office spaces and sometimes even to close down altogether, without always finding ways to have their files stored in public archives.

Fortunately, over the years, almost all of them had faithfully sent their newsletters to the Royal Library in The Hague, where they are accessible to the public. In addition, some of the precursor organisations were able to place their materials in an archival institution. For some organisations, the absence of archival sources could be overcome by using media archives and interviewing those who had been there at the start. For others, that start was simply too long ago. In the case of *De Pijler* (The Pillar), an organisation of parents of children with learning and behavioural problems dating back to 1972, I simply did not find enough leads to be able to shed light on its earliest years. In the case of Labyrint, the absence of an archive could be compensated with documents in the archive of In Perspektief, together with which it worked closely from the start. In combination with this, I interviewed more eye-witnesses to Labyrint's early history than I did for any other organisation.

Making the most of the scattered sources that turned out to be available to me, I used oral history interviews, archives and libraries in a mutually reinforcing way. People who had played a part in the history of the family organisations not only told me how they remembered the past, they also pointed me in the direction of essential grey literature finds, or pulled archival materials they had held onto from their own bookcases. Reciprocally, I used archival sources to find additional conversation partners and to corroborate what I was told during interviews. A remark by Ypsilon's Bas van Raaij, for example, prompted me to search for Paul van Trigt of the Cliëntenbond. Then after having interviewed Van Trigt about his time with the league, I realised that the Ypsilon file in the Maasoord psychiatric hospital archives in the Rotterdam city archives held additional material on the secret collaboration between the two organisations that both men told me about.

Combining all sources, I compiled a database of all mental health clients' and family organisations that I could find that were initiated by relations or by allies who from the start collaborated with activistic family members. Overseeing the timeline, I started to discern how family activism had developed in three stages. First, there were the undercover initiatives of Al-Anon and Pandora in the 1960s, when stigma still completely stifled open activism. From 1971 onwards, the first relations came out of the closet to set up the Cliëntenbond, the Nederlandse Vereniging voor Autisme and the Stichting Anorexia Nervosa, in which people with mental health issues and their relations fought together for improvements in care and for patient's rights. And then, in the early 1980s, the relations started to organise for themselves, pointing out in doing so that their interests did not always run parallel to the interests of their children, siblings, parents, partners and close friends with mental health issues. For the sake of practicality, I decided to name each of these stages: the anonymous years, that roughly coincide with the 1960s; the allied years, that almost exactly correspond with the 1970s; and the assertive years, that begin in the early 1980s.

In each stage, I focused my research only on those organisations whose beginnings illustrated the new development. As soon as a new stage commenced, I shifted my attention to the organisations associated with the development that followed. The consequence of that was that new organisations being set up with the characteristics of a previous stage were not part of my research. For example, even though the Nederlandse Stichting voor Manisch Depressieven (NSMD, Dutch Foundation for the Manically Depressed)[73] can be considered a typical exemplar of the solidarity years, it is not highlighted in this book because it was not founded until 1987, well into the assertive years.

The three-stages structure also facilitated my interleaving of an additional category of sources: contemporary novels. As Erica van Boven has argued, best-sellers are unique sources for cultural history, in particular for the history of mentalities. They are products of their time to such an extent that they offer additional insights into societal issues of the period during which they were written and published, as well as into the values that lie behind them, both explicit and implicit.[74] When such literary sources become part of a current debate, however, they not only mirror opinions, in turn, they also shape them. Ideas and mentalities that are implicitly or passively present in society are not only picked up and actively reproduced by authors, but the mentalities connected to them are reinforced and (re)produced by their creative and evocative force. For each chapter, therefore, I selected a widely read work of fiction that had a strong connection to the public debate on mental health of the time.

Illustrative of the 1960s is the novel *Terug naar Oegstgeest* (Return to Oegstgeest, 1965) by Jan Wolkers, for its depiction of how patients in a psychiatric hospital and their relations were regarded by the public during the anonymous years. For the 1970s, I selected the short story ‘Keefman’ (1972) by Jan Arends, which is an expression of how during the solidarity years, patients found their voice in society, while the relations stayed in the background. Just how eager relations in the 1980s were for education on mental health issues is illustrated by *Hersenschimmen* (Out of Mind), a novel by J. Bernlef (1984). The making of Yvonne Keuls's novel *De moeder van David S., geb. 3 juli 1959* (The

---

[73] The NSMD was later renamed Vereniging voor Manisch-Depressieven en Betrokkenen (Association for the Manically Depressed and their Close Bystanders), and is today known as PlusMinus.

[74] Erica van Boven, *Bestsellers in Nederland 1900-2015* (Antwerpen, Apeldoorn 2015) 19.

Mother of David S., Born 3 July 1959, 1980) was not only intertwined with the birth of the Landelijke Stichting Ouders van Drugsverslaafden, the reception of the novel also shows similar difficulties in creating understanding for the position of relatives.

With all the beginnings in place, the question was where to end. Focusing on the origins of the family organisations in the early 1980s, this book should end when they were becoming established, when they were no longer so unconventional and without institutional channels. Scanning the sources, I realised that at some point, the atmosphere changed: when central offices left private homes to move into rented spaces, for example, or when founders were increasingly replaced by professionals and board members who were not experts-by-experience. Of course, that did not all happen at the same time within an organisation, let alone in the family movement as a whole, but in the second half of the 1990s, it is clear that this process had largely been completed in all of them. This impression is supported by the observation Dercksen and Van 't Hof made in 1996, that the clients' and family movement in the Netherlands was changing from a position of *buitenstaanders op de barricaden* (outsiders on the barricades) into one of *binnenstaanders aan tafel* (insiders at the table), because the movement's biggest issues of the 1970s and 80s had become part of the debate on government policies.[75] Although in hindsight, this observation is most appropriate for the clients' movement, towards the turn of the century, the family organisations too were increasingly recognised as a party of interest in mental health care. This study ends, therefore, in the second half of the 1990s.

Experienced health movements

To historians of social movements like the clients' and family movement in mental health care, sociology has a lot to offer. The sociological subfield that studies social movements is very large and well developed. Like historians, however, sociologists have not studied the clients' and family movement very much – neither internationally nor in the Netherlands – despite the fact that sociologists themselves have pointed to the great impact of social movements on health care arrangements,[76] including, or even especially, in mental health care.[77] As we saw, however, those sociologists who have studied social

---

[75] Dercksen & Van 't Hof, *Erkenning gevraagd,* 39, 89.

[76] Phil Brown et al., 'Embodied Health Movements: New Approaches to Social Movements in Health', *Sociology of Health and Fitness* 26 (2004) 1, 50-80, 51; Nicholas C. Smith, 'How can stigma contribute to our understanding of the formation and mobilization of collective identities in health social movements?', *Sociology Compass* 14 (2020) 1-2.

[77] Dick Oudenampsen & Majone Steketee, 'De patiëntenbeweging: van afhankelijkheid naar eigen

movements in mental health care, have contributed considerably to the historiography – the studies by Crossley, Henckes, and Nederland, Duyvendak and Brugman mentioned before, are largely historical studies using a sociological lens.

The theoretical outlook that these sociologists have most often chosen to examine social movements in mental health care, is that of the rational perspectives that were dominant in social movement theory from the late 1960s to the end of the century. In reaction to earlier theories that looked at social movements as irrational actions by irrational people creating chaos, sociologists during this period emphasised the rationality of movements. Resource mobilisation theories, for example, focused on how people started protest movements when they were able to mobilise enough manpower, knowledge, money and other means. And political opportunity structure theories focused on how individuals assessed their chances of success in their decision to mobilise or not. While these rational theories remained important, the 1980s showed the first signs of a cultural turn. Starting with theories focusing on how movements framed their protest, in the following years, sociologists began to highlight cultural and psychological aspects of social movements like emotions, identity and biography.[78] These new approaches, however, did not appear in the aforementioned sociological studies of social movements linked to mental health.

This century, the cultural turn in social movement research has been further developed theoretically and combined with earlier rational insights that had asserted their relevance. In recent years, James Jasper has pointed out that with this elaborate set of tools at their disposal, sociologists have tended to zoom in so much on the social movements themselves, that they risked losing sight of how these movements interacted with the world outside. To counter that, Jasper proposed a 'strategic interaction perspective' that uses the metaphor of players and arenas to illustrate how social movements and the organisations in them are always part of a particular field of contention together with other stakeholders.[79]

---

regie', in: Thijl Sunier et al. (eds.), *Emancipatie en subcultuur. Sociale bewegingen in België en Nederland* (Amsterdam 2000) 76-97, 76.

[78] James M. Jasper, *The Art of Moral Protest: Culture, Biography, and Creativity in Social Movements* (Chicago, London 1997) Chapter 1; Jan Willem Duyvendak, Conny Roggeband & Jacquelien van Stekelenburg, 'Politics and People. Understanding Dutch Research on Social Movements', in Olivier Fillieule & Guya Accornero, *Social Movement Studies in Europe: The State of the Art* (New York, Oxford 2016) 232-249; Deana A. Rohlinger & Haley Gentile, 'Sociological Understandings of Social Movements: A North American Perspective', in: Conny Roggeband & Bert Klandermans, *Handbook of Social Movements Across Disciplines* (second edition; Cham 2017) 9-32.

[79] James M. Jasper, 'Introduction: Playing the Game', in: James M. Jasper & Jan Willem Duyvendak, *Players and Arenas: The Interactive Dynamics of Protest* (Amsterdam 2015) 9-32; Jan Willem Duyvendak & Olivier Fillieule, 'Patterned Fluidity: An Interactionist Perspective as a Tool for Exploring Contentious Politics', in: James M. Jasper & Jan Willem Duyvendak, *Players and Arenas: The Interactive Dynamics of Protest* (Amsterdam 2015) 295-318. Crossley (*Contesting*

This players-and-arenas notion is mirrored by a triadic model that the Dutch family organisations would come to use to illustrate their claim that relations should be included in the conversation on mental health care. In this model, the patient, the family and the professional form a triangle in which they are mutually connected, thus asserting that in individual matters of care, the family could not be missed. Elsewhere, this model was further developed in a way that is also helpful in showing the historical relevance of the family movement: the basic triad was encircled by a ring of stakeholders, like advocacy organisations, health care systems, science, political forces, the media and society in general.[80] This ring is the equivalent of Jasper's arena.

Consequently, Jasper's theoretical notion is also useful in studying the history of the family movement. It prevents the researcher from focusing too much on the movement itself and helps to show how it took shape in interaction with the arena it came to enter, while in turn shaping that arena. In the Dutch mental health care arena of the early 1980s, the family organisations encountered four main players: the media and the public, mental health care and research, the government and the clients' movement. Throughout this book, the interactions of the organisations in the family movement and their predecessors with these players will serve as a structure for tracing the organisations' development.

Although the players-and-arenas perspective is very useful for studying the workings of an arena once it is established, it does not, however, offer a framework that helps to determine what initially sparks a movement that aims to enter a certain arena. A strand of social movement theory that is tailored specifically to health-related social movements *and* primarily focuses precisely on their beginnings, is that of 'embodied health movements'. Building on existing social movement concepts, the theory of embodied health movements was developed by an American research group around sociologist Phil Brown in a series of publications between 2004 and 2012. The great value of their work lies in its great sensitivity to the importance of personal experience: the deep, emotional level on which illness experiences touch a person and can motivate them to activism. Activists in this type of movement frame their organising efforts and critique of the system through a personal awareness and understanding of their experience.[81]

Psychiatry, 16) developed a similar concept of fields of contention, but the players and arenas metaphor makes it easier to grasp. The metaphore has been used before, though, for instance by Beltman, *Buigen of barsten,* 25-27.

[80] Ronda C. Talley & John E. Crews, 'Framing the Public Health of Care Giving', *American Journal of Public Health* 97 (2007) 2, 224-228, 227.

[81] The main publications in which they developed their approach are: Phil Brown et al., 'Embodied health movements' (2004); Phil Brown et al., 'Health Social Movements: History, Current Work, and Future Directions', in: Chloe E. Bird et al. (eds.), *Handbook of Medical Sociology* (sixth edition; Nashville 2010) 380-394; Phil Brown, Rachel Morello-Frosch & Stephen Zavestoski (eds.), *Contested Illnesses: Citizens, Science, and Health Social Movements* (Berkeley 2012).

In their earlier publications on embodied health movements, Brown and colleagues extended these experiences beyond the purely physical and beyond the purely personal: beyond the purely physical to include mental health,[82] and beyond the purely personal to include the experiences of close relations of a patient.[83] Later, they seem to have limited their theory to include a person's direct physical experiences only. The concepts brought together under the heading embodied health movements, however, are very well suited to analysing the origins of the Dutch clients' and family movement in mental health. But to make explicit that I use the theory in a broad sense, applying it beyond the purely physical and personal, I speak of *experienced* health movements.

In this book, I use three concepts from embodied health movements theory to shed light on the very beginnings of the clients' and family movement, on that initial spark. Experience is central to the first: the concept of politicised collective illness identity, or, as I will call it, *politicised collective experience identity*. The experience of mental suffering – in yourself or in someone close to you – can be so intense that it shapes your identity. When people with similar problems come together to share such experiences, they discover they are not alone and can develop a *collective* experience identity. From there, they can conclude that their troubles are not just personal, but point to a structural problem. That is when a *politicised* collective experience identity can develop and make a group mobilise for action. Nicholas C. Smith has argued that such an identity not only comes from within, but also from without: through the stigma a person experiences in their dealings with neighbours, authorities or through the media.[84] We will see that in the story of the family movement, this is very much the case.

The second concept from the embodied health movements package that is helpful for understanding the history of the family movement, is *spillover*. That stands for the strategies, goals and framings that previous movements have developed, that have already led to certain results and that are available to be used or learned from. Think, for instance, of the action repertoire of the women's movement and the *praatgroepen* (discussion groups) they developed. These examples were there to be appropriated, and the family movement did so.

The third and final concept is that of the *dominant epidemiological paradigm*. This will turn out to be so fundamental to the understanding what made the relations mobilise in a separate movement, and why they did so in a fragmented way, that we need to delve into this concept deeper than into the first two. An epidemiological paradigm is defined by Brown and his colleagues as "the codification of beliefs about disease and its causation

---

[82] Brown et al., 'Embodied Health Movements' (2004); Phil Brown et al., 'Field Analysis and Policy Ethnography in the Study of Health Social Movements', in: Jane C. Banaszak-Holl et al., *Social Movements and the Transformation of American Health Care* (New York 2010) 101-116.

[83] Brown et al., 'Embodied Health Movements' (2004).

[84] Smith, 'How can stigma contribute', 6.

by science, government and the private sector".[85] In other words: it is about what we think illness is and what causes it. Those beliefs also have consequences for practice: for diagnosis, treatment and prevention.[86] For example, a professional who operates from the idea that mental health problems stem from biological processes in the body will probably call them an illness, prescribe medication and support research into heredity, whereas a colleague working from the idea that society is the cause might call such problems a healthy reaction to unhealthy societal demands, recommend treatment in a therapeutic community, and support raising children in communes instead of families.

Although in practice, many mental health care workers combine perspectives in trying to tailor their support to each individual's needs, in every time period there is usually one dominant paradigm. Whenever a dominant paradigm is seriously challenged, it starts to shift, creating more space for alternative beliefs or even a new paradigm.[87] But beliefs about disorders and their causation are not only central to the debates among scientists and practitioners, they also shape the experience of patients and those close to them. It makes a huge difference to a mother, for example, whether the mental suffering of her child is interpreted by doctors as a symptom of something wrong in the chemistry of the brain, or as the result of the way she raised her child. When lay people reject a particular scientific interpretation, and start doing so collectively, this forms the basis for an experienced health movement. Indeed, Brown and his colleagues define such movements as "collective challenges to medical policy and politics, belief systems, research and practice".[88]

In my view, the belief systems – the ideas on cause, diagnosis, treatment and prevention – in this definition are more fundamental than the other elements: these beliefs effectively shape medical policy and politics, as well as research and practice. When medical policies and practices are guided by the conviction that mental suffering primarily stems from illnesses of the brain, they will focus on investing in pharmaceutical research, for example, and on medical diagnostic and treatment methods, whereas authorities who believe that mental health problems are mainly caused by social factors will prioritise policies combatting factors like poverty, poor working conditions and stigma.

Brown and colleagues make clear how protest movements on health do not so much have parties as their adversaries, but convictions. What they challenge is medical science and beliefs in all their guises, whether that be in the therapist's office, in research labs,

---

[85] Phil Brown et al., 'Embodied health movements', in: Phil Brown et al. (eds.), *Contested Illnesses: Citizens, Science, and Health Social Movements* (Berkeley 2012) 15-32, 24.

[86] Rachel Morello-Frosch, Phil Brown & Stephen Zavestoski, 'Introduction: Environmental Justice and Contested Illnesses', in: Phil Brown, Rachel Morello-Frosch & Stephen Zavestoski (eds.), *Contested Illnesses: Citizens, Science, and Health Social Movements* (Berkeley 2012) 3-14, 5.

[87] See also Whooley, *On the Heels of Ignorance*.

[88] Brown et al., 'Embodied Health Movements' (2004), 52.

with members of parliament, at the Ministry of Health, in the media or on the street. What they challenge is ideas around the cause, diagnosis, treatment and prevention of mental health problems. What they challenge is the dominant epidemiological paradigm.

These challenges take on a particular sharpness when dealing with mental health issues, because despite its promises, in over two hundred years of research, psychiatry has not come any closer to explaining mental illness, let alone come up with solid remedies. It has basically only been able to identify different dimensions that can play a part in mental suffering, and develop diagnostics, treatment and prevention methods connected to each of these dimensions. Usually, three main dimensions are discerned: the biomedical dimension, that locates the cause of mental health problems in the body, the brain's structure or chemistry, or in a person's genetic heritage; the psychological dimension, that looks for the cause in the individual's psyche and how that has been shaped by life experiences; and the social dimension, that points to society and its demands and complexities as the root of mental suffering.[89]

Although in working with individual patients, mental health care workers usually combine dimensions in order to treat each according to their specific needs, medical researchers and philosophers continue efforts to integrate the dimensions on a more theoretical level too.[90] Historians of psychiatry usually work in the opposite direction: in their analyses, they tend to unravel instead of to integrate the dimensions, thus laying bare the different approaches to mental illness, their influence and their interplay in a certain historical context. They have shown that over the past two hundred years, the three dimensions have functioned as paradigms or explanatory models in psychiatry, shifting in dominance every couple of decades.[91]

These shifts have resulted in a 'disjointed, cyclical' history, as Owen Whooley has put it. Time and again, throughout the history of psychiatry, the field's lack of understanding of its own fundamental expertise, he writes, has been presented as temporary, each time creating hope that a new research direction, rooted in another explanatory model than the one preceding it, will deliver the answers. The hope that something will finally be found to help those who suffer so badly, makes expectations run so high as to create a hype around the 'new' explanatory model. When it fails to produce the promised results, and continues to do so, this invariably ends in a crisis of the entire explanatory model. That is when a shift occurs in the dominant paradigm, and another dimension and its

---

[89] Scull, *Madness in Civilization*; Whooley, *On the Heels of Ignorance*; Scull, *Desperate Remedies*.

[90] Dutch scholars active in this field include psychiatrist and philosopher Gerrit Glas, psychologist Denny Borsboom and philosopher Sanneke de Haan. See for example Gerrit Glas, *Person-Centred Care in Psychiatry: Self-relational, Contextual and Normative Practices* (London 2019); Denny Borsboom et al., 'Network analysis of multivariate data in psychological science', *Nature Reviews Methods Primers* 58 (2021) 1, doi.org/10.1038/s43586-021-00055-w; Sanneke de Haan, *Enactive Psychiatry* (Cambridge 2022).

[91] For example: Shorter, *A History of Psychiatry*; Scull, *Madness in Civilization*.

explanatory model is embraced, recreating the cycle of hope, hype, disappointment, crisis and reinvention.[92] What Brown and colleagues have called shifts in the dominant epidemiological paradigm for medicine in general, Roy Porter for psychiatry has called 'shifts in culpabilization': with every shift comes a fundamental change in ideas on what mental suffering is and what causes it, identifying a different 'culprit' every time.[93]

Joost Vijselaar has traced these historical shifts for the Netherlands, showing how explanatory models exist side by side, but alternate in dominance. Before 1950, social, psychological and biomedical explanations were at work side by side. During the 1950s and 60s, however, the biomedical perspective became dominant, based on optimism about the introduction of the first psychopharmaceuticals. Despite the popularity of new developments in sociotherapy and experiments with halfway housing to bridge the gap between psychiatric hospital and society, the social explanatory model took the backseat to the biomedical one.[94]

A shift occurred when, in the 1970s, the biomedical was rejected and a social and psychological explanatory model became dominant that was tied in with anti-psychiatry and the broader protest culture of the time. Two decades later, this radical model was challenged by an equally fierce, renewed biomedical model, that gained dominance in the early 1990s and has remained dominant until today.[95] In recent years, however, it has been increasingly challenged by psychiatrists who again seem to favour a social perspective: in the Netherlands, Floortje Scheepers and Jim van Os are prominent voices in that debate.[96] That the next paradigm shift may be on hand is already noticable even in the historiography: after having shown derailment after derailment of biomedical, psychological and sociological attempts to find the key to mental health, Andrew Scull concludes in *Desperate Remedies* (2022) that such a key is as far out of reach as ever.[97]

In addition to showing how the biomedical, psychological and sociological explanatory models rose and fell in dominance, Vijselaar also included a fourth category, that predates the age of psychiatry: the transcendent or religious explanatory model.[98] In religious beliefs, the cause of mental suffering can be located, for example, in a lack of faith in God, and

---

[92] Whooley, *On the Heels of Ignorance*.

[93] Porter, 'Anti-Psychiatry and the Family', 275.

[94] Joost Vijselaar, 'Biologische psychiatrie 1850-1900', 'Psychiatrie in meervoud', 'De jaren vijftig' (GGZ Ecademy video lecture series 'Geschiedenis van de psychiatrie' [2019], https://ggzecademy.nl/product/geschiedenis-van-de-psychiatrie/ accessed 1 April 2024).

[95] Joost Vijselaar, 'Antipsychiatrie', 'Psychiatrie als neurowetenschap 1980-2000', 'Einde van de inrichting?' (GGZ Ecademy video lecture series 'Geschiedenis van de psychiatrie' [2019], https://ggzecademy.nl/product/geschiedenis-van-de-psychiatrie/ accessed 1 April 2024).

[96] Floortje Scheepers, *Mensen zijn ingewikkeld. Een pleidooi voor acceptatie van de werkelijkheid en het loslaten van modeldenken* (Amsterdam 2021); Myrrhe van Spronsen & Jim van Os, *We zijn God niet. Pleidooi voor een nieuwe psychiatrie van samenwerking* (Amsterdam, Leuven 2021).

[97] Scull, *Desperate Remedies*.

[98] An aspect that Sanneke de Haan also brought back to the fore in *Enacting Psychiatry*.

the remedy in prayer.[99] In Vijselaar's view, this dimension vanished over the course of the twentieth century – and indeed, with secularisation, this explanatory model may have become obsolete to many Westerners, scientists in particular. But that does not mean that it was not still relevant to religious or otherwise spiritual patients and relations, as we will see in this book. I will therefore keep an eye out for all four of Vijselaar's dimensions.

An overview of this book

In this history, I investigate what sparked and shaped the Dutch family movement in mental health care of the 1980s from the perspective of how family organisations challenged dominant beliefs about mental suffering that had previously marginalised and stigmatised relations. In the process, I will also cover precursors of the movement that entered the stage in the 1950s, 60s and 70s, and continue towards the end of the 1990s to include the years in which the organisations established themselves firmly.

Chapter 1 opens with a brief overview of the origins of the associations of parents of mentally handicapped children, before focusing on the anonymous years of family actions in the 1960s. This chapter highlights the creation stories of two predecessors of the family movement: Al-Anon and Pandora. It uncovers what made people set up these organisations and how, at a time when stigma around mental illness was all-encompassing in the Netherlands, relations faced doctors and nurses whose authority was unquestioned in the mental health arena. For a fictional reflection on how 'the mad' and their relations were regarded by their communities, we turn to Jan Wolkers' novel *Terug naar Oegstgeest* (Return to Oegstgeest, 1965).

Chapter 2 deals with the next generation of predecessors of the later family movement – organisations that were founded in the 1970s, a period I refer to as the allied years. In a society in which marginalised groups were increasingly challenging authorities and inequalities, a movement arose that united people with mental health issues and (their) relations in openly protesting against the lack of patient's legal rights, poor circumstances of care and continued stigma. In this chapter, the spotlight is on the Cliëntenbond, the NVA (Nederlandse Vereniging voor Autisme, Dutch Association for Autism) and the Stichting Anorexia Nervosa. It shows how the relations took the bold step to speak out about their problems in public, how they teamed up with (ex-)patients, and how the established parties in the mental health care arena responded to them. Jan Arends's short story 'Keefman' (1972) serves as testimony to how psychiatric patients in this decade found their voices.

---

[99] Joost Vijselaar, 'Biologische psychiatrie 1850-1900', 'Psychiatrie in meervoud', 'De jaren vijftig', 'Antipsychiatrie', 'Psychiatrie als neurowetenschap 1980-2000', 'Einde van de inrichting?' (GGZ Ecademy video lecture series 'Geschiedenis van de psychiatrie' [2019], https://ggzecademy.nl/product/geschiedenis-van-de-psychiatrie/ accessed 1 April 2024).

In Chapter 3, we arrive at our main subject: the formative years of the Dutch family movement, the early 1980s. The start of these assertive years is told through the histories of the origins of the LSOVD, In Perspektief, Ypsilon and Labyrint. The chapter shows how relations developed the collective spirit they needed to form their own organisations, what triggered them to do so, and which examples were helpful to them. The reception of *Hersenschimmen* (Out of Mind), a novel by J. Bernlef (1984), illustrates how hungry for education relations who were dealing with the severe mental health issues of a loved one were in the 1980s.

Chapter 4 continues to examine the assertive years by tracing how the same four organisations built themselves up during the 1980s and 90s. It deals with how they responded to and interacted with each other, and considers how they were received when they entered the mental health care arena. That arena was still largely shaped by mental health care professionals and researchers, while a retreating government and a rising clients' movement also increasingly gained influence, and the public began to educate itself on mental health matters. Yvonne Keuls's novel *De moeder van David S., geb. 3 juli 1959* (The Mother of David S., Born 3 July 1959, 1980) shows how challenging it was to foster understanding for the position of relations in mental health care.

In the conclusion, I present the results of this historical investigation of the rise of the Dutch family movement in mental health care. The book ends with an epilogue that gives a brief impression of where the family organisations stand today. Are the reasons why a separate family movement emerged back then still valid, or has the movement come full circle?

This book aims to contribute to Dutch historiography of psychiatry in general and that of the clients' and family movement in particular, by capturing the quickly vanishing roots of the family movement. It aims to contribute to the international historiography of psychiatry by offering a building block for future international comparative research and transnational analyses. It aims to contribute to the general Dutch historiography of the 1960s, 70s and 80s, that is so focused on the spirit of liberation of the age, but shows important gaps when it comes to the social movements that embodied that spirit. And last, but far from least: I hope to offer to those who were and are part of the family movement a historical perspective that they find enlightening and inspiring for coming to know more about those on whose shoulders they stand.

Chapter 1

The anonymous years: The predecessors of the family movement in the 1960s

In the historiography of psychiatry, the family has been portrayed as either a positive or a negative force in the life of someone with severe mental health issues. On the one extreme is the family that suffocated, suppressed or even abused its weakest members, played a major role in those members being labelled mentally ill, and preferred to hide them away or cast them out, so they could no longer bring shame to the family.[1] On the other extreme is the family that supported their child, spouse, sibling or parent no matter what, caring for them, dealing with their moods and behaviours, taking over their duties and shielding them from the pressures and reactions of the world outside.[2]

Most families probably just tried to cope from day to day, sometimes for the better, sometimes for the worse. In the Netherlands of the mid-twentieth century, that fundamental experience was no different. Coping was not easy, and not just as a result of the burden that is inherent in dealing with severe mental health problems. It was also dependent on how mental health issues were dealt with, both culturally in society and professionally in mental health care. The average Dutch person of the 1960s knew very little about anything to do with mental health problems or mental health care. As a result, prejudice and stigma ran high. But this also meant that it was difficult for the relations, especially when they were first confronted with a mental crisis in a loved one, to assess the situation and handle it as well as possible. And that did not change greatly when the professionals were brought in. Only sparingly were patients and their relations educated and involved in decisions on treatment and care. Even asking questions about these topics was uncommon, not just in mental health care, but in health care overall. Doctor – and head nurse – knew best, and the patient was best left in their capable hands, for lay people did not understand these things.[3]

---

[1] Edward Shorter, *A History of Psychiatry: From the Era of the Asylum to the Age of Prozac* (Chichester 1997) 1-4.

[2] Martje aan de Kerk, *Madness and the city: Interactions between the mad, their families and urban society in Amsterdam, Rotterdam and Utrecht, 1600-1795* (PhD thesis University of Amsterdam 2019) Chapter 3; Joost Vijselaar, *Het gesticht. Enkele reis of retour* (Amsterdam 2010) 61-67.

[3] Harry Oosterhuis & Marijke Gijswijt-Hofstra, *Verward van geest en ander ongerief. Psychiatrie en geestelijke gezondheidszorg in Nederland (1870-2005) Band II* (Houten 2008) 536-575, 654-663,

While in the 1960s young people increasingly challenged authorities, medical authority remained untouched. In the relationship between psychiatrist and patient, the patient was completely dependent on the benevolence of the doctor, whose expertise and great devotion to the task were unquestioned, and whose freedom to decide what was best for the patient was uncontested. There was no notion that legal rights might be necessary to protect patients in this dependent position. In fact, the limited legislation that was in place, was often circumvented or neglected in practice, for example when patients were involuntarily admitted to a psychiatric hospital based on medical statements that contained barely any information. Patients and their relations had no choice but to put their trust in the professionals, and if that trust turned out to be undeserved, they largely suffered in silence.[4]

What added to the suffering was how the general public regarded people who suffered from mental health problems: large parts of the Dutch population considered patients and ex-patients as incurable, untrustworthy, unpredictable and dangerous.[5] It was painful for relations to see how, after a stay in an institution, their child, spouse or parent was shunned, gossiped about, feared and shut out. In addition, family members were themselves confronted with stereotypes, prejudice and discrimination. As a result, many tried to hide the traces of mental health problems in their loved ones, making up excuses for emotional outbursts overheard by the neighbours, covering up for an alcoholic spouse who could not go to work in the morning, cancelling visits and parties when the situation at home took a turn for the worst. Over time, many patients and relations ended up isolated, even in their own communities.

In a few European countries, the first relations of people with severe mental health problems started to organise and openly challenge a broad spectrum of issues in the 1960s.[6] For Dutch relations, such public activism was too soon. Some, however, found ways to take action against isolation and discrimination, while at the same time protecting themselves and their loved ones from stigma and taboo: by organising anonymously. That was how the predecessors of the family movement arose: wives of alcoholics created self-help groups in which they supported each other, called Al-Anon

---

664-744; Reinhilde van der Kroef, *25 jaar en nog steeds geen normaal mens ontmoet. Pandora, psychiatrie en beeldvorming* (Baarn 1990) 22-24.

[4] P. Laurs, *Recht voor psychiatrische patiënten. Een onderzoek naar de rechtsbescherming voor in psychiatrische ziekenhuizen opgenomen patiënten* (PhD thesis Rijksuniversiteit Utrecht 1988) 37-41; C.A. van Eijk-Osterholt, *Laten ze het maar voelen.... Vijfentwintig jaar belangenbehartiging voor een verpleegde* (Amsterdam 1972) 40-41.

[5] Jan Weima, *Beeldvorming ten opzichte van geestelijk gestoorden* (Leidschendam 1962) 19-24, 75-84; J.R. van Weerden-Dijkstra, *De houding ten opzichte van geestelijk gestoorden. Verslag van een onderzoek* (Groningen 1969) 7, 20-21, 41-43.

[6] See for example Nick Crossley, *Contesting Psychiatry: Social Movements in Mental Health* (London, New York 2006).

(1961), and 'father-of' and 'husband-of' Arnold van Ameringen set up an anti-stigma foundation that he baptised Stichting Pandora (1964).

This chapter uncovers the origins and early years of these organisations. After a brief sideline that shows how parents of mentally handicapped children set up their advocacy organisations in the 1950s when a separate care sector for this group began to develop, we will discover how Al-Anon and Pandora came to be. The relations who founded these organisations were not only restrained by stifling stigma, but also triggered to action by it – by the stigma around alcoholism for Al-Anon, that around mental health issues in general for Pandora. Excerpts from the novel *Terug naar Oegstgeest* (Return to Oegstgeest) by Jan Wolkers will shed more light on what these organisations were up against. There were also sources of inspiration, however, tools and thoughts that helped them on their way – sources that reached them from America. But the fact that these organising relations had ideas and examples to build on, did not mean that their entry in the Dutch mental health care arena was easy. Rather, with the field largely unknown to the public they wanted to reach and protected by the professionals who considered it their exclusive territory, the organisations were not necessarily received warmly.

Awakenings of the predecessors of the family movement in the 1960s

Helpt Elkander (1952), Philadelphia (1956), Het Zorgenkind (1957)

"Wij stuitten op de nood van honderden kinderen: door te weinig op hun speciale behoeften afgestemde verzorging, angstig, chaotisch, soms ontremd, soms contact afwerend, in slechte lichamelijke conditie, in exces gevallen: bezwaard binnen prikkeldraad omheining, varkensschuur of met blik beslagen zolderkamers, soms ook verwaarloosd in ondeskundig geëxploiteerde onderkomens, die de naam van verpleeghuis tot een aanfluiting maakten. Daar is ook de nood van de ouders, door de niet aflatende, voor hen niet alléén te dragen belasting verzand in een vertwijfelde,

("We came upon the needs of hundreds of children: due to care that was not sufficiently tailored to their special needs, fearful, chaotic, sometimes disinhibited, sometimes rejecting contact, in poor physical condition, fallen in excess: held inside a barbed wire fence, pig sty or attic rooms covered with tinplate, sometimes also neglected in inexpertly operated shelters, that made a mockery of the name of nursing home. There is too, the distress of the parents, having gotten stuck in a desperate, sometimes resentful and above all narrowed attitude to life,

> *soms rancuneuze en vooral vernauwde levensinstelling, niet zelden met misplaatst schuldbesef, mede onderhouden door hun falen om hun kind op te voeden, soms zelfs voerend tot onverhulde doodswensen. Dit kan dan door de omgeving weer worden misduid, waarbij soms leken zich te buiten gaan aan fantasieën over erfelijkheid met alle kortsluitreacties van dien."*[7]

> due to the unrelenting burden that they cannot bear on their own, often with a misplaced sense of guilt, partly maintained by their failure to raise their child, sometimes even leading to undisguised death wishes. This can then be misinterpreted by the environment, with laymen sometimes indulging in fantasies about heredity with all the short-circuiting reactions that entails.")

The first relations who joined forces in their own organisations were parents of mentally handicapped children. In the 1950s, the social movement of these parents emerged simultaneously with the independent care sector that, over the course of the second half of the twentieth century, would take people with an intellectual disability out of psychiatry. After the Second World War, the large majority of these children lived at home with their families – a consequence of a lack of places in institutions. Shame and rejection had resulted in many of these families living their lives in isolation. In addition, as psychiatrist and 'parent-of' H.J. Ronner observed in the quote above, the circumstances of the children could be worrisome. No doubt there were families who were able to navigate the challenges and raise the child happily and comfortably. But as the quote shows, there were also a lot of children who were hidden and locked up in an effort to cope with their difficult behaviour, or due to the shame their families felt. Relations were desperate for support and for modern facilities that would help their loved ones blossom.[8]

When that specialised care sector finally began to expand in the 1950s, parents wanted to be involved in order to make sure that it would fit their demands. Hence, it was in this field, adjacent to psychiatry, that the first Dutch family associations arose, set up by parents and teachers who were familiar with the needs of such families. Neatly drawn along the dividing lines that in the 1950s still largely governed social life in the Netherlands, the religiously neutral Helpt Elkander (Help Each Other) was the first such association in 1952, followed by the Protestant Philadelphia in 1956, and the Catholic Voor Het Zorgenkind (For The Worrisome Child) in 1957.[9]

---

[7] Quote from 1962, cited by Henk Beltman, *Buigen of barsten. Hoofdstukken uit de geschiedenis van de zorg aan mensen met een verstandelijke handicap in Nederland 1945-2000* (PhD thesis Rijksuniversiteit Groningen 2001) 154.

[8] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 523-532; Beltman, *Buigen of barsten,* 154; Cees Weber, '25 jaar NVA. Enige kanttekeningen en notities', *Wetenschappelijk Tijdschrift Autisme* 2 (2003) 3, 88-95, 88-89.

[9] Beltman, *Buigen of barsten,* 153-156; Weber, '25 jaar NVA', 88-89.

Although mentally handicapped people had been considered a category of their own since the nineteenth century, only a few specialised institutions had been established. As a result, when their families were no longer able to cope, these people often ended up in psychiatric hospitals.[10] When, in the 1950s, new medical discoveries suggested that certain 'abnormalities' were biochemical or genetic in origin and that some might even be curable, however, the number of new institutions started to grow quickly. Professionals urged parents to send their children to live in such places – the burden of care was considered too much for families to bear, and they would not be able to give the kind of care experts had to offer anyway. As doctors knew best, and there was no alternative, parents often followed this advice, even if they were unhappy about having to send their children to these faraway places where strangers would take care of them.[11]

Those same scientific developments, however, started to empower parents. Not only had the new insights brought about the new institutions, they had also led to the realisation that these children were born in all sorts of families, whereas before, they had been seen as the product of 'bad seeds', of 'degenerate' families associated with poverty, unemployment, alcohol abuse and prostitution.[12] Modern science thus lightened the guilt, blame and shame that had weighed on parents and families, to such an extent that middle-class parents found the courage to stand up and organise. In each other, they found recognition, as well as the spirit to take action.[13]

Helpt Elkander, Philadelphia and Voor Het Zorgenkind started by offering parents mutual support and education, but soon also advocated for better care for their children and spoke out against the stigma that both children and families faced. From the 1960s onwards, the organisations would come to be a major force in the field, both individually and united in the Federatie van Ouderverenigingen (FVO, Federation of Parents' Associations, 1964). The parents criticised the distant locations, large scale and hospital atmosphere of the new institutions. And when boards of directors did not respond to their demands, they took initiatives themselves to build smaller, more homely facilities, closer to home, where their children would enjoy more personal attention and activities. No longer would they allow the professionals to take their responsibility as parents away from them.[14]

The assertiveness that these parents displayed, was not echoed in mainstream psychiatry. The first initiatives there would be very different in nature and cloaked in anonymity.

---

[10] Inge Mans, *Zin der zotheid. Vijf eeuwen cultuurgeschiedenis van zotten, onnozelen en zwakzinnigen* (Amsterdam 2004) 180-181, 173-181; Beltman, *Buigen of barsten,* 39-40, 45.

[11] Mans, *Zin der zotheid,* 180-181, 268-269; Beltman, *Buigen of barsten,* 45, 153-154.

[12] Beltman, *Buigen of barsten,* 56.

[13] Beltman, *Buigen of barsten,* 153-155.

[14] Beltman, *Buigen of barsten,* 153-155; Weber, '25 jaar NVA', 90; Mans, *Zin der zotheid,* 270.

Al-Anon (1961)

“Wij vrouwen van alcoholisten hebben jaren van wanhoop, bitterheid, angst en armoede gekend. Wij hebben veel leed doorstaan wat niemand kan begrijpen, die dat niet heeft meegemaakt. Leed en angst om de man, leed en smart om de kinderen. Onze mannen hebben ons dikwijls belogen en bedrogen. De grote kracht van ons huwelijks- en gezinsleven, de onderlinge steun en het vertrouwen in elkaar, heeft jaren lang een gevoelige deuk gekregen en onze persoonlijkheid is daardoor veel baziger en ook veel egoïstischer geworden. Wij moesten immers jarenlang zelf onze plannen maken – gezinszorgen, financiële zorgen, onderhoud van de kinderen enz. Dikwijls hebben wij veel moeten camoufleren voor de buitenstaanders, voor de familie, voor de eigen ouders, vrienden en kinderen, omdat wij nog een te groot eergevoel hebben om onze man uit te laten maken voor een dronkaard.”[15]

(“We wives of alcoholics have known years of despair, bitterness, fear and poverty. We have endured a lot of suffering that no one can understand who has not experienced it. Sorrow and anguish for the husband, sorrow and pain for the children. Our husbands have often lied to us and deceived us. The great strength of our married and family life, the mutual support and trust in each other, has been severely damaged for years, and our personalities have become much bossier and also much more selfish as a result. After all, for years we had to make our own plans – family worries, financial worries, maintenance of the children, etc. Often we have had to camouflage a lot, for the outsiders, for the family, for our own parents, friends and children, because we still have too great a sense of honour to let our husband be called a drunkard.”)

The dawning of the first family organisation in the Dutch mental health care field is tucked away in the archives so well that even its own members have nowadays lost sight of it. On 10 March 1956, wives of men who suffered from alcoholism founded a self-help group in Amsterdam.[16] The group branched off from the Anonieme Alcoholisten (AA, Alcoholics Anonymous), the now internationally known organisation of people with a drinking problem who support each other in their struggles to stay sober. Initially, the wives’ initiative was simply referred to as ‘the family group’. In 1961, after the first AA World Service Conference, the Dutch family groups adopted the name of their American sister organisation, Al-Anon.[17]

---

[15] ‘Vrouwen aan het woord in de A.A.’, *De Boei* 6 (1961) 2, [2-3, 2].

[16] D.H. Wester, *Lusten en lasten van alcohol* (third edition; Den Haag 1961); ‘De eerste familiegroep aan het werk’, *De Boei* 1 (1956) 12, [1].

[17] Wil-Amsterdam, ‘Een verlengstukje van de AA: Al-Anon’, *De Boei* 6 (1962) 6, [1].

It is unclear to what extent the initiative was taken by the wives of alcoholics themselves. AA was introduced in the Netherlands in 1948, when patients of the Amsterdam Medisch Consultatiebureau voor Alcoholisme (Clinic for Alcoholism) took the suggestion of its director Henk Krauweel to organise regular group meetings using the AA format he had discovered on a study trip to the United States. It is possible that the idea for the family groups was also first raised by Krauweel, or by his colleague and competitor Piet Esser – the two had an ongoing dispute about who deserved the credit for having brought AA to the Netherlands.[18] But it may very well have been an initiative of the wives' own, even without knowing about the American example. L. Timmer, adjunct-director of the Amsterdam Jellinek-kliniek (Jellinek Clinic) in the 1960s, saw wives of alcoholics engage with each other in the waiting room, sharing experiences they couldn't share with anyone else.[19] That might just as well have happened in the clinic's waiting room ten years earlier.

The reason why I can only speculate about Dutch Al-Anon's exact beginnings or the identities of the wives who should be recognised for founding it, is that the sources allow only a very limited view on them. That is not just because the time elapsed means that these people are most likely no longer among us – it is that we simply do not know who they were. In the AA newsletter *De Boei,* the principal historical source on early Dutch AA and Al-Anon, they remain anonymous. That is not surprising: anonymity has always been fundamental in AA and its affiliate organisations. As a consequence, individuals were only referred to in *De Boei* by aliases such as 'Wil-Amsterdam' or simply 'Al-Anonne'.[20]

Early contributions of wives to *De Boei* show the stress they and their families went through when their husbands were drinking.[21] Sitting at home waiting for him to come home, full of fear that he would be drunk again; out of money after his drinking had made him lose his job, while the bailiff was ringing the doorbell; being cast out of their social circle for the shame linked to alcoholism. Fearing for his life, in the worst case scenario, as the story of an anonymous woman illustrates:

---

[18] J.C. van der Stel, *Drinken, drank en dronkenschap. Vijf eeuwen drankbestrijding en alcoholhulpverlening in Nederland* (Hilversum 1995) 310. Both were mentioned in *De Boei* regularly, for example as members of the first advisory board ('Gedelegeerden overzien het jaar', *De Boei* 3 (1959) 4, [4]). However, Krauweel's name appears more often and he is referred to as the 'father' of Dutch AA ('Verslag van het gesprek dat Margreet had met Dammes-Den Haag 7 september 1978', *De Boei* 22 (1978) 10, 14-15), whereas Esser is merely qualified as 'an old friend' ('Opgedragen aan de AA', *De Boei* 4 (1960) 11, [4]).

[19] Hans, 'Mej. L. Timmer, Alcohol ook groot gevaar voor jongeren. Vrouw van alcoholist vaak ook "patiënt" ', *De Boei* 12 (1968) 10, [1-2, 1].

[20] Wil-Amsterdam, 'Een verlengstukje van de AA: Al-Anon', *De Boei* 6 (1962) 6, [1]; Al-Anonne, 'De eerste stap in de Al-Anon', *De Boei* 7 (1963) 3, [2].

[21] [Tonny S.], 'Als een vreemde vrouw', *De Boei* 3 (1959) 4, [2]; De vrouw van een AA-er, 'Ik kan mijn geluk niet op', *De Boei* 3 (1959) 8, [3].

> *"Jarenlang is dat zo gegaan, met een man die financieel en moreel steeds meer naar de zelfkant van de maatschappij ging, steeds dieper de afgrond in. Voor mij en voor de kinderen was er geen uitzicht meer. De dokter had mijn man ook al opgegeven."*[22]

> ("It went like this for years, with a man who financially and morally strayed to the fringes of society ever more, deeper and deeper into the abyss. For me and for the children there was no perspective anymore. The doctor had already given up on my husband too.")

The purpose of Al-Anon, De Boei explained in 1956, was *"familieleden van een alcoholist moreel te steunen in hun moeilijke positie en inzicht te geven in de aard van de ziekte, die alcoholisme heet"* ("to support family members of an alcoholic morally in their difficult position and give them insight in the nature of the illness that is called alcoholism").[23] The groups were open to all relations of alcoholics seeking ways to deal with the problems at home, whether they were in AA or not, whether their loved one was sober or not. In practice, in the early years, it was wives of alcoholics who gathered there. Female alcoholics joining AA were still rare in the Netherlands at that time, as were men seeking support in Al-Anon, while Dutch Al-Anon ACA and Alateen groups, for adult and minor children of alcoholics respectively, would not be set up until the 1970s.[24]

The idea behind the weekly meetings was to do something about the isolated position many wives found themselves in, and to offer them a place where they could find solace and strength in each other. Even if the husband managed to keep away from the drink, wives needed years to rebuild their trust in him, to recover from the financial hardships, and to become adjusted to him (still) being away from home a lot, no longer in bars, but in AA meetings.[25] But it was not just shoulders to cry on that the women found in Al-Anon: they were also expected to work on themselves. Like her husband who had to become and stay sober, every wife was supposed to make a recovery of her own. Al-Anon's purpose, as it was formulated in 1962, was therefore threefold: to break away from isolation, to gain knowledge on alcoholism and everything connected to it, and to achieve personal growth through self-examination.[26]

It was probably no coincidence that these three goals were formulated from the perspective of the participant in Al-Anon, not from that of the organisation. Like AA,

---

[22] De vrouw van een AA-er, 'Ik kan mijn geluk niet op', *De Boei* 3 (1959) 8, [3].

[23] 'De eerste familiegroep aan het werk', *De Boei* 1 (1956) 12, [1].

[24] Alex, 'Wat is Alateen voor mij?', *De Boei* 17 (1973) 10, [6]; 'Wat is Jong Al-Anon?', *De Boei* 24 (1979) 11.

[25] [Tonny S.], 'Als een vreemde vrouw', *De Boei* 3 (1959) 4; De vrouw van een AA-er, 'Ik kan mijn geluk niet op', *De Boei* 3 (1959) 8, [3].

[26] Wil-Amsterdam, 'Een verlengstukje van de AA: Al-Anon', *De Boei* 6 (1962) 6, [1].

the Al-Anon groups were what would later become known as self-help groups: groups in which people who share a certain problem support each other in their efforts to solve the problem or cope with it better, without the involvement of professionals.[27] The crux here, as psychiatrist Esser put it in 1960, was that people had the same experiences, had done the same things out of the same motivations, and from there were able to muster an empathy that was unattainable to the professional who had never had the experience himself.[28]

The Stichting Pandora (1964)

Like in Al-Anon, anonymity was also key, but in quite a different way when, on 4 June 1964, Arnold van Ameringen founded the Stichting Pandora in Amsterdam. Changing the preconceptions of the Dutch public about people suffering from psychiatric problems was its aim, in support of the 'rehabilitation', as its initiator called it, of (former) patients.[29] Van Ameringen was a 'Dutch American', the newspapers would write, who had been born in Rotterdam in 1891 and emigrated to the United States after the First World War. Having made his fortune there, he felt indebted to his fatherland.[30] Inspired by the work of the American National Committee for Mental Hygiene, of which he had been treasurer in the late 1940s,[31] he had already set up a mental health charity, the Van Ameringen Foundation, in his country of residence, and now it was the turn of his country of birth. He named his initiative Pandora, after the ancient Greek myth about Pandora's box – a box that produced one disaster for humankind after another, until only one thing was left at the bottom: hope.[32]

When Pandora first presented itself to the Dutch public five years later, in 1969, (the by then late) Van Ameringen was celebrated as a millionaire who had presented his homeland with a remarkable charity, but his very personal stake in taking action against mental health stigma was not revealed. The fact that it was his lived experience as a 'relation-of' that motivated him – and that marks Pandora as an important predecessor of

---

[27] Pieter van Harberden, *Zelfhulp bij Anonieme Alcoholisten* (Groningen 1986) 45. For a discussion of the numerous definitions of self-help, see Katerina Flora, Antonis Raftopoulos & Theodote Pontikes, 'A Look at the Evolution of the Self-Help Movement', *Journal of Groups in Addiction and Recovery* 5 (2010) 3, 214-225.

[28] P.H. Esser, *Alcoholisme* (Kampen 1960) 137.

[29] A.J. Heerma van Voss, 'De geschiedenis van de gekkenbeweging. Belangenbehartiging en beeldvorming voor en door psychiatrische patiënten (1965-1978)', *Maandblad Geestelijke Volksgezondheid* 33 (1978) 6, 398-428, 398; Van der Kroef, *25 jaar,* 13, 24; interview Treeske Blase, 28 September 2018.

[30] J. Mijs, 'Waarom gek? Omdat ie anders is?', *Algemeen Handelsblad* 20 June 1969; P. van der Eijk, 'Voorlichting over psychiatrie', *De Tijd* 22 November 1969; Nico van Hees, 'Trees Blase vecht tegen angst voor – genezen – psychiatrisch patiënt', *Het Vrije Volk* 18 December 1969.

[31] Van der Kroef, *25 jaar,* 14.

[32] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 398; Van der Kroef, *25 jaar,* 24-25.

the Dutch family movement – remained undisclosed for years. With hindsight, it seems journalist Arend Jan Heerma van Voss may have hinted at it in 1978: an article that he wrote that year casually mentioned that Van Ameringen's interest in psychiatric stigma was awakened during conversations he had with a psychiatrist when visiting a hospital in Paris on his honeymoon.[33] But Reinhilde van der Kroef's very thorough historical study of Pandora's first twenty-five years, published in 1990, sticks to the official story from the 1960s that it was the American mental hygiene movement that had inspired him.[34] An educational Pandora brochure for teenagers from 2003, however, revealed the complete story about Van Ameringen's honeymoon in the 1930s: during the trip, his new wife Hedwig experienced a mental crisis and had to be admitted to a Parisian psychiatry ward. Although she returned to the United States fully recovered, she was scarred by the stigma she encountered upon her return, the brochure said:

> *… thuis bleef iedereen uit haar buurt. Iedereen behalve de Nederlandse Amerikaan. Ze waren bang voor haar. Ze geloofden niet dat ze was genezen. Ze dachten dat ze gevaarlijk was en ze vonden het een schande dat ze vrij rondliep.”*[35]

> "… at home everybody stayed away from her. Everybody but the Dutch American. They were afraid of her. They did not believe she was cured. They thought she was dangerous and they thought it was a disgrace that she walked around free.")

Research by Cecile aan de Stegge has revealed that there were more members of the Van Ameringen family who suffered from mental health issues: one of Arnold's sisters and one of his daughters also spent time in psychiatric hospitals in the 1930s and 40s.[36]

---

[33] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 398.

[34] Van der Kroef, *25 jaar.*

[35] Lise Broekaar, *Wie dit leest is gek. Een boekje voor jongeren over gekke normalen en normale gekken* (Amsterdam [2003]) 29. Unfortunately, Pandora's archive has largely been lost and it is impossible to pinpoint exactly when they started using the story of Van Ameringen and his wife. But based on the fact that previous editions of this brochure were published in 1989 and 1994, it seems likely that it surfaced in the 1990s (e-mail correspondence with Lise Broekaar, 4 July 2023).

[36] Van Ameringen's sister Betsy was a patient in the Willem Arntz Hoeve in Den Dolder in the late 1930s and passed away in 1942 (e-mail Cecile aan de Stegge to Irene Geerts, 4 July 2018). His daughter Patricia recovered, went on to become a trained nurse and followed in her father's footsteps as a philanthropist (just like all his three children), creating her own Patricia Kind Family Foundation for vulnerable people ('Well-known Midwife Nurse van Ameringen: Where did she suddenly go in the middle of the war?', https://www.stolpersteine-dordrecht.nl/het_voorbije_joodse_dordrecht_midwife_nurse_van_ ameringen.html; and 'Patricia Kind Obituary', https://www.legacy.com/us/obituaries/nytimes/ name/patricia-kind-obituary? id=21478181, both accessed 30 June 2023).

His son Henry was convinced that his father's main motivation for founding Pandora was the misfortune of his sister: "She was, with good reason, my father's favorite and he was much marked by her illness," he wrote to Aan de Stegge in 2016.[37] But in 1965, that was not even a subject that Van Ameringen spoke about openly with his right-hand-woman Treeske Blase:

> *"… dat heb ik hem nooit durven vragen in die tijd. Want ik was natuurlijk toch nog wel steeds het meisje tegenover al die mannen. In een onbekende wereld. Dat durfde ik niet te vragen. Maar ik heb later wel begrepen dat er in de familie mensen waren die opgenomen waren geweest. Ja. Ook van zijn zoon, van Henk* [Henry], *heb ik dat begrepen. Maar ook van hemzelf."*[38]

> ("… I never dared to ask him that at the time. Because, of course, I was still the girl in front of all those men. In an unknown world. I didn't dare ask. But I did understand later that there were people in the family who had been hospitalised. Yes. I also understood that from his son, Henk [Henry]. But also from himself.")

Van Ameringen felt there was a gap between mental health professionals and the public, and wanted to keep Pandora on the side of that public – a remarkable choice, as up to that point only experts had provided anti-stigma education. He made it a statutory requirement that on the Pandora board, lay people would always have a majority over mental health care experts. Those lay people were not patients or former patients, nor were they necessarily 'relations-of' like himself. In Van Ameringen's opinion, Pandora's board members needed to be people who were held in the highest esteem and had an outstanding reputation: members of the (business) elite. Although the gentlemen who joined him on the board were very involved in the work of the young organisation, Van Ameringen continued to be the driving force behind his initiative. Based in New York, however, there was only so much he could do, and he decided to hire a local director. When he approached several doctors for the job, however, one after another declined, but one of them suggested that Pandora could look for someone with a publicity background instead. Board member and banker Allard Jiskoot, a close personal friend of Van Ameringen, figured his secretary Treeske Blase might be a match.[39]

---

[37] E-mail correspondence between Cecile aan de Stegge and Henry Van Ameringen, 21 January 2016. With many thanks to Cecile aan de Stegge for her generous sharing of research data.

[38] Interview Treeske Blase, 28 September 2018.

[39] Interview Treeske Blase, 28 September 2018; Heerma van Voss, 'De geschiedenis van de gekkenbeweging'; Van der Kroef, *25 jaar*, 26-29.

When Van Ameringen offered Blase the job, she insisted on taking a week to think it over, as she didn't know the first thing about mental health problems or the stigma that stuck to those who had experienced them. In fact, she would say later: *"Ik zat zèlf met taboes, tot over mijn oren"* ("I was full of taboos myself, up to my ears").[40] During that week, she discussed the matter with friends who had been in medical school. After all of them had advised her against it, she decided to do it anyway. The telegram she sent to Van Ameringen to inform him read tellingly GLADLY ACCEPT PANDORA CHALLENGE. As of 1 May 1965, Blase's lodgings in Amsterdam became the first Pandora office, and her private telephone number the organisation's. She gave herself a year to spend on orientation, to find her feet and come up with a plan.[41]

The factors that enabled the family movement's predecessors of the 1960s to emerge

Elsewhere in Europe, the first family organisations had appeared in the early 1960s: the Danish SIND (short for Landsforeningen Sindslidendes Vel, National Association for the Welfare of the Mentally Ill, 1960),[42] and the French UNAFAM (short for Union nationale des Familles et Anciens malades mentaux et de leurs associations, National Union of Families and Elders of the Mentally Ill and of Their Organisations, 1963).[43] These were associations of relations who were challenging medical and state authorities on mental health care issues. It was too soon for that in the Netherlands. Al-Anon and Pandora, the first predecessors of the family movement were initiatives that only engaged critically with the public.

I have not come across traces of contact between Pandora or Al-Anon and the early initiatives in Denmark and France. But that does not mean that the two earliest Dutch predecessors of the family movement did not follow some example. The roots of both go back to the United States. Although we tend to associate the rise of the American cultural and scientific influence in the Netherlands with this post-war period, historians have shown that Americanisation was indeed at its height in the 1960s, but had already

---

[40] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 399.

[41] Interview Treeske Blase, 28 September 2018; Heerma van Voss, 'De geschiedenis van de gekkenbeweging'; Van der Kroef, *25 jaar*, 24-26, 33-36.

[42] Knud Christensen, 'Retfærdig harme over de fortvivlede forhold...'; Henrik Harring Jørgensen, 'Fra kronik til landsforening paa faa maaneder'; Henrik Harring Jorgensen, '1.900 medlemmer paa fire aar'; all found in *SINDbladet* 5 (2010) 11-13. With special thanks to Karen Nedergaard for translating.

[43] Nicolas Henckes, *La politique du handicap psychique. Familles, psychiatres et Etat face à la chronicité des maladies mentales des années 1960 aux années 1970* (s.l. 2011), hal.archives-ouvertes.fr/hal-00769756, 27-40.

begun in the interbellum period.[44] The same holds true for Dutch mental health care, as we will see in the following section.[45]

The international mental health movement promotes education and prevention

Before Pandora stepped into the Dutch mental health care arena in 1964, many anti-stigma campaigns had preceded it. The Nederlandsche Vereeniging voor Hulp aan Zieken van Geest (NVHZG, Dutch Association for Help for the Mentally Ill, 1925), for example, was an initiative of psychiatrist and theologist Johan van der Spek to improve attitudes towards psychiatric patients and involve lay people, like relations, in their care. The Voorlichtingsdienst van de Algemene Psychiatrische Inrichtingen (Educational Service of the General Psychiatric Institutions, 1948) hired retired nurse Frédérique Meijboom to educate the public on modern methods of cure and care, in order to recruit desperately needed new nurses, which she did tirelessly for eighteen years.[46] And in 1960, the Katholiek Nationaal Bureau (Catholic National Bureau), distributed large numbers of the artistic, poetic photo essay *Zij zijn van ons geslacht* (They are of our kind), making an appeal to readers to show charity to fellow human beings with mental health problems.[47]

What these campaigns had in common was that they were all inspired by the ideas of the international mental hygiene movement, or as it was called from 1948 onwards, the mental health movement. When Arnold van Ameringen joined the board of its American organisation, the National Committee for Mental Hygiene (NCMH), in 1947, this movement had already existed in the United States for almost thirty years. Founded in 1909 by former patient Clifford Beers and prominent psychiatrist Adolf Meyer, the NCMH had been set up with the goal of reforming institutional psychiatry. It was often cited as an early example of patient activism, but was in fact a movement of psychiatrists, campaigning to raise the poor reputation of their field and obtain the means to improve

---

[44] Doeko Bosscher, 'Toward a Community of Interests: the Netherlands and the United States between the World Wars', in: Hans Krabbendam, Cornelis A. van Minnen & Giles Scott-Smith, *Four Centuries of Dutch-American Relations 1609-2009* (Amsterdam 2009) 401-419; James C. Kennedy, 'Cultural Developments in the Dutch-American Relationship since 1945', in: Hans Krabbendam, Cornelis A. van Minnen & Giles Scott-Smith, *Four Centuries of Dutch-American Relations 1609-2009* (Amsterdam 2009) 931-948.

[45] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 734-744; Leonie de Goei, *De psychohygiënisten. Psychiatrie, cultuurkritiek en de beweging voor geestelijke volksgezondheid in Nederland, 1924-1970* (Nijmegen 2001) Chapter 2, 4.

[46] Van der Kroef, *25 jaar,* 17-21.

[47] Albert Bergers & Daniël de Lange, *Zij zijn van ons geslacht* (Hilversum 1960); 'R.-k. fotoboek over geestelijk gestoorden', *Het Parool* 1 December 1960; 'Elk lijden lijkt absurd zonder de medemens', *de Volkskrant* 1 December 1960.

institutional care. Historians have shown that Meyer and his colleagues only tolerated layman Beers in their midst because of his high-class background and network: both were very useful for raising funds for their cause, as well as raising the status of the profession.[48]

Through the NCMH, Meyer and his colleagues promoted innovations in social psychiatry (like aftercare, outpatient clinics and psychiatric social work) and epidemiological research into the origins of severe mental health issues. In 1912 and 1913, they organised a travelling exhibition that educated the American public on the cost of mental health problems and the importance of scientifically developed treatment methods and prevention. Although a lot of social psychiatry activities were aimed at prevention – aftercare, for example, was considered important to prevent relapse in patients – in the early 1920s, the focus of the movement started shifting explicitly towards prevention. Severe mental health issues were seen as the last stage in a developmental process that began in childhood, meaning that priority should be given to early treatment of deviant children and early intervention in adults who developed 'bad mental manners'.[49]

In her dissertation on the Dutch branch of the international mental hygiene movement that developed from the American example, Leonie de Goei considers it likely that the eminent Dutch psychiatrist Klaas Herman Bouman saw the exhibit when he visited the United States in 1913. He was certainly the one who, inspired by the American movement, founded the first Dutch mental hygiene organisation in 1924. That same year, the young lawyer Eugenia ('Eus') Lekkerkerker successfully started promoting the American mental hygiene concept of child guidance clinics, laying the foundation for a national network of Medisch Opvoedkundige Bureaus (MOBs, Medical Pedagogical Bureaus). Looking for a way to integrate the mental hygiene approach with their particular religious orientations, religious psychiatrists subsequently founded parallel Catholic and Protestant organisations. As a result, by the mid-1930s, half a dozen organisations each promoted their own interpretation of mental hygiene in the Netherlands. In 1934, most of them were brought together in the Nationale Federatie voor Geestelijke Volksgezondheid (NFGV, National Federation for Mental Health).[50]

Part of the prevention agenda was to keep people with mental health problems in the community or make their stay in a psychiatric hospital as short as possible. Facilities such as aftercare and medical pedagogical bureaus contributed to implementing that goal. But the co-operation of the home front was crucial. That meant the way people treated 'their' mentally ill needed to change. To educate families on the subject, psychiatrist

---

[48] De Goei, *De psychohygiënisten,* 70-74.

[49] De Goei, *De psychohygiënisten,* 70-74.

[50] De Goei, *De psychohygiënisten,* Chapter 1-2; Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 375-421.

Arie Querido published a booklet in 1935 entitled *De omgang met geesteszieken in het gezin* (Dealing With Mentally Ill in the Family). Fear and miscomprehension, Querido observed, informed the way families dealt with their mentally ill:

> *“… om de zielszieke wordt steeds een cirkel van angst, zelfs van afschuw getrokken.* […] *Bij krankzinnigheid denkt men aan gevaar, aan griezelige dwangmaatregelen, aan dolle, vertrokken gezichten, aan onbegrijpelijke grimassen, aan daden van geweld, waarvoor men geen oorzaak ziet.”*[51]

> (“… around the soul-sick is drawn a circle of fear, even of horror. […] When thinking of insanity people think of danger, of scary coercive measures, of crazy, convulsed faces, of incomprehensible grimaces, of deeds of violence, for which they see no apparent cause.”)

Not only did the psychiatrist make clear that these associations were wrong, they were also harmful, as they stood in the way of successful treatment. To help his readers change their ways, he described in detail what families were confronted with when a member became mentally ill – for various disorders, respectively, including alcoholism and ‘mental retardation’ – and gave strict directions on how to deal with such situations.[52]

After the last Dutch mental hygiene organisation joined the ranks of the NFGV in 1945, the movement became an undeniable force in Dutch mental health care. As the central institute representing the sector in consultative bodies, advising the government and directing subsidies, it would shape the mental health care sector in the Netherlands in the decades to come to the point that they were almost synonymous. The blossoming of the mental hygiene movement was not limited to the Netherlands. Considering the mental devastation the Second World War had brought upon people, at its first post-war international conference in London in 1948, the movement re-ignited its ambitions in a spirit of hope and idealism. It even rechristened itself: the mental hygiene movement became the mental *health* movement. That name in itself did not imply a major change for the Dutch movement, whose federation had held the Dutch equivalent name since 1934, but it underlined the distinction the international movement wanted to make. It was no longer about eradicating mental health problems, it was about fostering mental health in the broadest sense: through healthy relationships between people, and between the individual and the community.[53]

---

[51] Arie Querido, *De omgang met geesteszieken in het gezin* (Practische gids voor medische en hygienische vraagstukken no. 2; Amsterdam 1935) 5.

[52] Querido, *De omgang met geesteszieken in het gezin.*

[53] De Goei, *De psychohygiënisten,* 90-100, 164-167; Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 375-421, 629-663.

In the first half of the 1960s, Dutch psychiatry was bursting with optimism. Not only was it strongly defined by the vibrant mental health movement, but there were also scientific developments that brought new hopes for the field. Recently introduced antipsychotics and antidepressants showed spectacular results, making communication possible even with patients who suffered from the severest disorders. That gave rise to the expectation that soon, they would be able to benefit from psychotherapy just like people with 'lighter' mental health problems. In turn, it would be possible for chronic patients to live their lives more independently outside the walls of the institutions, in half-way housing or supported by community care services. The field oozed with the confidence that psychiatry would finally be able to offer effective cures.[54]

That was the atmosphere when Pandora arrived on the scene. We might expect that it would have been easy for Arnold van Ameringen, as former treasurer of the central American mental health organisation, to connect with Dutch psychiatry at a time when that largely had a similar orientation. But even though he had managed to have two psychiatrists who were connected to the NFGV join the first Pandora board, his death in 1966 may have been part of the reason why the reception of Pandora in mental health care would be chilly. As a lay person, Treeske Blase was not taken seriously – a reminder, perhaps, of how Clifford Beers was regarded in the early American movement. Many of Pandora's founding ideas – that the public needed to be convinced that mental health issues were illnesses, that they could be cured by modern medicine, and that mental health prevention starts with the young – were, however, directly inspired by the international movement that had its origins in the early twentieth century.[55]

AA spreads the gospel of self-help

Compared to Pandora, the American roots of Dutch Al-Anon are more obvious to the contemporary reader, as AA and its affiliate organisations are widely known today. Like the ideas and methods of mental hygiene, those of AA and Al-Anon came to the Netherlands from the United States by way of mental health care professionals. It was director Henk Krauweel of the Amsterdam clinic for alcoholism who discovered AA through his contacts in the United States and introduced it to the Netherlands by helping a group of seven of his patients start up in 1947.[56] The twelve-step self-help programme that had been developed in American AA had been documented and first published in

---

[54] De Goei, *De psychohygiënisten,* 90-100, 232-236; Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 536-575, 654-663, 664-744; Joel T. Braslow & Stephen R. Marder, 'History of Psychopharmacology', *Annual Review of Clinical Psychology* 15 (2019) 25-50, 33-35 shows how in the United States similar developments happened a decade earlier.

[55] Van der Kroef, *25 jaar,* 28-29.

[56] '30 jaar A.A. in Nederland', *De Boei* 22 (1978) 10, 6-9, 8.

1939, in order for it to be easily copied elsewhere;[57] while in 1946, the twelve traditions that guide the organisation of the AA groups were hot off the presses.[58]

And with that, an approach to alcoholism that was completely new to the Dutch public was imported. The prevailing opinion in Western countries had for a long time been that alcohol abuse was a moral problem. Among medical professionals, the alternative idea, to regard it as a disease, had been around since the nineteenth century, but it had never been paid much attention.[59] When in the 1930s, a doctor explained this idea to Bill Wilson, a New York businessman whose alcoholism was ruining him, that was an eyeopening experience for Wilson, one that helped him sober up. After he and fellow sufferers discovered the power of mutual contact for staying strong and resisting their cravings for alcohol, they started self-help groups. The organisation that grew from there was named Alcoholics Anonymous (AA). Wilson drew up a programme consisting of twelve spiritual steps to guide an alcoholic to recovery. The belief fundamental to his programme was that what an alcoholic was dealing with, was a disease.[60]

That belief gained prominence when in the 1940s, the American psychiatrist Elvin Morton Jellinek developed the first systematic theoretical underpinnings of this point of view in a research project with American AA groups. His ideas were embraced so widely that, in 1948, the World Health Organisation (WHO) officially acknowledged alcoholism as a disease. Through Jellinek's international advisory and teaching activities, in particular for the WHO, his theories and methods became very influential worldwide, including in the Netherlands. After he visited Krauweel in 1955, the two kept in touch, and the treatment that people received in the Amsterdam clinic for alcoholics – set up by Krauweel in 1960 – was modelled on Jellinek's ideas. In 1964, a year after the American passed away, the clinic was renamed the Jellinek-kliniek, soon abbreviated in the vernacular to 'the Jellinek'.[61]

This radical turn in the explanatory model for alcoholism in the Netherlands seems to have dealt the final blow to the traditional Dutch temperance movement, which dated back to the early 1800s. This movement saw alcohol use as an evil and alcoholism as a moral problem, especially of the underprivileged who used it as an escape from their pitiful lives. Bringing together dignitaries as well as ex-alcoholics and 'wives-of' in a variety of organisations against alcohol use, the organisations in the temperance movement tried to help people with an alcohol addiction through a combination of discipline and support. Historian Gemma Blok sees one of these organisations, De Goede Tempelieren (the Dutch branch of The Independent Order of Good Templars, founded in the United States in

---

[57] *Alcoholics Anonymous: The Story Of How One Hundred Men Recovered From Alcoholism* (New York 1939).

[58] *Alcoholics Anonymous Comes of Age* (New York 1957) vii-viii.

[59] Van der Stel, *Drinken, drank en dronkenschap,* 201-202, 229.

[60] *Alcoholics Anonymous Comes of Age,* 1-48.

[61] Van der Stel, *Drinken, drank en dronkenschap,* 310-322; Gemma Blok, *Ziek of zwak. Geschiedenis van de verslavingszorg in Nederland* (Amsterdam 2011) 108-109, 138.

1851) as the predecessor of AA: with a mixture of collective rituals, fellowship and mutual support that resemble some present in the later AA, this group, which largely consisted of recovered drinkers, tried to help alcoholics become sober.[62]

The temperance movement was very successful in the Netherlands. In the 1920s, and especially after the Second World War, it even looked like its work was done. Alcohol use and abuse had declined to the point that only a small group of mentally troubled drinkers seemed to remain, with problems too complicated for the morally inspired volunteers to handle. At the same time, however, the problem was coming back in a different guise: whereas before, alcohol had been a coping mechanism of the poor and uneducated, now it was quickly becoming the way the more affluent classes attempted to cushion the pressures of prosperity.[63] So when Krauweel suggested to his Amsterdam patients that they set up their own AA group, there was a growing need. Although support groups with a strong spiritual character that sounds similar to AA's were part of the traditional temperance movement both in the United States and in the Netherlands, its disease-approach made AA fundamentally different.[64]

Al-Anon did not just embrace this approach with regard to the alcoholic loved one, it superimposed it onto the relations, too. The first family group in AA was formed in 1936 when the wife of AA co-founder Dr Bob Smith, Anne Ripley Smith, started to organise meetings for relations who sat in their cars or in her kitchen, waiting while the alcoholic in the family was attending a meeting at her house. Bill Wilson's wife Lois followed her example in New York in 1940. But the wives found early on that just coming together and sharing experiences was not enough to help their husbands stay sober – as wives, they needed to change too. Looking at alcoholism as an illness of the whole family, they found that the same twelve steps that guided their husbands helped them examine their own feelings, attitudes and behaviours, and make things better for everyone at home.[65]

In 1951, American family groups formed their own umbrella organisation under the title Al-Anon, and that name, as we saw, was adopted in the Netherlands after the international congress of 1961.[66] More information seems to have become available to the Dutch family groups from that point on: issues of *De Boei* between 1961 and 1963 in particular hold articles explaining how wives should interpret the twelve steps for themselves. Step no. 1, for instance – "We admitted we were powerless over alcohol – that our lives had become unmanageable" – not only held true for an alcoholic, but also for his wife and the entire family. Who had not begged and preached to her husband to leave the

---

[62] Blok, *Ziek of zwak,* 69, 75-78.

[63] Van der Stel, *Drinken, drank en dronkenschap,* Chapter 5-8; Blok, *Ziek of zwak,* Chapter 2-3.

[64] Van der Stel, *Drinken, drank en dronkenschap.*

[65] *Leven met een alkoholist met de hulp van Al-Anon* (New York 1978) 11-13; 'The first years of Al-Anon', http://www.Al-Anon-pierce-wa.org/history/4585444152, accessed 28 August 2019.

[66] *Leven met een alkoholist met de hulp van Al-Anon;* 'The first years of Al-Anon'.

drink alone, to no avail? Acknowledging that she was powerless like her husband could be a first step for a wife to start approaching the problems at home in a different way.[67]

The experiences that triggered the family movement's predecessors of the 1960s

Stigma was too strong for relations in the 1960s to challenge head on, but at the same time, it was the most important trigger for taking the initiative to establish Al-Anon and Pandora. As a perennial phenomenon,[68] scientists had already intensely studied stigma when in 1963, the field was decisively boosted by the publication of sociologist Erving Goffman's book *Stigma*.[69] Stigma, he wrote, is an attribute that makes a person different and of a less desirable kind to others.[70] Stigma touches people with all kinds of undesirable attributes, but Goffman recognised that mental health issues form one of the most deeply discrediting categories of all stigmatised conditions, as they are more likely to be considered reproachable, especially in the case of addiction.[71] Nonetheless, all types of stigma can be deeply damaging.[72]

Familiarising ourselves with some basic concepts will help us understand how stigma provoked the first precursors of the Dutch family movement, Al-Anon and Pandora. Fundamental to stigma are stereotypes that lead to prejudice and discrimination.[73] Stigma

---

[67] Al-Anonne, 'De eerste stap in de Al-Anon', *De Boei* 7 (1963) 3, [2].

[68] Horacio Fabrega, 'Psychiatric Stigma in the Classical and Medieval Period: A Review of Literature', *Comprehensive Psychiatry* 31 (1990) 4, 289-306; Horacio Fabrega, 'The Culture and History of Psychiatric Stigma in Early Modern and Modern Western Societies: A Review of Recent Literature', *Comprehensive Psychiatry* 32 (1991) 2, 97-119.

[69] Bruce G. Link & Heather Stuart, 'On Revisiting Some Origins of the Stigma Concept as it Applies to Mental Illnesses', in: Wolfgang Gaebel, Wulf Rössler & Norman Sartorius (eds.), *The Stigma of Mental Illness – End of the Story?* (Cham etc. 2017) 3-28, 5-17.

[70] Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (New York 1963) 3-5.

[71] Link & Stuart, 'On Revisiting Some Origins of the Stigma Concept', 16; Patrick W. Corrigan, Amy C. Watson & Frederick E. Miller, 'Blame, Shame, and Contamination: The Impact of Mental Illness and Drug Dependence Stigma on Family Members, *Journal of Family Psychology* 20 (2006) 2, 239-246.

[72] Patrick W. Corrigan & Frederick E. Miller, 'Shame, blame, and contamination: A review of the impact of mental illness stigma on family members', *Journal of Mental Health* 13 (2004) 6, 537-548; Patrick W. Corrigan, Benjamin G. Druss & Deborah A. Perlick, 'The Impact of Mental Illness Stigma on Seeking and Participating in Mental Health Care', *Psychological Science in the Public Interest* 15 (2014) 2, 37-70; Marisa D. Serchuk et al., 'Vicarious Stigma and Self-Stigma Experienced by Parents of Children with Mental Health and/or Neurodevelopmental Disorders', *Community Mental Health Journal* 57 (2021) 1537-1546.

[73] Lindsay Sheehan, Katherine Nieweglowski & Patrick W. Corrigan, 'Structures and Types of Stigma', in: Wolfgang Gaebel, Wulf Rössler & Norman Sartorius (eds.), *The Stigma of Mental Illness – End of the Story?* (Cham etc. 2017) 43-66.

comes in various shapes and forms. When an undesirable attribute in a person leads to other people or society in general avoiding, rejecting, shaming, ridiculing or excluding them, that is called public stigma; when it leads to a person being disadvantaged or excluded by laws, regulations or other cultural constructions, we call that structural stigma.[74] People can also suffer from stereotypes that they have internalised, making them think less of themselves: that is called self-stigma.[75]

Stigma not only affects people with the characteristic themselves, however: it can also extend to those who are closely related to them, who are obliged to share some of the discredit, and as a result, in some respects, are treated as one with them. Goffman called this courtesy stigma; nowadays the more current term is stigma by association or associative stigma.[76] This particular form of stigma can lead to relations themselves experiencing public stigma, self-stigma and structural stigma. That may result in them avoiding social interaction or trying to hide any connection with the stigmatised person. When a relative – usually a parent – feels so strongly connected with a loved one who is stigmatised that the experience touches them as if it were their own, that is called vicarious stigma.[77] The effects, again, can be damaging and can result in mental and physical health problems.[78]

In response to stigma, Goffman noted, people can isolate or build safe havens in the shape of self-help groups, which can sometimes grow into a social movement challenging the stigma.[79] How stigma played its part as the main trigger for the first predecessors of the family movement, of Dutch Al-Anon and Pandora, is the subject of this section. We will first look into the experiences that made wives of alcoholics huddle together in Al-Anon groups, and then move on to the dynamics behind the painful experiences that provoked Arnold van Ameringen into founding Pandora.

Ignorance, isolation and stigma associated with alcoholism

In the 1960s, alcohol use in the Netherlands had become a sign of affluence, of sophistication. Having wine, beer or spirits in the house for visitors became practically mandatory, and so did the art of being able to drink socially. Alcohol had become

---

[74] Jaap van Weeghel et al., 'Proloog: een onderschat probleem op de agenda', in: Jaap van Weeghel et al., *Handboek destigmatisering bij psychische aandoeningen. Principes, perspectieven en praktijken* (Bussum 2016) 21-41, 23.

[75] Link & Stuart, 'On Revisiting Some Origins of the Stigma Concept', 6.

[76] Remko van der Sanden, *Stigma by association: Among family members of people with mental illness* (PhD thesis Maastricht University 2015) 13-14.

[77] Serchuk et al., 'Vicarious Stigma', 1538.

[78] Remko L.M. van der Sanden et al., 'Stigma by Association Among Family Members of People with a Mental Illness: A Qualitative Analysis', *Journal of Community & Applied Social Psychology* 25 (2015) 5, 400-417.

[79] Goffman, *Stigma*, 22-26.

synonymous with good times, with celebrating, and refusing a drink was considered unsociable.[80] But not only were adults – men in particular – supposed to be able to hold their liquor, they were also supposed to be able to stop when enough was enough. People who crossed that line, and regularly drank themselves into a stupor, wandering the streets, getting into bar fights and ending up in jail or delivered home by the police, were seen as weak-willed, spoilt, self-indulgent drunks – bad people, sinners, criminals. They were shunned, treated with contempt and gossiped about as a result.[81]

The burden on the individual as well as on the relations stemmed from the direct consequences of alcohol abuse itself, of course, but a big part of their suffering was also linked to the shame and stigma that came with it. Even for those who learned to interpret alcoholism as an illness, it was hard to lose that shame. To a specialist like psychiatrist Esser it might have been logical that an illness was nothing to be ashamed of,[82] it was something else for someone who was addicted or a relative to shake off that feeling. And even if they did, their neighbours, colleagues or extended family could painfully remind them that, in the eyes of most people, it was a disgraceful moral shortcoming. Even today, addiction is more stigmatised than other mental health issues.[83]

For relations of alcoholics, experiencing stigma by association could be very tough. Children ran the risk of being bullied, for example, like the little girl who came home wounded and crying after having defended her father's honour with her fists.[84] Her pain touched him so deeply that it motivated him to go to AA. John Otte was not so lucky. Looking back in the 1980s on growing up with mentally ill and alcoholic parents in the 1960s, he remembered not only neglect and violence at the hands of his mother, but also how other adults looked away and made him feel ashamed. *"De buren zien alles, maar steken geen hand uit. Ze doen niet anders dan klagen en praten over ons"* ("The neighbours see everything, but they do nothing to help. All they do is complain and talk about us").[85] In school, Otte got low grades and was always reprimanded for being absent and forgetting things. In the memoir that he wrote in his twenties, after both parents had passed away, Otte was still outraged about his professional educators ignoring all the

---

[80] A.R.-Amsterdam, 'Geachte familieleden en vrienden', *De Boei* 4 (1960) 10, [4] ; P.H. Esser, 'Is alcoholisme een ziekte? Voordracht gehouden op 9-1-1965 voor de AA Nieuwjaarsbijeenkomst te Haarlem', *De Boei* 9 (1965) 4, [1-3, 1]; Hans, 'Alcoholgebruik: nog veel onbegrip...', *De Boei* 12 (1968) 7, [1-2, 1]; Bob Eureka-Waregem, 'Moet men zich schamen, omdat men AA-er is', *De Boei* 12 (1968) 1, [4]; Van der Stel, *Drinken, drank en dronkenschap,* 279-280.

[81] 'Wat A.A. niet doet en wel', *De Boei* 2 (1958) 4, [2]; 'Kleinste en kostbaarste gemeenschap', *De Boei* 4 (1959) 2, [1]; Esser, *Alcoholisme*, 122-123.

[82] Esser, *Alcoholisme*, 159.

[83] Leonieke van Boekel et al., 'Comparing stigmatising attitudes towards people with substance disorders between the general public, gps, mental health and addiction specialists and clients', *International Journal of Social Psychiatry* 61 (2015) 6, 539-549, 539.

[84] B.-Haarlem, 'Mijn dochtertje deed het', *De Boei* 3 (1959) 9, [4].

[85] John Otte, *Getekend Lenny. Kind van alcoholisten* (Amsterdam 1987) 127.

warning signs: *"O ja, meester, nog iets anders: waarom heb jij je nooit eens afgevraagd waarom ik zo was?"* ("By the way, teacher, why did you never ask yourself why I was like that?")[86]

Adult relations might have been less dependent, but they had their share of painful reactions from outsiders, albeit more subtle. 'Wives-of' wrote in *De Boei* about how even well-meant reactions from neighbours, friends or members of the extended family could leave them with the feeling that no-one understood. Many of their relations, in the long run, stayed away.[87] And in turn, shame made families of alcoholics isolate themselves. It made women come up with excuses for their husbands' behaviour, call their bosses to say they were ill, make sure they looked decent, and cover for them even if they were violent towards their children. Wives stopped inviting people to the house or going out with friends for fear their husbands might be drunk again. An Al-Anon member observed in 1969 that those who suffered from isolation most of all, even to the point that they were afraid to join Al-Anon, were women in more well-to-do circles:

> *"Degene, die in een volksbuurt woont, zal het meestal langer uithouden dan degene, die in een zogenaamde 'betere' buurt woont. Waarom? De saamhorigheid, loyaliteit of solidariteit, hoe men het ook wil noemen, is in de volksbuurt meestal veel groter dan in de nieuwe of betere buurten. Wie in een volksbuurt woont kan, als haar man 's avonds dronken thuis is gekomen en herrie heeft geschopt, de volgende morgen bij de buurvrouw beneden of boven gerust* [...] *met grote vrijmoedigheid haar hart luchten, haar gal uitspuwen,* [...] *spuien, ontladen. Zij heeft afgereageerd en kan er dan wel weer even tegen. Maar juist zij, die dat niet hebben, kunnen in de Al-Anon de steun vinden, die men zo hard nodig heeft."*[88]

> ("Those who live in a working-class neighbourhood will usually be able to cope longer than those who live in a so-called 'better' neighbourhood. Why? The togetherness, loyalty or solidarity, whatever you want to call it, is usually much greater in the working-class neighbourhood than in the new or better neighbourhoods. In a working-class neighbourhood, if someone's husband has come home drunk in the evening and has caused mayhem, the next morning she can safely [...] go to the downstairs or upstairs neighbour boldly get it of her chest, spit out her bile, [...] unload, discharge. She has vented and can take it again for a while. But it is precisely those who do not have that, who can find in Al-Anon the support they so desperately need.")

---

[86] Otte, *Getekend Lenny,* 62.

[87] 'Vrouwen aan het woord in de A.A.', *De Boei* 6 (1961) 2, [2-3, 2]; 'Voor de vrouwen', *De Boei* 11 (1967) 7/8, [3-4]; 'Al-Anon familie-groepen', *De Boei* 12 (1968) 12, [3].

[88] Annie-Amsterdam, 'Waarom en voor wie Al Anon', *De Boei* 13 (1969) 3, [4].

Stigma associated with other mental health issues

In 1958, psychiatrist J.H. Gravestein felt confident that the stigma associated with mental health problems was quickly transforming into understanding, thanks to the modernisation of psychiatric hospitals:

> *"De open deuren, het vriendelijke huiselijke meubilair, en het gewone bestek op tafel bij de maaltijden, maakten dat de patiënten die langer verpleegd moeten blijven, zich in dit sanatorium thuis gaan voelen. De familie komt in dit milieu graag op bezoek, en hierdoor is de patiënt ook weer minder geïsoleerd, terwijl hij, wanneer hij herstellende is, al gauw een weekend naar zijn familie mag reizen,* waardoor het contact met het gezin en de hele maatschappij beter behouden blijft."[89] [cursief in origineel]

> ("The open doors, the friendly homely furniture, and the ordinary cutlery on the table at mealtimes made the patients who need to be hospitalised for a longer period feel at home in this sanatorium. The family enjoys visiting in these surroundings, and that makes the patient less isolated, while he, when recovering, is soon allowed to travel to his family for the weekend, *which preserves the contacts with the family and the whole of society better.*") [italics in original]

Modern psychiatry, with its revolutionary new forms of medication, psychotherapy and aftercare, was able to improve the way people with mental health issues reacted to the world, and the world in turn would respond differently to them, the article suggested. Under the able guidance of psychiatrists and other mental health professionals, both sides would readjust and come closer together. That would support psychiatry's ambition for patients to be able in the future to remain in the community instead of having to spend a lot of time, or even their lives, in psychiatric hospitals. It all seemed to be just around the corner.[90]

Gravestein's colleague Eugène Carp was less optimistic. In 1960, he concluded a gloomy exploration of the stigmatising human mind by saying *"het menselijk vooroordeel – en niet slechts ten aanzien van geesteszieken – zal zelf wel onuitroeibaar blijven, zolang de angst blijft behoren tot de essentie van het menselijk zijn en de drang tot zelfbehoud hiervan een noodwendig uitvloeisel is"* ("it will probably remain impossible to wipe out human

---

[89] J.H. Gravestein, 'De veranderde houding tegenover de psychiatrie', *Tijdschrift voor Ziekenverpleging* 11 (1958) 14, 406-409, 408.

[90] Gravestein, 'De veranderde houding', 409.

prejudice – and not just with regard to the mentally ill – as long as fear is part of the essence of being human and the necessary consequence of that is the urge of self-preservation").[91] He saw it as his responsibility to bridge the gap between the mentally ill and the world, but did not seem very confident about his abilities to do so: *"Deze bijna onmogelijke taak weet de psychiater op de schouders gelegd, maar tevens zegt zijn noodzakelijk optimisme, dat juist het onmogelijke gedaan moet worden"* ("The psychiatrist carries this almost impossible task on his shoulders, but at the same time his necessary optimism says that the impossible should be done.")[92]

To Arnold van Ameringen, this almost impossible task was a mission too, a mission he tried to accomplish in his country of birth by setting up the Pandora foundation. He summarised the prejudices that (ex-)psychiatric patients were confronted with in a slogan: mental illness is incurable, shameful and dangerous.[93] When Pandora started its first campaign, Treeske Blase explained in more detail to the press how people regarded those who were or had been in a psychiatric hospital: they were weak in morals, in character; delinquent, psychopaths; and they would always remain that way. To the average Dutch person, she said, mental health issues were mysterious, intangible and unpredictable. And that was the justification for keeping patients as far away from 'normal' society as possible, and behind bars.[94] *"De traditie wil dat je de geestelijk gestoorde buiten de samenleving houdt,"* Blase summarised, *"er zelfs niet in de openbaarheid over praat"* ("Tradition wants us to keep the mentally disturbed outside of society, and even not to talk about them in public").[95]

Van Ameringen and Blase were not exaggerating. Surveys done by sociologists in two regions in the Netherlands in the early 1960s showed how large parts of the Dutch population thought of people with mental health issues. Many respondents felt that these people should be given equal opportunities, but preferred that they stayed in institutions as long as possible. On their return in society, respondents were open to contact, as long as it was without obligation, but they also wanted former patients to be closely monitored, to make sure that their potential threat to the community was managed.[96] Shameful, dangerous and incurable – Van Ameringen's slogan runs through many of the quotes in researcher Jan Weima's survey report:

---

[91] E.A.D.E. Carp, 'Vooroordelen tegen geesteszieken', *R.K. Artsenblad* 39 (December 1960) 273-280, 279.

[92] Carp, 'Vooroordelen tegen geesteszieken', 280.

[93] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 398.

[94] P. van der Eijk, 'Voorlichting over psychiatrie', *De Tijd* 22 November 1969; Maria Hendriks, 'Contact met gestoorde kan mening wijzigen', *de Volkskrant* 14 January 1970; Mirjam Bartelsman, 'Stichting Pandora: "Waarom gek?"', *De Tijd* 14 August 1971.

[95] J. Mijs, 'Waarom gek? Omdat ie anders is?', *Algemeen Handelsblad* 20 June 1969.

[96] Weima, *Beeldvorming ten opzichte van geestelijk gestoorden,* 19-24, 75-84; Van Weerden-Dijkstra, *De houding ten opzichte van geestelijk gestoorden,* 7, 20-21, 41-43.

"... als ze een tik hebben, dat [sic] *komt-ie vroeg of laat altijd wel weer terug. Vooral als het een beetje stevige tik is geweest. Nee, de meesten kun je beter een kogel door hun kop schieten. Andere mensen zitten er maar mee opgescheept."*[97]	("... once they have a crack, it will come back sooner or later. Especially when it was quite a heavy crack. No, most of them you should just shoot in the head. They are just a burden to other people.")

Back in the 1960s, 'sister-of' Corrie van Eijk-Osterholt did a little – involuntary – survey of her own, when she went door to door selling lottery tickets to raise funds for a recreation pavilion in the psychiatric institution where her twin sister Mies Osterholt lived. It would be such a profound experience of the stigma associated with mental health problems, that she recalled it in a video interview in the late 1980s:

"Bij de een was het: o nee hoor, die gekken, geen ontspanningspaviljoens, laat ze maar opgeborgen blijven. Of een ander zei: o nee zeg, dat zijn toch halve misdadigers, kom nou, daar gaan we geen geld voor geven. Dat soort... Ook: in onze familie komt het niet voor. Ik zei: ach mevrouw, als straks uw kleinzoon met zijn bromfiets tegen de trottoirband oprijdt en hij beschadigt zijn hersenen, dan zit ie d'r ook. Oh nee, dat was al genetisch bepaald blijkbaar, dat gebeurde bij hen niet."[98]	("One said: oh no, those lunatics, no recreation pavilions for them, better keep them locked up. Or another said: oh no way, those people are half criminals, are you kidding, we are not giving money for that. That kind of... Also: there is nothing like that in our family. I said: oh Madam, if your grandson bumps into the curb with his moped and he damages his brain, he will end up there too. Oh no, apparently that was already genetically determined, that did not happen in their circle.")

Stigma by association, or how people thought about the *relations* of such patients, was not a part of the 1960s surveys, but of course that does not mean it didn't exist. One way to get an impression of such stigma, is to turn to the popular advice column *Margriet weet raad* (Margriet knows what to do) in *Margriet*, a popular women's weekly and a well-researched source on taboo issues.[99] In 1964 – the year Pandora was founded – the column included

---

[97] Weima, *Beeldvorming van geestelijk gestoorden,* 20.

[98] Museum of the Mind, Haarlem, Audiovisual Collection, De bittere werkelijkheid, undated video interview Prof. Dr Gersons with Mrs. C. van Eijk-Osterholt [1980s].

[99] C. Brinkgreve & M. Korzec, *'Margriet weet raad'. Gevoel, gedrag, moraal in Nederland 1938-1978* (Utrecht 1978).

letters from a young woman whose dates cancelled as soon as they found out about her mentally ill mother,[100] a mother who emotionally appealed to the public to stop calling children like hers 'crazy' or 'lunatic',[101] and a man who had postponed visiting his cousin in a psychiatric institution for years because he had been scared to go there.[102] These examples show three kinds of stigma that relations could experience: being excluded directly as a relative of someone with mental health issues, undergoing the pain of vicarious stigma when a loved one was stigmatised, and discovering prejudices in themselves that created a barrier between themselves and a loved one.

A literary reflection: Terug naar Oegstgeest (1965)

Whereas today, mental health issues are a common theme in literary writing, it is very hard to find them in Dutch novels of the 1960s – illustrating, perhaps, what a taboo subject this was at the time. In the work of Jan Wolkers, however, they are a minor, but recurring motif in stories based on memories of his youth. These writings in themselves mirror how stigmatised mental health issues were at the time. But Wolkers not only reflected negative stereotypes and prejudice. In the name of art, he also exaggerated them to an extreme and in doing so contributed to stigmatising mental health problems even more.

Wolkers became known, in the early 1960s, as a taboo-breaking author for whom nothing was sacred. The main reason why his books were controversial, was the graphic way he wrote about sex and his blasphemous portrayals of the Reformed faith in which he had been raised. Embraced by the young, progressive part of the nation that wanted to break away from the stifling atmosphere they had grown up in, while maligned by 'decent', religious, traditional folk, Wolkers became a literary sensation.[103]

How psychiatric patients came to be part of Wolkers's work had to do with the strong autobiographical character of his work: he had been born and raised in the town of Oegstgeest, where Endegeest psychiatric hospital was located. For a while, his family even had a patient, Marie, live with them as part of her treatment. The author used that experience for the story 'Gezinsverpleging' (Family Care) in his debut short story collection *Serpentina's petticoat* (1961). Based on Wolkers's childhood memories, the story portrays the family as taking Marie in for the money, talking about her in the most derogatory way and treating her so badly that in the end, the hospital takes her back. Like in other towns where large institutions were established, the story suggests that the ties between Endegeest

---

[100] 'Margriet weet raad', *Margriet* 27 (1964) 39, 164.

[101] 'Margriet weet raad', *Margriet* 27 (1964) 6, 93.

[102] 'Margriet weet raad', *Margriet* 27 (1964) 14, 125.

[103] Erica van Boven, *Bestsellers in Nederland 1900-2015* (Antwerpen, Apeldoorn 2015) 127-128; Onno Blom, *Het litteken van de dood. De biografie van Jan Wolkers* (Amsterdam 2017) 544-546.

and the local population were quite close, but it also shows how that did not necessarily mean that the stigma in such communities was less than elsewhere. Little Jan Wolkers, the narrator of the story, seems to enjoy portraying Marie in the worst light possible.[104]

The author's disregard of Marie is underlined by the fact that he presented her under her real name, in full. When a health inspector discovered this, he demanded that the book be withdrawn from the shops, and any further printings of the story should no longer reveal the patient's identity. Wolkers's publisher replied that – although Marie was a young woman and still a patient in Endegeest – the author had had no idea that she was still alive. The book was not withdrawn. Only the first lines of the story were changed a little, and Marie's last name was deleted.[105] Meanwhile, *Serpentina's petticoat* continued to be read widely – in 1977, after twenty-seven print runs, one hundred sixty thousand copies had been sold.[106]

Wolkers's fifth book, the novel *Terug naar Oegstgeest* (Return to Oegstgeest, 1965), was entirely inspired by his memories of growing up in Oegstgeest.[107] It was an immediate success in the 1960s – within a month, twenty thousand copies were sold – and became Wolkers's first bestseller, with a total of one hundred sixty copies sold in 1977, and probably reaching a readership many times that through public libraries.[108] It has been enjoyed by generations of readers ever since – in 2015 the forty-first print run was produced – and is considered the author's most important book.[109] A minor storyline in *Terug naar Oegstgeest* portrays patients in Endegeest hospital and their relations, again through the eyes of a young Jan Wolkers.

From his side of the fence, the boy watches patients and the family members who visit them sitting on benches in the hospital gardens. Describing the patients as lumps of flesh, barely recognisable as humans, the only thing that makes these individuals human to the narrator is the loving attention of their relations. That humanity is so incomprehensible to him that it disappears as soon as it is time for the visitors to go home:

"... als het bezoek- en uitgaansuur voorbij was bleven ze allemaal levenloos achter het hek staan, en op al het wuiven en daggeroep kwam geen teken van herkenning. Als de familieleden wegliepen

("... when visiting hour was over, they all stood lifeless behind the fence, and there was no sign of recognition in all the waving and calling goodbye. When the family members walked away, sometimes

---

104 Jan Wolkers, 'Gezinsverpleging', in: *Alle verhalen van Jan Wolkers* (Amsterdam 1981) 14-21.

105 Blom, *Het litteken van de dood,* 88-93.

106 Rob van den Dobbelsteen, 'Eigen succes verbaast Jan Wolkers', *Het Parool* 7 April 1977.

107 Jan Wolkers, *Terug naar Oegstgeest* (Amsterdam 1965).

108 'Literair nieuws', *Algemeen Handelsblad* 11 December 1965; Rob van den Dobbelsteen, 'Eigen succes verbaast Jan Wolkers', *Het Parool* 7 April 1977.

109 Blom, *Het litteken van de dood,* 560-563; August-Hans den Boef, 'Jan Wolkers, Terug naar

sprong er soms één een eindje achter het hek met doorgezakte knieën mee, maar bleef dan ineens stilstaan, draaide zich om en verdween met een hoge kreet tussen het struikgewas."[110]

one hopped along behind the fence, with sagging knees, but then suddenly stopped, turned around and disappeared with a high-pitched cry into the bushes.")

The way the boy views these patients resembles passages elsewhere in the book bearing witness to the boy's fascination for nature and animals. Through imaginative detail and colourful contrasts, Wolkers likens the patients to ungainly animals, and then describes one as an elegant deer. He highlights the loving way the patients and their relations interact, but ridicules them at the same time when he points out how senseless that is to him.

The passage continues with the little boy overhearing an orderly talk to his father about the extreme deformities of some patients and how, in his eyes, it is a crime against the Creator that these motionless beings were left alive. Those remarks inspire the boy to let his fantasy run free. While continuously adding aesthetic details, the depiction of the patients becomes an outright horror story that dehumanises them even further, reducing them to amoeba or plants:

"Vanaf die tijd waren voor mij de zolders van die strenge gebouwen die daar in de verte tussen het donkere geboomte lagen bevolkt met afzichtelijke wezens, die niet eens in bedden lagen maar op vochtige aarde of die in aquaria ronddreven. Wezens tussen plant en dier, met hoofden als weke meloenen, waarbij het vlees groeide als stengels en bladeren. Die er misschien weken over deden om hun vormeloze ledematen vijf centimeter vooruit te schuiven. Die doorzichtig waren zodat je de organen zag zitten, als bij een visje of een kale jonge vogel. Die als kwallen tot een plasje vuil vocht zouden wegsmelten als de zon op ze scheen."[111]

("From that time on, in my mind, the attics of those austere buildings that lay there in the distance among the dark trees were populated with hideous creatures, that were not even in beds but on damp earth or floating about in aquariums. Creatures between plant and animal, with heads like soft melons, with flesh growing like stems and leaves. That may have taken weeks to move their shapeless limbs forward five centimetres. That were transparent so that you could see the organs, like a fish or a featherless young bird. That would melt away like jellyfish into a puddle of dirty liquid when the sun shone on them.")

Oegstgeest,' in: Ton Anbeek, Jaap Goedegebuure & Marcel Janssens, *Lexicon van literaire werken. Besprekingen van Nederlandstalige literaire werken 1900-heden* (Groningen 1990) 12-13.

[110] Wolkers, *Terug naar Oegstgeest,* 65.

[111] Wolkers, *Terug naar Oegstgeest,* 66.

In a lecture Wolkers held at the centenary of Endegeest in 1997, he revealed where the inspiration for these images came from: from the stories told by a boy in his class whose father was an orderly in the hospital. One afternoon, the boys managed to get into one of the attics where these creatures were supposedly kept – only to find the space occupied by freshly washed sheets, hung out to dry.[112] That experience did not stop the young author from using the fantastical stories as a source of inspiration. And when *Terug naar Oegstgeest* was first published, no critic commented on these passages. Assessing Wolkers's writing as a whole, some critics noted his 'cruel realism', but saw a great sensitivity below its surface.[113]

Reading these passages in the context of stigma, what is striking is the grotesque fantasy of the little boy who inflates the stereotypical images of psychiatric patients. Those images are exaggerations of the stereotypical images that already lived in the mind of large parts of the public, as the contemporary stigma surveys showed. And through their exaggerated character, it is conceivable that these images in turn promoted and enlarged stereotypical and stigmatising ideas about people with severe mental health issues for the many readers of *Terug naar Oegstgeest.*

The cynical reader might observe, however, that Wolkers' poetic rendition of the madhouse sounds quite similar to the way psychiatrist Willem van der Scheer described Dutch mental institutions in the 1950s:

"Zolang het verplegend personeel niet eens bemerkt, dat de patiënten met afzakkende broek rondlopen, indien tijdens de maaltijd druppels van patiëntenneuzen in het eten van de buurman vallen, als men patiënten ziet zitten met naakte benen blauw van de kou, als men achter hoge hekken patiënten maar heen en weer ziet lopen met een uitdrukkingsloze blik, of onbeweeglijk ziet staan in katatone houding, indien men nog inrichtingen heeft waar patiënten hun behoeften moeten doen op een open wc ten aanschouwe van de andere patiënten, of waar men hen vastgebonden vindt aan de spijlen van hun bed, in een dwangbuis

("As long as the nursing staff does not even notice that the patients are walking around with sagging pants, if drops from the patients' noses fall into their neighbour's food during the meal, if one sees patients sitting with naked legs blue from the cold, if one sees patients walking back and forth behind high fences with an expressionless look, or motionless in catatonic stance, if there still are establishments where patients have to relieve themselves in an open toilet in front of the other patients, or where one can find them tied to the bars of their bed, squeezed into a straitjacket

---

[112] Jan Wolkers, 'De geest waait', in: Gemma Blok & Joost Vijselaar, *Terug naar Endegeest. Patiënten en hun behandeling in het psychiatrisch ziekenhuis Endegeest 1897-1997* (Nijmegen 1998) 139-145, 140.

[113] *Jan Wolkers: Serpentina's petticoat* (Nederlandse keur no. 59, Purmerend 1967) 15.

geperst of met een spanlaken geïmmobiliseerd, of hen naakt aantreft in cellen met stevige grendels op de deuren en men reeds uit de verte hoort razen, gillen, schelden, dan wordt het toch moeilijk de niet-ingewijden te vertellen dat onze geesteszieken het toch zo goed hebben en goed worden verpleegd."[114]

or immobilised with a restraint sheet, or naked in cells with strong bolts on the doors and one hears them raging from afar, screaming, cursing, then it becomes difficult to tell the uninitiated that our mentally ill are so well off and well cared for.")

In the arena

The Dutch mental health care arena that Al-Anon and Pandora entered in the 1960s consisted of the professionals and their institutions, the government and the public. In the general public, as we have seen, most people had more preconceptions than actual knowledge of mental health issues and mental health care, and thought it best to keep those suffering from such issues and their relations at a distance. The government was also not very involved. Mental health care legislation, for example, had been neglected to the point that a proposal for a new law replacing the *Krankzinnigenwet* (Insanity Act) of 1884, a proposal that was drafted in 1955, had vanished in a drawer.[115] The mental health care arena of the 1960s was exactly that: the arena of mental health care professionals, where doctors and nurses, as benevolent (or less benevolent) 'fathers' and 'mothers', cared for voiceless patients. Voiceless in a new way, even: the new types of medication that were hailed by the experts as the road to recovery did indeed calm down restless patients, but numbed and stupefied them too. As a consequence, journalist Michiel Louter found that former patients he interviewed about their experiences in Dutch psychiatric hospitals in the twentieth century were unable to tell him much about the 1960s.[116]

Those voiceless patients surely had relations, but once a child or an adult loved one was admitted to an institution, the family often vanished into the background. Many patients were hospitalised far away from home, in places that were hard to reach, and regular visits were not a luxury everyone could afford.[117] Relatives were not told much about diagnosis

---

[114] Quoted in G. Blok, ' "Onze eigen kleine wereld". De provinciale ziekenhuizen in het tijdvak 1945-1965', in: Joost Vijselaar (ed.), *Gesticht in de duinen. De geschiedenis van de provinciale ziekenhuizen van Noord-Holland van 1849 tot 1994* (Hilversum 1997) 168.

[115] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 858.

[116] Michiel Louter, *Uit de inrichting. Vertelde verhalen over tachtig jaar inrichtingspsychiatrie in Nederland (1925-2005)* (Amsterdam 2005) 58.

[117] Joost Vijselaar, ' "Vrijheid, gelijkheid en broederschap". Een revolutie in de psychiatrie', in: Joost

or treatment – there was no need to worry, hospital staff usually told them, and they could rest assured, as the patient was in the capable hands of the experts. Getting in touch with the doctor was hard, if only because his office hours were extremely limited, and he often spoke in a jargon that was hard for a lay person to understand – instead, the relatives were guided with a firm hand by the institution's social worker. Doctors and head nurses were authorities whose decisions, for patients and relations alike, were hard to challenge, or even ask questions about.[118] Looking back, psychiatric nurse Wil van der Laak, who started working in Voorburg psychiatric hospital in Vught in 1967, feels embarrassed about the blind spot he and his colleagues had for the family. But he also remembers seeing them only after a patient had passed away, when they came to collect the savings from welfare benefits that had never been used.[119]

It is with the professionals on the one hand, and the general public (including relations) who were guided by ignorance and prejudice on the other, that Al-Anon and Pandora engaged. Those experts were important allies to them; that public was their target group. It is on these two main players in the arena that the following sections focus, uncovering how the young organisations approached them, how the organisations were received by them, and how the interactions between them shaped ideas and actions on both sides.

The mental health care field

To both Al-Anon and Pandora, mental health care professionals and institutions were important allies, whom they needed to be able to start working towards their goals. Both had some support to begin with. As we saw, Dutch Al-Anon was either directly or indirectly introduced to the Netherlands by the professionals who had brought AA to the country, Henk Krauweel and Piet Esser. They also served on the advisory board of Dutch AA, they were speakers at national and regional meetings, and they were regular contributors to newsletter *De Boei*.[120] That did not mean, however, that it became common for addiction care workers and psychiatrists who treated alcoholics to have a relationship with AA and Al-Anon. Far too few professionals collaborated with AA, Esser complained in his book *Alcoholisme* (Alcoholism, 1960), that he dedicated to AA.[121] As a consequence, not many relations of alcoholics may have been referred to Al-Anon.

Vijselaar (ed.), *Gesticht in de duinen. De geschiedenis van de provinciale ziekenhuizen van Noord-Holland van 1849 tot 1994* (Hilversum 1997) 192.

[118] Van der Kroef, *25 jaar,* 22-24.

[119] Interview Wil van der Laak, 11 January 2023.

[120] Esser, 'Is alcoholisme een ziekte?', *De Boei* 9 (1965) 4 [1-2]; Hans, 'Wensen voor de AA... Mildheid en blijheid', *De Boei* 13 (1969) 1 [1]; Van der Stel, *Drinken, drank, dronkenschap,* 310.

[121] Esser, *Alcoholisme.*

The way in which addiction care experts who were involved in AA were generally referred to in *De Boei* indicates a warm but paternalistic relationship between professionals and AA members. That did not mean, however, that AA members were completely docile. When Esser complained in his book that Dutch AA groups did not work together, that senior members dominated their juniors and that they followed their own course too much,[122] an article in *De Boei* challenged him by asking why he, as a member of their advisory council and long-standing ally, had never taken up his issues with AA directly. The article showed that AA members did not unquestioningly accept everything the doctor said:

> *"Wij begrijpen dat de psychiater Esser zo zijn eigen gedachten heeft over de rol die de psychiatrie zou kunnen spelen rondom, boven en zelfs in de AA. En wij hopen dat hij van zijn kant zal billijken dat de AA hierover eveneens haar eigen gedachten heeft."*[123]

> ("We understand that psychiatrist Esser has his own thoughts about the role psychiatry could play around, above and even in AA. And we hope that he, for his part, will agree that AA has its own thoughts on this matter as well.")

By contrast with AA, professionals had nothing to do with the initiative to set up Pandora. Still, the foundation intended – needed – to build up a fruitful relationship with the field in order to be able to expand its activities. Although Pandora prided itself in being a lay organisation, for its first board, Arnold van Ameringen had also invited two psychiatrists who worked at the NFGV, the federation of the organisations in the Dutch mental health movement.[124] It is unclear, however, to what extent they supported Blase in her efforts to build a relationship with the field, although the two knew the arena well enough to expect resistance, as one of them said: *"...'t wereldje kennende dacht ik nou, we beginnen wèl wat, want de psychiatrische inrichtingen zijn van oudsher tamelijk gesloten bastions"* ("... knowing the field, I thought, we are taking on quite a challenge, as the psychiatric institutions traditionally are quite closed bulwarks").[125]

Psychiatry, traditionally, was indeed a lonesome island in medicine, as historian Reinhilde van der Kroef put it. The general opinion of psychiatrists was that their patients were better left in peace in their own little world. And then Treeske Blase came along looking for information and collaboration, oblivious of what mental health care was, and uninhibitedly acknowledging that she was full of taboos herself. After Van Ameringen suddenly passed away from a heart attack in early 1966, not even a year after he had

---

[122] Esser, *Alcoholisme*, 133.

[123] 'Opgedragen aan de A.A.', *De Boei* 4 (1960) 11, [4].

[124] Van der Kroef, *25 jaar,* 25.

[125] Van der Kroef, *25 jaar,* 35.

hired her, she had been left to build the foundation largely on her own.[126] But having no knowledge and no status at all, doors were closed in her face, sometimes literally:

> *"... niemand zat op Pandora te wachten. Ik was geen psychiater, ik maakte mij het vakjargon niet meester omdat ik aan de kant van de leek wou blijven staan, en daardoor was ik een quantité negligeable. Ik herinner me nog een geneesheer-directeur die tegen me zei: 'Alles wat van Pandora komt, verscheur ik meteen. Ik heb niks met u te maken.' "*[127]

> ("... nobody was interested in Pandora. I wasn't a psychiatrist, I didn't master the jargon because I wanted to stay on the side of the lay person, and that made me a negligeable quantity. I remember a medical superintendent who said to me: 'Anything that comes from Pandora, I tear up right away. I have nothing to do with you.' ")

Just like Clifford Beers had only been a poster boy for the original American mental hygiene movement, lay people like Van Ameringen and Blase were not supposed to stick their noses in matters regarding the Dutch mental hygiene movement in the 1960s either. Yes, they should get involved in mental health care, as psychiatrists had suggested since the 1930s, but only on the professionals' terms and directions, in ways that supported them in their difficult work.[128] That authoritarianism was not about to go away. Despite the progressive and even revolutionary atmosphere that started spreading through Dutch mental health care from the late 1960s onwards, paternalism remained a clear hallmark of the field until at least the mid-1970s.[129]

Letting adversity discourage her, however, was not Blase's style. But she needed a different approach to get in. Van Ameringen had initially offered her the title of director, but she insisted on presenting herself as a secretary – there was nothing to direct yet, she felt, only a sum of money, plus she associated a 'director' with a stern matron and did not want to be regarded that way.[130] Although her attitude may have been fitting with the rising democratic spirit in society, this worked against her in a sector that was nowhere near allowing lay people to enter it on an equal footing. When after a few years, Blase started using the title *gedelegeerde van het bestuur* (delegate of the board), the first doors started to open.[131]

---

[126] Van der Kroef, *25 jaar,* 33-37; Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 401-402.

[127] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 401.

[128] Van der Kroef, *25 jaar,* 18.

[129] De Goei, *De psychohygiënisten,* 289.

[130] Interview Treeske Blase, 28 September 2018; J. Mijs, 'Waarom gek? Omdat ie anders is?', *Algemeen Handelsblad* 20 June 1969.

[131] Van der Kroef, *25 jaar,* 35-37.

The media and the public

Reaching the public was fundamental for both Al-Anon and Pandora. But for Al-Anon, the way to go about that was not as straightforward as we might think. As anonymity was one of its most important traditions, it was out of the question for AA and its affiliate organisations to launch a PR campaign to inform the public and recruit new members. Their message was spread through 'attraction', or personal contact, as tradition 11 prescribed.[132] The stigma surrounding alcoholism and the silence and isolation that resulted from that must have made that attraction quite complicated. But the addiction care professionals who were allied with AA could make up for that by referring people.

In 1960, however, there were only two active Al-Anon groups in the Netherlands: the original one in Amsterdam and another one in Rotterdam. At that point in time, AA, in contrast, had groups in 32 cities and towns all over the country.[133] In 1964, a third Al-Anon group in Arnhem was mentioned in *De Boei*,[134] but the groups operated with such a low-profile that the editor of the newsletter wondered later that year if any of the groups were still active at all.[135] And apparently, it was so unclear what the Al-Anon groups did, that the suggestion was even put forward that they take in female alcoholics, as surely they would be better equipped to deal with them and their 'female psyche' than the all-male AA groups.[136]

We might expect that AA members would refer their spouses to the self-help groups that were there for them. Articles in *De Boei* suggest, however, that the husbands were indeed well aware of the wives' groups, but that many were distrustful of what happened there. They were afraid that they would be bad-mouthed and gossiped about, and therefore forbade their spouses from joining.[137] In addition, many wives were too scared to join Al-Anon because of 'the environment': trying at all cost to keep their family's problems hidden from neighbours and members of the extended family, the risk was too high for them, despite the promised anonymity.[138] Supporters of Dutch Al-Anon repeatedly countered those fears and misconceptions by presenting the example of Belgian AA and Al-Anon. In the neighbouring country, those who joined AA were *expected* to refer their relations – wives as well as husbands and children – to an Al-Anon group, and if the family did not show up there, a social worker paid them a visit. As a result, Belgian Al-Anon was thriving.[139] But apparently, the example was not followed in the Netherlands, leaving Dutch Al-Anon in the 1960s to depend on couples brave enough to resist the prejudice that stood in the way of the family group initiative.

---

[132] *Alcoholics Anonymous Comes of Age*, 286; Esser, *Alcoholisme*, 133-134.

[133] 'Contacten', *De Boei* 5 (1960) 1/2, [6].

[134] 'Contacten', *De Boei* 8 (1964) 3, [6].

[135] 'Al-Anon waar?', *De Boei* 8 (1964) 9, [2].

[136] 'Vrouwelijke alcoholisten', *De Boei* 8 (1964) 11, [2].

[137] Al-Anon-Rotterdam, 'Al-Anon', *De Boei* 9 (1965) 11, [4]; 'Voor u, Al-Anon', *De Boei* 14 (1970) 6, [2-3].

[138] Annie-Amsterdam, 'Waarom en voor wie Al Anon', *De Boei* 13 (1969) 3, [4].

[139] 'Al-Anon', *De Boei* 11 (1967) 10, [6].

It was not until the 1976 national convention, when for the first time a separate session was organised for Al-Anon members, that Dutch Al-Anon was boosted significantly. From that moment on, representatives of local groups held regular national meetings, filled one or two pages in every issue of *De Boei*, and one of them, 'An-Eindhoven', stepped up to the plate and became the nationwide contact for international Al-Anon.[140] This may be why Dutch Al-Anon places its origins in 1976;[141] they can be traced back however, as we saw before, to 1961, when it took on the name Al-Anon, or even to 1956, when the first family group started.

Pandora, by contrast, set out to engage actively and openly with the public as soon as its first activities were ready to go. That happened in 1968, when with the help of new ally psychiatrist Alexander Poslavsky, the medical superintendent of the Willem Arntszhoeve in Den Dolder, Blase organised Pandora's first excursions to the psychiatric hospital. Convinced that the young generation was more open-minded and not yet set in its opinions, Blase focused on students in their late teens. An excursion group would first be received by the medical superintendent, then join patients during occupational therapy, and share their experiences in a group discussion to conclude the day.[142] The effects of the excursions were scientifically researched, resulting in the conclusion that the students' knowledge of psychiatry and attitude towards psychiatric patients improved only temporarily. But that was enough for Pandora to build on.[143]

The excursions were the start of Pandora's first anti-stigma campaign. As a souvenir, students who had taken part in an excursion were offered a Pandora poster in contemporary flower-power style. Blase was well aware of what was popular among young people in the late 1960s and early 70s, when Pandora got started: the hippie youth culture with its message of love and understanding and its colourful artistic expressions. It was the contemporary style of young people who were liberating themselves from the conservative, stifling atmosphere they had grown up in, claiming their freedom to let their hair grow long, dress alternatively, play rock music, use drugs, live communally and have sex without the limitations of marriage.[144]

Although Pandora's board and its delegate were anything but hippies, Blase figured that that style was an ideal vehicle for communicating Pandora's taboo-breaking message to its main target audience. The hippie design of the poster she had commissioned was not a problem for Pandora's board of upper-class gentlemen. But the slogan she put on it, '*Waarom gek? Omdat-ie anders is?*' (Why crazy? Because he's different?), brought her

---

[140] An-Eindhoven, 'Bericht voor de Al-Anon familieleden', *De Boei* 20 (1976) 12, [7]; 'Al-Anon', *De Boei* 21 (1977) 1, [3].

[141] 'Al-Anon/Alateen', https://nl.wikipedia.org/wiki/Al-Anon/Alateen accessed 28 July 2023.

[142] J. Mijs, 'Waarom gek? Omdat ie anders is?', *Algemeen Handelsblad* 20 June 1969.

[143] Van der Kroef, *25 jaar*, 33.

[144] Nelleke Bakker, Jan Noordman & Marjoke Rietveld-van Wingerden, *Vijf eeuwen opvoeden in Nederland. Idee en praktijk 1500-2000* (second revised edition; Assen 2010) 380-385.

to the brink of losing her job. The use of the word 'crazy', the board members felt, was completely inappropriate. Blase managed to convince them, however, that the public should be addressed in its own terminology.

The poster became a big hit, and the *'Waarom gek?'* campaign was expanded with a brochure and an educational film that was shown in schools. Inspired by Van Ameringen's slogan that the prejudice that mental illness was incurable, dangerous and shameful should be fought, Blase's campaign conveyed a message drawn from the biomedical explanation that mental health issues were in fact illnesses, and that people suffering from them were not 'crazy' but patients, who after treatment with modern medication by modern professionals in modern hospitals, were cured when they returned home.[145] In the brochure, she wrote:

"Zo bezien, zijn geesteszieken normale mensen die afwijken. Mensen die (tijdelijk) ziek zijn en dus geholpen moeten worden. Net als andere zieken."[146]	("When you see it that way, the mentally ill are normal people who are different. People who are (temporarily) ill and have to be helped. Just like other people who are ill.")

Al-Anon basically introduced the same biomedical explanatory model to their (potential) members, in proposing that alcoholism was an illness. Their message was more complicated, though, because the spouse of the alcoholic was to be considered ill, too. Dealing with an alcoholic for years, *De Boei* explained, changed a partner's behaviour towards the addicted person to the extent that it also became problematic.[147] For example, many wives made excuses for their husbands' behaviour, kept up appearances, stayed home out of shame, or went out to work because their husbands were unable to provide. In doing so, they unwillingly enabled their husbands' drinking and made the suffering of their families continue.[148] In addition, their efforts to control their husbands' behaviour also drove the men to drink:

"Omdat een alcoholist een eenzaam mens is, moeilijk voor z'n omgeving als hij dronken thuis komt en dan maar al te vaak ontvangen wordt op een manier, die hem alleen maar naar de borrel drijft – daarom vormt de A.A.	("Because an alcoholic is a lonely person, difficult for his environment when he comes home drunk and then is all too often received in a way that only drives him to drink – that is why AA forms

---

[145] Van der Kroef, *25 jaar*, 31-33.

[146] Quoted in Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 403.

[147] Wil-Amsterdam, 'Een verlengstukje van de AA: Al-Anon', *De Boei* 6 (1962) 6, [1].

[148] 'Goede raad voor de huisgenoten van de alcoholist', *De Boei* 11 (1967) 4, [4-6].

familiegroepen, waarin de moeilijkheden die een alcoholist heeft en geeft worden besproken met de naaste familieleden."[149]

family groups, in which the difficulties an alcoholic has and causes are discussed with close family members.")

The situation could be turned around if a wife took on the 'magnificent task' of supporting her husband's recovery in AA.[150] To many, the biomedical or illness approach offered the intended relief,[151] but there was criticism too for the way it took the responsibility away from the alcoholic.[152]

AA and Al-Anon considered alcoholism a chronic illness, even if a person had been sober for many years. Pandora, by contrast, did not mention that mental illnesses could be life-long. The foundation presented the optimistic expectation that soon all severe mental illnesses would become curable as a fact. In addition, they portrayed the psychiatric hospitals as modern, light, comfortable places to stay. Journalists criticised the *'Waarom gek?'* campaign for painting a picture of Dutch psychiatry that was far too flattering.[153] After the newspaper *Het Parool,* in response to the brochure, published an interview with a former patient who spoke about forced feeding and isolation cells, Blase wrote in Pandora's defence:

"Het zou niet eerlijk zijn om te stellen dat alle 39 psychiatrische centra in ons land een toonbeeld zijn van hypermoderne behandelingsmethoden, schitterende verpleegafdelingen en paradijselijke sferen. [...] *Maar het is wél bezijden de realiteit om deze centra voor te stellen als oorden waar zich dag in dag uit huiveringwekkende taferelen zouden afspelen.*"[154]

("It would not be fair to say that all 39 psychiatric centres in our country are a paragon of hypermodern treatment methods, magnificent wards and heavenly atmospheres. [...] But it is far from reality to present these centres as places where terrifying scenes take place every day.")

When asked why the campaign film did not show patients with severe, chronic issues, director René van Nie responded:

---

149 'Zo probeert men het', *De Boei* 1 (1956) 15, [1-2, 2].

150 'Vrouwen aan het woord in de A.A.', *De Boei* 6 (1961) 2, [2-3, 2].

151 Rie-Haarlem, 'Echtgenote van een A.A.-er aan het woord', *De Boei* 14 (1970) 6, [3].

152 'Wat is alcoholisme', *De Boei* 10 (1966) 7-8, [1-2, 1].

153 P.v.d.E., 'René van Nie geeft een rooskleurig beeld', *De Tijd* 21 March 1969; T. Blase, 'Nog eens: terug in maatschappij', *Het Parool* 24 October 1970.

154 T. Blase, 'Nog eens: terug in maatschappij', *Het Parool* 24 October 1970.

"Maar als we dit zouden hebben laten zien, zouden alle lichtere patiënten, die de grote meerderheid vormen, toch met deze ernstige situatie in verband zijn gebracht. Dat zou averechts werken."[155]	("But if we had shown that, all milder patients, who are the great majority, would have been associated with this serious situation. That would have been counter-productive.")

Blase knew that they were presenting Dutch psychiatry in a too-favourable light, and it was a conscious choice: *"Ik dacht toen: je moet een beetje de reclamewetten volgen – een iets te sterk positief beeld tegenover het negatieve stellen, om neutraal uit te komen"* ("At the time I thought: you should follow the advertising rules – use a slightly too-positive image opposing the negative, so you end up neutral").[156]

Even if critics considered the picture that Pandora painted of mental health care too rose-tinted for the reality of the psychiatric hospitals, or the picture of alcoholism in Al-Anon as too-greatly absolving for alcoholics, the intention in both was to lift the burden of shame from the shoulders of alcoholics and other patients alike, and, in the case of Pandora, to change the perception the public had of them for the better. These concerns did not extend to the relations. What stands out in the messages of both predecessors of the family movement is how they approached the bystanders: the closer they were to the patient, the more they were reproached and lectured on what they had done wrong and how they should change their ways. A recurring theme in *De Boei* was how friends, business relations and members of the extended family pushed recovering alcoholics towards that 'first drink' that would ruin their sobriety:

"Als Jantje onder een auto is geraakt en met beenbreuken in het ziekenhuis ligt, zult U hem niet gaan vertellen dat thuis nieuwe rolschaatsen op hem wachten zodat hij onmiddellijk weer met vallen kan beginnen! Noch zult U oom Kobus, die met een dubbele longontsteking ligt, vertellen dat U alvast een pond goede dubbelgesausde shag voor hem heeft gekocht. [...] *Maar wat doet U wel, als U familieleden gaat bezoeken*	("If Jantje were hit by a car and were in the hospital with leg fractures, you are not going to tell him that new roller-skates are waiting for him at home so that he can immediately start falling down again! Nor will you tell uncle Kobus, who is in bed with double pneumonia, that you have already bought him a pound of good double-sauced tobacco. [...] But what do you do when you go to

---

[155] P.v.d.E., 'René van Nie geeft een rooskleurig beeld', *De Tijd* 21 March 1969.
[156] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 402.

> *die waar dan ook een ontwenningskuur ondergaan omdat ze alcoholist zijn? Dan plaatst U de volgende beloften (aan de praktijk ontleend!):*
> *- Nou Kees, als je weer thuis komt dan gaan we gezellig een avondje uit, en dan drink je maar eens rustig een klein borreltje met ons mee!*
> *- Niet zo somber, ome Joop! Je blijft hier niet eeuwig! Zodra je hier weg gaat kom je maar eens gauw bij ons langs en dan geven we hem eens ouderwets van katoen!*
> *- Ik heb thuis nog een litertje staan, vader, en dat bewaar ik totdat je weer thuis bent. Je zult zien: als je het maar kalm aan doet, dan komt alles in orde.*
> [...] *Als u alcoholisten bezoekt dan heeft U te doen met mensen die aan een kwaal lijden. Een ongeneeslijke kwaal. Een aandoening die onmiddellijk en in alle hevigheid zich openbaart zodra de patient alcohol drinkt* [...].*”*[157]

> visit family members who are in rehab somewhere because they are alcoholics? Then you make the following promises (derived from practice!):
> - Well, Kees, when you come home we will go out one night, and then you can calmly have a little drink with us!
> - Not so gloomy, uncle Joop! You won’t stay here forever! As soon as you leave here, you better come and visit us and we’ll go for it like we used to do!
> - I still have a little gallon at home, father, and I’ll hold on to it until you get home. You’ll see: as long as you take it easy, everything will be fine.
> [...] If you visit alcoholics, you are dealing with people who are suffering from an illness. An incurable illness. A condition that manifests itself immediately and in full intensity as soon as the patient drinks alcohol [...].”)

But the spotlight fell on the wife of the alcoholic more than on anyone else. In his book *Alcoholisme*, psychiatrist Piet Esser acknowledged how hard her life was with her husband, but in describing their symbiotic relationship, she was the one who was made to look bad:

> *“De vrouw kan b.v. bevrediging vinden in het bemoederen van haar infantiel gebleven of geregredeerde man, als hij, na een drinkpartij, huiswaarts keert. Ook zal het haar soms op masochistische wijze bevredigen door hem te worden geslagen en uitgescholden. Weer andere vrouwen*

> (“The wife, for instance, may find satisfaction in mothering her infantile or regressed husband when he returns home after a drinking binge. Also, it will sometimes satisfy her in a masochistic way to be beaten and scolded by him. Still other wives

---

[157] A.R.-Amsterdam, ‘Geachte familieleden en vrienden’, *De Boei* 4 (1960) 10, [4].

gebruiken de drankzucht van hun man om hem in een afhankelijkheidspositie te brengen of te houden.”[158]

use their husband’s drinking to make or keep him dependent on her.”)

Articles in *De Boei* gave attention to her misery at length, but also held up a confronting mirror to her own behaviour. By reproaching him, accusing him, nagging him, ridiculing him, shaming him, threatening him, misleading him or begging him, understandable though such efforts to make him change were, she would drive him back to the drink. Instead, every wife should educate herself about alcoholism, about how to support the recovering alcoholic, and how to change her own reactions to him. She should learn to take responsibility for herself and let him take his, and to treat him with the compassion a sick man deserved, but at the same time with the respect a husband deserved, without distrust or dragging things up from the past. Although towards the end of the 1960s, the accent on the wife’s responsibility for her own life grew stronger, most of the advice to the wives up to that point in time was directed at restoring the traditional hierarchy in the marriage by having her let him take back the lead role:

“Het is een gewoonte die we hebben aangekweekt in de jaren dat we zelf de teugels wel in handen móésten nemen, maar als we zien dat het niet meer nodig is, zullen we op den duur die teugels toch met plezier weer moeten overlaten aan de man, die tenslotte toch beter geschikt is als voerman dan wij.”[159]

(“It is a habit that we have cultivated in the years when we had to take the reins into our own hands, but if we see that it is no longer necessary, we will eventually have to happily leave those reins to the man, who after all is better suited as a driver than we are.”)

Just as in Al-Anon relations were confronted to change their ways, so was the young reader of Pandora’s *‘Waarom gek?’* brochure:

“Als zo iemand de laan van het ziekenhuis komt afwandelen met een treinkaartje in z’n zak naar huis, is hij beter. Dat beter betekent:

(“When such a person comes walking down the hospital driveway with a train ticket home in his pocket, he is cured.

---

[158] Esser, *Alcoholisme*, 190.

[159] ‘Vrouwlief-Amsterdam’, ‘Het wonder is van nabij het schoonst’, *De Boei* 3 (1959) 12, [2].

> *weer goed voor de maatschappij. En láát hij dan... misschien... soms eens wat eigenaardig doen. Net zo eigenaardig als wij allemaal van tijd tot tijd. Mag ie alsjeblieft!"*[160]

> Cured as in: good for society again. And yes, perhaps sometimes he will act a little strange... Just as strange as we all act from time to time. Can he, please?")

The tone of the brochure was quite straightforward, but it was very friendly in comparison with another Pandora publication: *Moeilijk in de omgang* (Difficult to Get Along With), an educational pocketbook the foundation gave away for almost a decade, from 1970 to 1979. In this book, psychiatrist Machiel Zeegers downright accused close family members, friends and neighbours of being resistant, mocking and hostile, usually because they were ignorant. Zeegers explained all the things the environment did wrong: not take patients seriously, laugh at them, tell them to man up and behave, ask too much, ignore or avoid them, hide them, downplay their problems, get angry or treat them as inferior. Although psychiatrists also had to deal with patients sabotaging their good work and the media and the government undermining it with discriminating policies, the largest chapter in the book caricatured specific types of relations and other people who worked against the doctor: the mother who knows the patient better, the indignant wife, the firm sister-in-law, the impatient husband, the preaching minister, the doctor who gives 'different' advice...[161]

Similar to how AA and Al-Anon educated their members, Zeegers lectured the relatives of people with other severe mental health problems. These relations would have to live with the problem just like patients did, many issues were manageable and patients could recover if only they were received well at home. Family members should treat them with patience, respect, honesty, trust, acceptance and love, especially when going through a difficult time. Of course, the author wrote, he also met good-natured, collaborative relations, but daily encounters to the contrary prompted him to deal the reader an ultimate blow with an insulting allusion to their position in the Second World War:

> *"Het is allemaal niet zo kwaad bedoeld, zegt men. Dat zeggen die echtgenoten, die familieleden, die kennissen, die dominee, die artsen, die instanties, die moppentappers ook. Het zijn niet zulke slechte mensen.*

> ("We don't mean any harm, they say. That is what those spouses, those family members, those acquaintances, that reverend, those doctors, those organisations, those jokers say. They're

---

[160] Quoted in Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 403-404.

[161] M. Zeegers, *Moeilijk in de omgang. Leven met zenuwzieken* (Nijkerk, Den Haag 1970) 90-102 (with imprint *"Aangeboden door de Stichting Pandora"* ("Offered by the Pandora Foundation")).

Maar de brave mensen waren het ook dikwijls, die door hun vooroordelen en valse oordelen het antisemitisme en de rassehaat in de hand werkten. 'Wir haben es nicht gewusst,' zeggen zij dan, als de gediscrimineerde minderheidsgroep omkomt voor hun ogen. Dat zeggen ze ook nu weer, als een zenuwziekte een dramatisch verloop neemt."[162]

not such bad people. But often it was the good people also, who through their prejudices and false judgements supported antisemitism and racial hatred. 'Wir haben es nicht gewusst,' they say, when the minority that is discriminated against dies in front of their eyes. That is what they say now, when a psychiatric disorder takes a dramatic turn.")

Despite the fact that both organisations promoted the idea that patients and their families should shake off the shame, the way the relations were portrayed and lectured by Al-Anon and Pandora illustrates that this was not so simple. Each organisation, however, had a very different way of going about this. Shaking off the shame in Al-Anon meant joining a family group, where a relative found others who had gone through the same hardships and could talk openly about their experiences. It did not mean coming out and confronting the public with their stigmatising attitudes.[163] The tradition of anonymity, although it was repeatedly debated, would always take precedence.[164] Pandora, by nature, chose the exact opposite as a strategy: openness. In the *'Waarom gek?'* campaign, they presented mental health issues as any other (biomedical) illness, as nothing to be ashamed of. But just as during Pandora's early years, the stigmatising experience of its founder Arnold van Ameringen was never mentioned, the patients remained the 'other', and the relations who bore the load of the stigma remained out of sight.

Conclusion

The stigma surrounding mental health issues was stifling in the 1960s. So stifling that the first relations used their painful experiences to take initiatives to do something about it, but also so stifling that they chose to take action without coming out in public. In Al-Anon, wives of alcoholics huddled together, sharing their hardships and shame with each other, but without disclosing their full identities. Pandora's founder Arnold van Ameringen set out to campaign against stigma full on, but did not share how he

---

[162] Zeegers, *Moeilijk in de omgang.*

[163] Van Harberden, *Zelfhulp bij Anonieme Alcoholisten,* 66.

[164] Hans-Delft, 'De anonimiteit der A.A.', *De Boei* 16 (1972) 3, [1-2]; 'Wij, A.A.-ers, en onze anonimiteit', *De Boei* 21 (1977) 3, [1-2].

was motivated by the pain he had felt watching his wife and daughter suffer from the reactions of others upon their discharge from psychiatric hospital. Public stigma, self-stigma, stigma by association and vicarious stigma went hand in hand to hold back the predecessors of the family movement.

That they were not open about how they were touched by stigma meant that they did not develop a politicised collective experience identity. The Al-Anon groups surely adopted a collective identity, but they stayed carefully away from influencing public opinion. That was precisely what Van Ameringen set out to do with Pandora, but he did not invite fellow 'relations-of' to join him in his quest – he engaged members of the elite, as charities had traditionally done, both in the Netherlands and in the United States. Both organisations depended heavily on the involvement of psychiatrists and other mental health care workers, and took inspiration from international developments in the field that were brought to them by their professional allies: the mental health ideology in the case of Pandora, the Alcoholics Anonymous model in the case of Al-Anon. Their target was the environment that made it so hard for people who (had) suffered from mental health problems to recover and be rehabilitated – the stigma and ignorance at the level of society, community and particularly the family.

The public needed to be educated on the biomedical explanatory model, that consisted of beliefs that were very new to them. They had to learn that mental health issues and alcoholism were not a sign of weakness, degeneration or danger; they were not for ever, and they certainly were not something to be ashamed of. Mental health issues were illnesses that could be treated by modern doctors with innovative psychotherapeutic methods and medication in state-of-the-art hospitals, and those who suffered from such illnesses should be treated with the compassion and respect every sick person deserved. The biomedical approach lifted feelings of guilt and shame from patients and their families, making it easier for them to accept their situation, learn how better to deal with it and take responsibility for their own recovery. Research into the preconceptions of Dutch people about psychiatric patients suggested, however, that convincing the wider public of this perspective would not be so easy. Perhaps that is why the organisations focused on educating those in the patient's direct environment, whose attitude and behaviour was deemed crucial to either supporting or undermining the work of the psychiatrist. Change would begin with them, the relations.

§

During the 1960s, Corrie van Eijk-Osterholt regularly took the bus to and from the institution where her sister Mies Osterholt was hospitalised. On those bus rides, she met relations of other patients who were just as unhappy with the appalling standards of care there as she was. She had tried several times to convince them to join forces and protest against poor practices and mistreatment together, so that they could make an impact. But it had been to no avail:

> *"Als velen zouden klagen, zou er misschien meer te bereiken zijn, want alleen was en bleef mijn stem als die van een roepende in de woestijn. Maar telkens bleek me, dat mijn suggestie een te grote stap was voor de mensen. Het idee alleen al maakte hen angstig. Misschien waren zij, die niets ondernamen, toch wijzer dan ik. Want wat bereikte je met je klachten? Ging je naar de dokter, dan beschouwden de nonnen je als vijandig aan hun systeem. Ging je* [...] *naar de Inspecteur, dan liep je je te pletter tegen de muur van de bureaucratie, waarachter zich in alle veiligheid diegenen bevonden, die omwille van hun functie of hun naam beschermd moesten worden."*[165]

> ("If many filed complaints, we might achieve more, because on my own my voice remained one crying out in the desert. But every time my suggestion turned out to be too big a step for the people. The idea alone made them anxious. Perhaps they, who did nothing, were wiser than I was. Because what did you achieve with your complaints? If you went to the doctor, the nuns would consider you in opposition to their system. If you [...] went to the Inspector, you would crash into a wall of bureaucracy, behind which those who needed protection because of their position or their name hid in safety.")

In the early 1970s, Van Eijk-Osterholt would succeed. She would find other courageous relations and together they would start to protest in public. And so indeed, change would begin with the relations, as the professionals had recommended in the years before, but in a way that would turn out quite different from what they had envisioned.

---

[165] Van Eijk-Osterholt, *Laten ze het maar voelen* (1972), 40-41.

Chapter 2

The allied years: The predecessors of the family movement in the 1970s

Looking back, Corrie van Eijk-Osterholt remembered all too well what a plunge in the deep end it was for her to give up her anonymity. For decades, she had kept silent to her colleagues and friends about her sister in the psychiatric hospital, for fear that they would think that there must be something wrong with her too, as an identical twin sister. And the reactions of the few people she had tried to confide in, had confirmed her fear that they did not understand. That is why she intended to keep her identity secret when in 1971 she started looking for a publisher for her book about twenty-five years of advocacy for her sister. But no publisher would accept that condition. After much consideration, she decided to take the leap:

> *"En toen dacht ik: een twee drie in godsnaam maar, maar ik had het wel benauwd. En de dag dat erover in de krant werd geschreven stond er een buurvrouw voor de deur met die hele pagina en zei: bent u dat? Ik dacht dat ik door de grond ging. En toen heb ik gedacht: dit moet over zijn. Ik moet nu zo flink durven te zijn, dat ik er niet langer meer omheen draai. En ik ben er dus over gaan praten* [...]."[1]

> ("And then I thought: one two three for God's sake let's do it, but I was very nervous. And the day that it was written about in the paper, a neighbour came to my door with the whole page and said: is that you? I thought I would die. And then I thought: this must be over. I have to be brave enough now and no longer beat around the bush. So I started talking about it [...].")

Before people with mental health problems and their relations could start to speak out at all, they first had to overcome that crucial hurdle: the taboo on mental health problems and the stigma that marked those who suffered from them. In addition to Corrie van Eijk-Osterholt with her memoir about her sister, *Laten ze het maar voelen...* (Let Them

---

[1] Museum of the Mind, Haarlem, Audiovisual Collection, *De bittere werkelijkheid,* undated video interview Prof. Dr B. Gersons with Mrs. C. van Eijk-Osterholt [1980s].

Feel It..., 1972), Egbert Tellegen took that step with the publication of his book *Waar was de dood nog meer...* (Where Else Was Death..., 1971), about his experiences as a patient during a psychotic episode in 1960. Evelien Paull's recollections of the time she spent in a psychiatric hospital were seen as the third influential book that broke the silence of patients and their relations in the early 1970s – but for her, it was apparently still too risky to publish *In het land der blinden* (In the Land of the Blind, 1973) under her own name.[2] In that early 1970s atmosphere, when possibilities for change were almost tangible, Tellegen and Paull were the first people with mental health problems and Van Eijk-Osterholt the first relative to find the courage to step into the public arena with their intimate personal stories.

Around 1970, the organisations that were set up in the previous decade had not yet had much of a chance to influence the fate of relations of people with mental health issues. In Al-Anon a few handfuls of wives of alcoholics were supporting each other, while Pandora was just getting started with taking groups of students on excursions to psychiatric hospitals. But if we zoom out and take a look at the entire mental health care field and its place in society, change was definitely in the air. Discontent was brewing among progressive mental health care workers, who had become increasingly disillusioned with the state of their profession and the limitations of what they could do for the people who turned to them for help. That discontent went hand in hand with a growing interest in psychiatry on the part of outsiders: intellectuals and activists whose critiques of society crystallised into a growing critical engagement with psychiatry. Combined with broad media attention around scandals and other turmoil in the field, from 1969 onwards, Dutch psychiatry became a major topic in public debate.

That public debate was all about liberation: of young people, of women, of homosexuals. They provided examples for others to start organising and to take action for change. Some did so more or less inconspicuously, like agoraphobia patient Marina de Wolf-Ferdinandusse, who set up the first non-anonymous patient-initiative in the mental health field, the Fobieclub (Phobia Club), in Woerden in 1969. The Fobieclub put the lack of specialised care for people with anxieties and phobias on the agenda, and organised mutual support as an alternative.[3] Although that was a courageous enterprise at the

---

[2] C.A. van Eijk-Osterholt, *Laten ze het maar voelen... Vijfentwintig jaar belangenbehartiging voor een verpleegde* (Amsterdam 1972); Egbert Tellegen, *Waar was de dood nog meer... Autografie van een psychose* (Bilthoven 1971); Evelien Paull, *In het land der blinden. Een martelgang door de psychiatrie* (Bilthoven 1973); see also A.J. Heerma van Voss, 'De geschiedenis van de gekkenbeweging. Belangenbehartiging en beeldvorming voor en door psychiatrische patiënten (1965-1978)', *Maandblad Geestelijke Volksgezondheid* 33 (1978) 6, 398-428, 412.

[3] Although the family of De Wolf-Ferdinandusse and those of other members of the Fobieclub were closely involved in the work of this association, it was primarily a patient initiative, and therefore it is not included in this history of the Dutch family movement. After De Wolf-Ferdinandusse

time, what would become known as the *psychiatrische tegenbeweging* (countermovement in psychiatry), or the *gekkenbeweging* (mad movement) was a much more radical current. The countermovement was initially driven by progressive mental health care workers combined with engaged outsiders, such as students in the increasingly popular social sciences, journalists, artists and intellectuals who organised to engage with psychiatry. Their local and national activist initiatives arose just before activist ex-patients and relations entered the scene.[4]

It was in that turmoil that relations initiated the Cliëntenbond in de Welzijnszorg (Clients' League in Welfare Care, Cliëntenbond for short) in 1971, a broad association of mental health care clients, advocating for patients' rights and better mental health care. More on the sidelines, relations set up organisations demanding better care for people with autism: the Noordelijke Oudervereniging voor Autisme (NOVA, Northern Parents' Association for Autism, 1973) and the Stichting ter Behartiging van de Belangen van Autistische Kinderen en hun Ouders (BBAKO, Foundation for the Advocacy for Autistic Children and their Parents, 1974), that would merge into the Nederlandse Vereniging voor Autisme (NVA, Dutch Association for Autism) in 1978. That same year, a 'father-of' brought the Stichting Anorexia Nervosa (Anorexia Nervosa Foundation) into being. These are the organisations on which I will focus in this chapter.[5]

In historiography, these organisations have been characterised as belonging to separate realms. Diagnosis-oriented foundations and associations, like those organised around autism or anorexia nervosa, are associated with the return of a biomedical explanatory model in the late 1980s and 90s, and thus set apart from the 1970s countermovement in psychiatry which adhered to the social explanatory model.[6] However, that obscures

---

passed away in 1997 and the organisation got into hot water, however, it was her daughter Josine van Hamersveld who made sure that her mother's legacy lived on by taking charge as director. Today, the organisation is known as the Angst, Dwang en Fobiestichting (ADF Stichting, Anxiety, Compulsion and Phobia Foundation). Van Hamersveld is still involved as chairwoman of the board. See Daan Heerma van Voss, 'Bloemen van geluk moet je zelf planten', *Vizier* 48 (2018) 3, 25-37; 'Bestuur en directie ADF', https://adfstichting.nl/bestuur-en-directie/, accessed 2 October 2023.

[4] Reinhilde van der Kroef, *25 jaar en nog steeds geen normaal mens ontmoet. Pandora, psychiatrie en beeldvorming* (Baarn 1990) 44; Gemma Blok, *Baas in eigen brein. 'Antipsychiatrie' in Nederland 1965-1985* (Amsterdam 2004) 13.

[5] A fourth initiative of relatives should have been dealt with here too: De Pijler (The Pillar, 1972), an association of parents of children with learning and pedagogical difficulties that could partly be categorised as mental health problems. Unfortunately, I have not been able to find enough sources to do so. In digital newspaper archive Delpher, the earliest mention of De Pijler is found in *De Telegraaf* in October 1976. Incomplete volumes of De Pijler's newsletter, bearing the same name as the organisation, from between 1977 and 1992, are found in the Royal Library in The Hague. In 1987, De Pijler would merge with the Stichting Buitenbeentjes (Foundation Outsiders) and the Werkgroep MBD (Working Group MBD, Minimal Brain Damage) to form Balans (Balance) (Riet Diemer, 'Drie verenigingen zetten zich samen in voor kind met leermoeilijkheden', *Trouw* 31 January 1987).

[6] Petra Hunsche, *De strijdbare patiënt. Van gekkenbeweging tot cliëntenbeweging. Portretten 1970-2000* (Haarlem 2008) 148-152.

the fact that this type of patient- or relation-driven organisation had already emerged in 1969 with the foundation of the Fobieclub, and continued, albeit almost unnoticed it seems, with the autism and anorexia nervosa organisations in the 1970s. There is an important trait that all the initiatives of the 1970s had in common, though: an implicit, unquestioned solidarity between people with severe mental health problems and their relations. In the case of the severely disabled minor and adult children the parents in the autism organisations focused on in the organisations' early years, this almost went without saying; it was perhaps a little less self-evident for families dealing with anorexia nervosa, as that usually begins in adolescence; and it was downright remarkable in the case of the Cliëntenbond, which shifted early on from advocacy for minor children in mental health care to activism in the interests of hospitalised adults.

This chapter focuses on the origins and early years of the three organisations that were initiated by relations in the 1970s: the Cliëntenbond, the NVA and the Stichting Anorexia Nervosa. They were able to arise in a society marked by a spirit of social change and liberation, and in a mental health care sector that was increasingly criticised – developments that will be illustrated by reflecting on Jan Arends's short story 'Keefman'. The chapter will reveal what prompted the organisations of the solidarity years to establish themselves: the poor circumstances in many psychiatric hospitals, the lack of patients' rights, how relations were blamed for the mental health problems of their loved ones, and how families were left to their own devices through a lack of scientific knowledge and supportive practices. And how they were received in a field that, despite the continued presence of stigma and medical omnipotence, suddenly became a topic of public concern and debate.

Awakenings of the predecessors of the family movement in the 1970s

The Cliëntenbond in de Welzijnszorg (1971)

Er staan narcissen op de grond in de isoleer.
Van mijn moeder?
Niemand vertelt het, vertelt niet eens of ze geweest is.
Voor hen niet belangrijk.[7]

(There are daffodils on the floor in the isolation cell.
From my mother?
Nobody says so, even says whether she was here.
Not important to them.)

Eleven men and women crowded the office of the notary when, on 9 September 1971, they registered the Cliëntenbond in de Welzijnszorg (Clients' League in Welfare Care). The group was not necessarily representative of the major driving forces behind the Cliëntenbond – some major initiators were absent, while others who were registered as board members in the original articles of association, have hardly left another trace in sources on the league.[8] This group was there solely for the formality of registering the association. The fact that on paper, they now formed a board, had no real meaning to them, as was customary for a modern, 'democratic' protest movement of the early 1970s. In organisations of that kind, there was no hierarchy; instead, in the Cliëntenbond, the highest authority was the *centrale overleggroep* (central consultative group) – chaotic meetings where everyone who was active in the league had an equal say.[9] So whose name was on the document was of little consequence. What was important was that their league existed.

The name Cliëntenbond in de Welzijnszorg did not immediately reveal what this association was about. It sounded similar to Consumentenbond (Consumer League), the well-known association that confronted companies with complaints and demands by

---

[7] Anonymous, untitled poem in *Bulletin van de Cliëntenbond* 2 (1974) 2, 7.

[8] 'Dagboek van de afgelopen twee jaar', *Bulletin van de Cliëntenbond* 1 (1973) 1, 13-14; Marijke Groot-Kingma, 'Ontstaan en eerste jaren van de Cliëntenbond', *Bulletin van de Cliëntenbond* 15 (1987) 1, 2-3, 3; National Archives, The Hague, Cliëntenbond, access no. 2.19.130 (hereafter NL-HaNA-CB) inv. no. 48, copy of the publication of the articles of association in the *Nederlandse Staatscourant*. The eleven names published there were (mw.=Ms, dhr.=Mr): mw. F.B. Delahay-Oosterbaan, Amsterdam; dhr. P.C. Rike, Amsterdam; mw. D. de Graaf-Sherston, Den Haag; mw. M. van den Bergh-Neelissen, Nijmegen; mw. H.G. Bethe-Eygendaal, Leiden; hr. J. Vlot, Bilthoven; mw. C. Lubberhuizen-Harmsen, Amsterdam; hr. A. Doornheim, Dordrecht; hr. C. Heezen, Rotterdam; mw. B. Wezelman, Amsterdam; mw. C.A. van Eijk-Osterholt, Rotterdam.

[9] 'Afscheidsrede van voorzitter Arie Groot', *Bulletin van de Cliëntenbond* 7 (1979) 30-34, 30.

consumers who bought their products. The analogy was intentional. It was inspired by social medicine professor Henk Leenen, who on his appointment in 1970 had formulated precisely the problem that they experienced as consumers of mental health care:

> *"In aanraking komen met de gezondheidszorg betekent tegenover de hoge-deskundigheid-in-de-witte-jas zitten.* [...] *Dat is anoniem. Daar kun je niet tegenop. Je bent afhankelijk, je voelt je ziek, beroerd. Je bent niet in de stemming om te vechten."*[10]

> ("Coming into contact with health care means facing the high-expertise-in-the-white-coat. [...] That's anonymous. You can't go up against that. You are dependent, you feel sick, miserable. You're not in the mood to fight.")

To empower the patient, or the (mental) health consumer, Leenen suggested that the country needed a consumer association in the 'health and welfare care' sector.[11] Child psychiatrist and supporter of the Cliëntenbond Sjef Teuns later summarised Leenen's argument as follows:

> *"In een tijd, dat de mensen mondig zijn geworden om een kritisch oordeel te vormen over het werk dat zij verrichten, de goederen die zij konsumeren en het milieu waarin zij leven, past het ook, dat zij mee denken en inspraak hebben in datgene, wat de gezondheids- en welzijnszorg te bieden heeft aan dienstverleningen."*[12]

> ("At a time when people have become empowered to form a critical judgement about the work they do, the goods they consume and the environment in which they live, it is also appropriate that they think along and have a say in the services health and welfare care have to offer.")

The group that had gathered in the notary's office had taken Leenen's plea quite literally. Their Cliëntenbond in de Welzijnszorg was precisely that consumer league in welfare care that he had suggested. Following his choice of the word *welzijnszorg* (welfare care) implied that they considered mental health care services in the broadest sense of the term as their terrain. Instead of the word *consument* (consumer), or the word *patiënt* (patient),

---

[10] Han G. Hoekstra, 'Prof. dr. H.J.J. Leenen: "Een consumentenbond voor gezondheidszorg zou ik graag zien" ', *Het Parool* 10 October 1970.

[11] Han G. Hoekstra, 'Prof. dr. H.J.J. Leenen: "Een consumentenbond voor gezondheidszorg zou ik graag zien" ', *Het Parool* 10 October 1970.

[12] Sjef Teuns, 'Een afscheid dat geen afscheid is', *Engagement* 5 (1978) 5/6, 9-15, 9.

however, they chose the word *cliënt* (client) to indicate the people the Cliëntenbond wanted to unite and represent. Willem Momma (one of its main initiators and early driving forces) explained it like this:

> *"Cliënt is het vervangende woord voor patiënt.* [...] *Maar een cliënt kan ook een ouder of een voogd zijn van een geestelijk gehandicapt kind. Cliënt is een verzamelnaam geworden."*[13]

> ("Client is the substitute word for patient. [...] But a client can also be a parent or a guardian of a mentally handicapped child. Client has become a collective term.")

Through the introduction of the word *cliënt*, the founders intended to create a new category that referred to people with mental health issues themselves, as well as, in the case of people who were unable to advocate in their own interests, their closest relations – parents of minor children in particular. Child psychiatrist Teuns, however, added that such parents were not just clients through their position of representatives of their children, but also in their own right, working with the professionals.[14] Over time, the word *cliënt* would lose that second connotation, and become the politically correct alternative for the word *patiënt* (patient) in mental health care, an alternative that was intended to be destigmatising and empowering and is used in the Netherlands to this day.[15]

To uncover what led to the foundation of this Cliëntenbond, we must zoom in on two of the eleven names in the articles of association. First, on Dorothy ('Doortje') de Graaf-Sherston, mother of three children who were patients of the local Medisch Opvoedkundig Bureau (MOB, Medical Pedagogical Bureau) in Leiden.[16] Second, on Corrie van Eijk-Osterholt, whom we met briefly in Chapter 1: the twin sister of Mies Osterholt, who was a patient in Sancta Maria psychiatric hospital in Noordwijkerhout.

In 1969, De Graaf-Sherston had been a *cliënt* at the Leiden Medisch Opvoedkundig Bureau (MOB, Medical Pedagogical Bureau) where she had found great support: both

---

[13] P.W. Russel, 'Die schaamte is niet nodig!', *Algemeen Dagblad* 23 January 1973.

[14] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 405.

[15] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 414; Van der Kroef, *25 jaar,* 44. Even though in the English-speaking world, activists replaced the term patient with user, consumer and later survivor (of mental health care services), I will retain the word client here in order to do justice to the specifically Dutch context.

[16] Marijke Groot-Kingma, 'Ontstaan en eerste jaren van de Cliëntenbond', *Bulletin van de Cliëntenbond* 15 (1987) 1, 2-3; interview Willem Momma, 29 November 2018.

for her children, who were dealing with mental health problems, and for herself as a parent. The bureau was led by child psychiatrist Sjef Teuns. Since his appointment in 1962, Teuns had turned this MOB from an academic department that examined children for research purposes and only gave limited advice, into a larger facility that offered specialised daycare and treatment to two- to eighteen-year-olds, as well as practical support and counselling to the parents. What was particularly remarkable here was that children were welcome even with issues for which Dutch psychiatry largely had nothing yet to offer, like drug addiction and in particular autism. In the eyes of the MOB board, however, these initiatives went beyond the responsibilities of an MOB, and cost too much money. But Teuns would not budge, with the result that he was fired. Virtually his entire staff gave notice in solidarity. It was a shock to the parents: losing this crucial support would be extremely damaging to their children, especially the autistic ones for whom no other help was available.[17]

Under the energetic leadership of De Graaf-Sherston, they decided to form a parents' association and collectively try to mediate between the two parties. Although the association represented about fifty parents and a hundred children, the board ignored them, dismissing them as incompetent in the matter, while the local government distanced itself from the conflict. Instead of discouraging the parents, however, the adversity made them more determined. When they approached member of parliament Til Gardeniers, she was able to arrange a meeting for them with State Secretary Roelof Kruisinga of Social Affairs and Health. To their surprise, there, at the highest national level, they were taken seriously for the first time.[18] To the parents, this was an eye-opening experience. Marijke Groot-Kingma wrote, looking back:

"Er werd ons gezegd dat ze niet om ons heen konden. We kregen een financiële steun en een regeling voor de afbehandeling door het ontslagen team voor onze kinderen.

("We were told they couldn't ignore us. We received financial support and an arrangement for the treatment of our children by the dismissed team. We

---

[17] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 405-406; Jac Vroemen, 'Affaire medisch opvoedkundig bureau Leiden. De guerilla tegen psychiater Sjef Teuns en zijn staf', in: *Dat wordt me te gek. De psychiatrie kritisch bekeken. Artikelen en interviews* (Amsterdam 1972) 89-96; Joost Vijselaar, 'Zonder Curium: het Medisch Opvoedkundig Bureau als spil van de Leidse kinderpsychiatrie en kinderpsychotherapie, 1962-1969', in: Leonie de Goei, Sonja van 't Hof & Giel Hutschemaekers (eds.), *Curium 1955-1995. Bladzijden uit de geschiedenis van de Nederlandse kinder- en jeugdpsychiatrie* (Utrecht 1995) 101-127; Inge Spruit, *Van wie zijn de kinderen? De passie en compassie van Sjef Teuns, strijdbare kinderpsychiater* (Nijmegen 2009) 152-191; Marijke Groot-Kingma, 'Ontstaan en eerste jaren van de Cliëntenbond', *Bulletin van de Cliëntenbond* 15 (1987) 1, 2-3, 2.

[18] Vroemen, 'Affaire medisch opvoedkundig bureau Leiden'; Spruit, *Van wie zijn de kinderen?*, 231-235; NL-HANA-CB inv. no. 25, *Bulletin speciaal voor de eerste ALV van 30 maart 1974,* 4-5; Marijke

Wij realiseerden ons toén dat één van ons alléén dat nooit had kunnen bereiken; hij zou niet eens ontvangen worden. Pas als vereniging word je voor vol aangezien, word je gezien als een macht die ze niet kunnen negeren. En toen rijpte in ons het plan om een bond op te richten.”[19]

realised then that one of us alone could never have achieved that; he wouldn’t even have been seen. It’s only as an association that you’re taken seriously, you’re seen as a force they can’t ignore. And then the plan to set up a league matured in us.”)

In November 1970, while the MOB conflict was still ongoing, De Graaf-Sherston read an announcement of the national conference *Te gek om los te lopen* (Outrageous, or – literally – Too Crazy To Be Out and About). It was organised that same month by the Nationale Federatie voor de Geestelijke Volksgezondheid (NFGV, National Federation for Mental Health, see Chapter 1). Reflecting the feeling of crisis in the sector, the conference was intended to bring together professionals and other parties interested in mental health care in order to start critically reorienting the sector so as to build a mentally healthy society. Reading about this, it suddenly hit De Graaf-Sherston that this was their chance: they should form a national pressure group of MOB parents, and speak up during the conference.[20]

At such short notice, however, no-one was able to clear their schedule and attend, and the conference turned out to be sold out anyway. But the parents did quickly form an informal organisation, the Initiatiefgroep Geestelijke Volksgezondheid (Initiative Group Mental Health).[21] At least four other original Leiden MOB parents were part of the group, and like De Graaf-Sherston, they would all play an important role in the early Cliëntenbond: Willem Momma, Marijke Groot-Kingma, her husband Arie Groot, and Bertie Bethe-Eygendaal.[22] The Leiden MOB parents were joined by members of a feminist mutual support group for relations of people with psychiatric problems that De Graaf-Sherston was also part of, expanding their focus from small children to people with mental health issues of all ages.[23] They took the British National Association for

---

Groot-Kingma, ‘Ontstaan en eerste jaren van de Cliëntenbond’, *Bulletin van de Cliëntenbond* 15 (1987) 1, 2-3, 2; interview Willem Momma, 29 November 2018.

[19] Marijke Groot-Kingma, ‘Ontstaan en eerste jaren van de Cliëntenbond’, *Bulletin van de Cliëntenbond* 15 (1987) 1, 2-3, 2.

[20] Heerma van Voss, ‘De geschiedenis van de gekkenbeweging’, 406; Leonie de Goei, *De psychohygiënisten. Psychiatrie, cultuurkritiek en de beweging voor geestelijke volksgezondheid in Nederland, 1924-1970* (Nijmegen 2001) 255.

[21] Heerma van Voss, ‘De geschiedenis van de gekkenbeweging’, 406; De Goei, *De psychohygiënisten*, 255.

[22] Marijke Groot-Kingma, ‘Ontstaan en eerste jaren van de Cliëntenbond’, *Bulletin van de Cliëntenbond* 15 (1987) 1, 2-3.

[23] Interview Willem Momma, 29 November 2018.

the Welfare of Children in Hospitals as their example, an action group that Teuns had made them aware of.[24] The prevention of severe psychiatric problems by improving the accessibility and transparency of outpatient mental health services became the initiative group's initial primary goal.[25] They quickly put together a tentative list of demands and sent it to the conference.[26]

The conference made history for how chaotic and emotional it turned out, bringing to the surface how powerless professionals felt in the face of a society that they saw as the source of their patients' psychiatric problems.[27] At some point, the initiative group's statement was read out loud from the podium, announcing that patients and relations were organising in order to become equal participants in the debates on mental health care.[28] The statement made it into the press, including the initiative group's list of demands: mental health care should be made as easily accessible for all as somatic health care was; a consumer guide to mental health care must be made available to all through bookshops; and the training of mental health care professionals should be improved.[29]

Part of the newspaper coverage was also the unexpected confrontation between a prominent speaker, a psychiatrist who was referred to as 'Dr J.', and a young man whose wife had recently been admitted to the hospital where Dr J. was the medical superintendent. The young man was pushed by another participant to tell the audience how this doctor had denied him access to her, and even banned him from the hospital grounds. After an awkward silence, emotional outbursts and great commotion followed: some audience members got angry at the young man, some shouted out at him in support, and some started pushing for an immediate solution, while others reproached the speakers for using this individual case for their own purposes. After taking a vote, the room decided that the matter should be dealt with behind the scenes, and the young

---

[24] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 405-406.

[25] Martin Ruyter, ' "Lastige" arbeiderskind komt niet terecht bij de hulpverleners', *de Volkskrant* 11 December 1971; 'Dagboek van de afgelopen twee jaar', *Bulletin van de Cliëntenbond* 1 (1973) 1, 13-14, 13.

[26] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 406; Sjef Teuns, 'Een afscheid dat geen afscheid is', *Engagement* 5 (1978) 5/6, 9-15, 9-10; Marijke Groot-Kingma, 'Ontstaan en eerste jaren van de Cliëntenbond', *Bulletin van de Cliëntenbond* 15 (1987) 1, 2-3, 3.

[27] De Goei, *De psychohygiënisten*, 256-257.

[28] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 406-407; M.E.I. Goudsblom-Oestreicher & W.M. Hirs, 'Oranje kongresenquête. Verantwoording en resultaten', *Maandblad Geestelijke Volksgezondheid* 26 (1971) 1, 26-40; M.E.I. Goudsblom-Oestreicher, 'De kongres-themagroepen. Verslag van de diskussies', *Maandblad Geestelijke Volksgezondheid* 26 (1971) 1, 30-36, 34. 'Dagboek van de afgelopen twee jaar', *Bulletin van de Cliëntenbond* 1 (1973) 1, 13-14; Sjef Teuns, 'Een afscheid dat geen afscheid is', *Engagement* 5 (1978) 5/6, 9-15, 9-10; Marijke Groot-Kingma, 'Ontstaan en eerste jaren van de Cliëntenbond', *Bulletin van de Cliëntenbond* 15 (1987) 1, 2-3, 3.

[29] 'Deelnemers aan congres nog meer in verwarring,' *De Tijd* 21 November 1970; 'Congres geteisterd door verbaal geweld', *NRC Handelsblad* 21 November 1971; Ferd. Rondagh, 'Chaotische disputen geestelijke gezondheid', *de Volkskrant* 21 November 1971.

man was led away.[30] The issue the man had put forward – the way relations were shut out by mental health care professionals – would have to wait until it became the central issue of the family movement of the 1980s.

Away from all the commotion, preparations for the Cliëntenbond continued, taking over De Graaf-Sherston's living room in The Hague.[31] In the summer of 1971, the initiative group put an advertisement in opinion weekly *Vrij Nederland* asking for sympathisers to join them. One of the people who did was Corrie van Eijk-Osterholt. For twenty-five years already, she had watched her twin sister Mies Osterholt suffer in Sancta Maria, a psychiatric hospital in Noordwijkerhout that was run by Catholic nuns. Housed on a large, bare ward, Osterholt spent her years in emptiness, treated with nothing but large amounts of medication that incapacitated her, suffering from tuberculosis for years before any nurse or doctor would take her symptoms seriously, bullied, mistreated and even robbed of her own money by the nuns.[32]

Making herself heard in protest was difficult for Osterholt. Complaints or wishes that she uttered were seldom taken into consideration, and she knew that when she rebelled in frustration, punishment was brutal: she would be kept in her bed under a restraint sheet for days, and carry the marks of the ties on her body even longer. Sometimes, the way she was treated was downright abusive: one time, a male nurse not only jerked Osterholt away from the glass with which she wanted to cut her wrists, but while she was on the floor, went on to kick her in the belly. Her sister Corrie van Eijk-Osterholt incessantly tried to address such issues with the nuns, the doctors and the health inspector, but to no avail. The only medical superintendent in Sancta Maria who made changes for the better had been dismissed in 1965 because he came into conflict with the nuns who ran the hospital.[33]

Although all those years, Van Eijk-Osterholt had exchanged such sad experiences with other relations of patients in Sancta Maria whom she met on visiting days, she had never found an ally in taking their protests to the next level.[34] In 1971, an election year, she decided to do so on her own. In addition to tirelessly pleading her sister's individual case privately, she now took steps towards advocating for the benefit of all patients in psychiatric hospitals. Her first step was to approach members of parliament. One of them asked her to write a report on her sister's experiences and send it to him, but after

---

[30] 'Deelnemers aan congres nog meer in verwarring,' *De Tijd* 21 November 1970; Ferd. Rondagh, 'Chaotische disputen geestelijke gezondheid', *de Volkskrant* 21 November 1971; Meta Petri, 'Er is een kliënt in de zaal: enkele gevoelens en gedachten rondom een incident', *Maandblad Geestelijke Volksgezondheid* 26 (1971) 1, 12-15.

[31] Dunya Breur, 'De Cliëntenbond: een terugblik op de beginperiode', *Bulletin van de Cliëntenbond* 15 (1987) 1, 5-21, 21.

[32] Van Eijk-Osterholt, *Laten ze het maar voelen* (1972).

[33] Van Eijk-Osterholt, *Laten ze het maar voelen* (1972), 7-128.

[34] Van Eijk-Osterholt, *Laten ze het maar voelen* (1972), 40-41.

she had, he never responded. When Van Eijk-Osterholt saw the advertisement of the Leiden initiative group in *Vrij Nederland*, she felt she had finally found the allies she had been seeking for so long.[35] And that is how she too ended up in the group of eleven who registered the Cliëntenbond in October 1971.[36]

The initiative group had a hard time formulating the goals of their new organisation, but in the end, they agreed that they wanted to improve mental health care and its accessibility, improve research and prevention, and influence policy and society.[37] Getting a say, as 'clients', in all matters of mental health care – in short, democratisation – was at the top of their list. The MOBs remained their primary focus.[38]

A few weeks after its official registration in September 1971, a meeting was held with all who had expressed an interest in joining the league. It became very hectic and emotional when participants shared what they or their loved ones had endured in psychiatry. If only someone could write a book about all the poor practices and mistreatment, meeting chairman Willem Momma sighed. Within two months, Van Eijk-Osterholt turned the report she had written for the member of parliament into a manuscript, and started looking for a publisher. By the end of 1972, *Laten ze het maar voelen...* (Let Them Feel It...) came out.[39]

The book immediately attracted a lot of attention and sold well.[40] In January 1973, television talk show *Een klein uur U* presented the book and its author as the starting point for a panel discussion on poor practices in psychiatry. Van Eijk-Osterholt's story was corroborated by the experiences of other relations on the panel who, like her, made a plea for the psychiatric hospitals to be more open to family members who wanted contact with the staff, who wanted to be acknowledged as partners in care, who wanted to do things in dialogue, who wanted to help. But the psychiatrists' reactions were dismissive, suggesting that family members did not want to be involved and preferred to turn their backs after a loved one was hospitalised. Psychiatrist Marius Romme explained that families were no good places to be, especially for the young, and he preferred to see them break away before conflicts ran too high and too much damage was done.[41]

The Cliëntenbond was represented on the panel by Momma, who underlined the point that the league wanted to take action against the lack of contact, the lack of warmth, and especially the lack of a relationship between mental health care and society. At the end of the show, the league's address was shown. Over the following weeks and

---

[35] Hunsche, *De strijdbare patiënt*, 21-22.

[36] NL-HANA-CB inv. no. 48, copy of the publication of the articles of association in the *Nederlandse Staatscourant*.

[37] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 410.

[38] Van der Kroef, *25 jaar*, 43.

[39] Hunsche, *De strijdbare patiënt*, 22.

[40] Van Eijk-Osterholt, *Laten ze het maar voelen* (1972), 133; Van der Kroef, *25 jaar*, 45.

[41] NL-HANA-CB inv. no. 49, typescript 'Een klein uur "U". Uitzending vrijdag 19 januari 1973'.

months, both Van Eijk-Osterholt personally and the Cliëntenbond as an organisation were flooded with phone calls and letters from people whose experiences confirmed what the book exposed. Suddenly, the Cliëntenbond was catapulted onto centre stage in the public debate on psychiatry. But the reactions also proved decisive for the course of the association. Instead of focusing on improving the quality and accessibility of outpatient mental health care services, as the MOB parents and their initiative group had intended, it was clear to all early members that their priority should shift: to putting an end to poor practices and mistreatment in psychiatric hospitals and the lack of rights of patients in them.[42]

The Nederlandse Vereniging voor Autisme (1978) and its predecessors

"Wij waren assertief. Wij zijn eindverantwoordelijk. Wij maken uit wat er gebeurt met ons kind."[43]

("We were assertive. We are responsible in the end. We decide what happens with our child.")

The media commotion over the Leiden MOB conflict had increased awareness about autism in the Dutch public. All over the country, there were families who were dealing with the pressures of raising a child who was extremely introverted, behaving in ways that were bewildering to others, who could react to the slightest change by screaming inconsolably or lashing out physically, and who often needed non-stop attention. Reading about the work of child psychiatrist Teuns and his colleagues in the newspapers, many parents found out for the first time that there was a name for their child's peculiarities: autism. And that they were not alone: that other families, too, became isolated, as having people visit in their situation was virtually impossible, and no outsider understood that the behaviour of their normal-looking child was not the result of bad parenting, but a disorder of some kind. That other families, too, experienced every day that professional expertise and help seemed nowhere to be found.[44]

---

[42] NL-HANA-CB inv. no. 49, typescript 'Een klein uur "U". Uitzending vrijdag 19 januari 1973'; Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 411-412; Hunsche, *De strijdbare patiënt*, 19-21; C.A. van Eijk-Osterholt, *Laten ze het maar voelen... Een verhaal over psychiatrische inrichtingen, belangenbehartiging, acties en de commissie-Van Dijk* (Amsterdam 1981) 133-149; Sandra Heerma-van Voss, 'Haar tweelingzus werd haar missie', *NRC Handelsblad* 21 March 2020.

[43] Interview Willem Momma, 29 November 2018.

[44] J.H.A. van der List, *Het zich autistisch gedragende kind en zijn ouders. Een onderzoek in opdracht van de Landelijke Stichting ter Behartiging van de Belangen van Autistische Kinderen en hun Ouders (BBAKO)* ([Amsterdam] 1975) 5-8.

Through the media coverage of the MOB conflict, desperate parents of autistic children from all over the country gained new hope: that in Leiden, help was to be found. But when two such parents, Sjef Hondelink and Molly Hillebrand-Bulten, turned to the Leiden MOB in the autumn of 1973, they found Teuns's therapeutic daycare facilities permanently closed. The consequences for the families that had been in treatment there were dire, as the parents had predicted. Children who had previously done better as a result of their participation in the MOB daycare groups and the counselling their parents received, were now getting worse, ending up in residential homes or preschools that did not fit their needs. The stress in the families led to serious conflicts and even suicide attempts by some of the children and their relations. But the experience of the parents with their association had empowered them, and they would no longer keep silent.[45]

Hondelink and Hildebrand-Bulten were referred to the Cliëntenbond, but soon concluded that the young league had so much on its plate that it would be hard to direct enough attention towards specific advocacy for their children. The good news was that they found an important ally there: Willem Momma, one of the original MOB Leiden parents and himself the father of a young autistic boy, Kees.[46] On 4 March 1974, Hondelink and Hillebrand-Bulten registered their BBAKO (Stichting ter Behartiging van de Belangen van Autistische Kinderen en hun Ouders, Foundation for the Advocacy for Autistic Children and their Parents).[47]

In the north of the country, just a few months earlier, another group of parents of autistic children had joined forces in the NOVA (Noordelijke Oudervereniging voor Autisme, Northern Parents' Association for Autism). These parents had found each other after the regional newspaper *Nieuwsblad van het Noorden* published an article in August 1973 about the dire situation of single father Leo de Wilde and his young autistic son Willem-Jan. Initially, Willem-Jan had gone to a daycare centre when his father was at work, and both had been doing well. When the boy was transferred to another daycare centre, however, the different approach there did not agree with him, and his behaviour became unmanageable for the staff. As a result, pressure was put on De Wilde to place his child in a home permanently. Having realised that the problem was the daycare centre, not the family situation or the boy, De Wilde insisted on raising Willem-Jan at home, where he was happy, with proper support to enable his father to work during the

---

[45] Spruit, *Van wie zijn de kinderen?,* 233-235, 284-285, 287-291; 'Gezin enige houvast voor een autistisch kind', *Leeuwarder Courant* 18 October 1973; interview Willem Momma, 29 November 2018.

[46] A. Willebrands, 'Twee scheidende bestuursleden', *Engagement* 4 (1977) 1, 2-3; Sjef Teuns, 'Een afscheid dat geen afscheid is', *Engagement* 5 (1978) 5/6, 9-15, 10; Arend G. Benner, *Streven naar limonade. De NVA als partner in een vertoogcoalitie rond autisme, 1973-2003* (Master's thesis Universiteit van Amsterdam 2003) 47.

[47] Benner, *Streven naar limonade,* 48.

day. Looking for a way to break the stalemate, De Wilde had contacted Helpt Elkander, one of the associations of parents of mentally handicapped children (see Chapter 1), written a report, and now he had taken his story to the press.[48]

The article provoked lots of reactions from parents in similar situations, and it was followed up with three articles containing more stories of families of autistic children and reactions of professionals to the lack of appropriate care for this particular group.[49] In response to the newspaper coverage, the child protective services branch of the Reformed Church decided to offer their support. With their help, De Wilde and six other parents organised a meeting on 31 October 1973, where forty parents came together. Although NOVA's official establishment date is unknown, autism history researcher Niels Springveld considers it is most likely that this was when NOVA was founded.[50]

NOVA's goal was the development of professional support for families in the Northern provinces to help them raise their autistic children.[51] In addition, in close collaboration with mental health professionals, the Northern parents set up a foundation dedicated to autism research in support of their goal: the Noordelijke Stichting tot Hulp aan Kinderen en Jeugdigen met Autistisch Gedrag (Northern Foundation for Help for Children and Adolescents with Autistic Behaviour), later renamed Noordelijke Stichting Autisme (NSA, Northern Foundation Autism).[52]

To do something about the lack of specialised facilities for children with autism, relations sometimes took up the challenge to found such a facility themselves, just like parents had set up homes for their mentally handicapped children. The most famous one in the Dutch autism field is the Dr. Leo Kannerhuis (Dr Leo Kanner Home, 1974) in Oosterbeek, an initiative of the Auping family – known in the Netherlands for their famous bed factory – in collaboration with child psychiatrists and pedagogues in the Stichting voor Hulp aan Autistische Kinderen en Adolescenten (SHAKA, Foundation for Help for Autistic Children and Adolescents).[53] But NOVA and BBAKO set out on a different path: rather than opening new facilities themselves, they wanted to put their energy towards stimulating the development of various options, including the adaptation of

---

[48] Harm van den Berg, 'Willem-Jan moest nu maar weg van huis', *Nieuwsblad van het Noorden* 11 August 1973.

[49] Harm van den Berg, 'Ook Cor moet maar weg van huis...', *Nieuwsblad van het Noorden* 21 August 1973; Harm van den Berg, ' "Betrokkenheid staat voorop" ', *Nieuwsblad van het Noorden* 28 August 1973; Harm van den Berg, 'Het gat in zwakzinnigenzorg moet snel gedicht worden', *Nieuwsblad van het Noorden* 4 September 1973.

[50] With many thanks to Niels Springveld for his generous sharing of research data and insights.

[51] Benner, *Streven naar limonade,* 37-46.

[52] A.W.M. Snijders-Oomen, 'Autistisch gedrag, een nieuw initiatief in het Noorden van Nederland', *Tijdschrift voor Zwakzinnigheid en Zwakzinnigenzorg* 13 (1976) 4, 61-72.

[53] *10 jaar dr. Leo Kannerhuis* ([Oosterbeek] [1984]); F. Schrameijer, *Springzaad, van kiemen tot verspreiden. Behandeling en beleid van het Dr. Leo Kannerhuis: leren, ervaren en overdragen* (Doorwerth 2003).

existing facilities, specialised daycare and training for parents who wanted to raise their child at home, and to take action to instigate government policies and create government funding in support of those actions.[54]

It did not take long for BBAKO and NOVA to find each other: in fact, their representatives had already met in March 1974, just after BBAKO had been officially founded.[55] But initially, each continued on its own course, NOVA working closely with the experts in the NSA, while BBAKO preferred to operate more independently. Both, for example, initiated surveys in order to provide basic data on the extent of the problems and needs they addressed. The northern parents collaborated to this end with the child specialists in the NSA, while BBAKO arranged for a researcher from outside the world of mental health care through the business networks of their board members, and published the results themselves.[56] Despite their very similar ambitions, the different approaches BBAKO and NOVA/NSA initially took, made it quite a puzzle for the two to come together.[57]

In 1976, representatives of the two parent organisations formed an interim board to work towards a merger.[58] One of its driving forces was Willem Momma, who had stepped down as chairman of the Cliëntenbond in December 1974,[59] and since then had combined volunteering for both the Cliëntenbond and BBAKO,[60] but now devoted his activism to the world of autism entirely. When on 17 June 1978, BBAKO and NOVA merged to form the NVA (Nederlandse Vereniging voor Autisme, Dutch Association for Autism), Momma became its first chairman.[61]

The goal of the NVA was advocacy for autistic people in the broadest sense of the word: in the interest of minors first, and of adults second. In order to create the best chances for the children's development, education and support for their relations was considered key. The association not only strove for knowledge dissemination, but also for early diagnosis and counselling, as well as forms of support tailored to the specific needs of people with autism and their relations, such as therapeutic home-training, educational support, and specialised daycare and group homes.[62] An essential part of the process

---

[54] Snijders-Oomen, 'Autistisch gedrag', 65, 67; W.J.J. Martinot, '1975-1976', *Engagement* 3 (1976) 1, 2-4.

[55] 'Tweede vereniging op landelijk niveau voor autistisch kind,' *Nieuwsblad van het Noorden* 1 March 1974.

[56] Snijders-Oomen, 'Autistisch gedrag', 65; Van der List, *Het zich autistisch gedragende kind.*

[57] Het bestuur, 'Een korte aantekening', *Engagement* 3 (1977) 7, 26-28.

[58] 'Interimbestuur Landelijke Vergadering. Intentieverklaring', *Engagement* 3 (1976) 9, 3.

[59] NL-HANA-CB inv. no. 45, 'Jaarverslag van het Bulletin van de Cliëntenbond 1974'75'.

[60] The last *Bulletin van de Cliëntenbond* mentioning Momma in an active capacity is the August 1976 issue, *Bulletin van de Cliëntenbond* 4 (1976) 2, 19.

[61] 'Beknopt verslag van de oprichtingsvergadering van de Nederlandse Vereniging Autisme 17 juni 1978 – Jaarbeursgebouw, Utrecht', *Engagement* 5 (1978) 7/8, 3-15, 13.

[62] Cees Weber, '25 jaar NVA. Enige kanttekeningen en notities', *Wetenschappelijk Tijdschrift Autisme* 2 (2003) 3, 88-95, 90.

was also improving the relationship between professionals and parents – without taking the responsibility for the children away from the latter.[63]

The Stichting Anorexia Nervosa (1978)

"Sommige mensen krijgen hun opdrachten van boven, ik kreeg mijn opdracht van [omroep] *de TROS."*[64]	"Some people receive their assignments from above, I got my assignment from the TROS [broadcasting organisation]."

In 1976, engineer René Sieders started studying a scientific field that was completely new to him: that of anorexia nervosa. His daughter had been diagnosed with the disorder, and the repercussions of her problems were severe for the entire Arnhem family. Sieders studied everything that could shed more light on the issue that burdened them, and on what could be done about it. Along the way, he came across Anorexic Aid and Anorexic Family Aid, British mutual support organisations for people with anorexia nervosa and their families. Something similar should be set up in the Netherlands, he felt. But he did not see himself taking on such a challenge.[65]

Somehow, however, he must have drawn attention to himself, because the editors of the radio show *Kernpunt* invited him in the spring of 1978 to join a panel they were putting together for an episode on anorexia nervosa. Together with an anorexia patient and her mother, a psychiatrist and an alternative healer, Sieders shared his experiences on air. He also shared the conclusions he had drawn from his research: Dutch professional literature on the subject was sub-standard, and nowhere in the Netherlands was there appropriate, specialised care for people with anorexia to be found. Although the primary concern of the two parents on the show was the health of their children, they both also mentioned their indignation over how in everything they read on the subject, their children's suffering was blamed on them: the mothers and the fathers.[66]

Afterwards, broadcasting corporation TROS was flooded with reactions from people in need, both those who suffered from anorexia nervosa and their relations. Desperation ruled in families where a daughter, a partner or a mother – nine out of ten people with anorexia

---

[63] Weber, '25 jaar NVA', 91-93.

[64] René Sieders, '20 jaar', *ANtenne* (1998) 107, 4-7 5.

[65] Personal digital archive Erik Vleeschdraager [hereafter Archive Vleeschdraager], zero issue of *ANtenne* antedated February 1979 (real publication date unknown), René Sieders, 'Openingstoespraak' (the speech Sieders held at the first two contact days of the Stichting Anorexia Nervosa in January and February 1979); René Sieders, '20 jaar', *ANtenne* (1998) 107, 4-5.

[66] Archive Vleeschdraager, zero issue *ANtenne* February 1979, Sieders, 'Openingstoespraak'; René Sieders, '20 jaar', *ANtenne* (1998) 107, 4-5.

nervosa is female – displayed an extremely worrisome eating pattern. So worrisome in fact that it created enormous tensions in the household over everything to do with food, drink or health in general, as anorexia patients tend to starve themselves to the brink of death – or beyond it. The reactions to the radio show also confirmed what Sieders had said: that there was no proper care for anorexia nervosa patients and their families in the Netherlands. Never before had the show received so many shocking stories in response.

In apparent disbelief, the editor, Manja Jordans, did her own research into the matter, only to conclude that the lack of care was real. Repeatedly, she contacted Sieders, making an urgent appeal to him to organise something for all those people in need. Still hesitant, Sieders first sent all those who had written to the show a survey, asking them if they were interested in contact with other people dealing with anorexia nervosa, and in joining an organisation. The majority answer was yes.[67]

Overwhelmed by the response to the survey and the many letters and phone calls that followed, Sieders shared his troubles with fellow members of his local Arnhem/IJssel Rotary Club. What had he started, he worried, without even knowing what he could offer to those in need? His Rotary friends decided to step in, form a board, raise money, provide printed matter, bylaws and an accountant, and on 18 December 1978, Sieders registered the Stichting Anorexia Nervosa (Anorexia Nervosa Foundation). Convinced that such an organisation should not be run by people like himself, who were too emotionally involved in the issue to do so with the necessary distance, he was grateful that other Rotary members were willing to form the first board. Sieders felt more at ease in the capacity of advisor to the foundation.[68]

The foundation's cause was straightforward: "*het bevorderen van de zorg voor personen die lijden aan de ziekte Anorexia Nervosa*" ("promoting care for those who suffer from the illness Anorexia Nervosa").[69] The new foundation intended to work towards that goal by stimulating research into anorexia nervosa and the development of better treatment methods for it. But knowing how intractable a mental health issue it was, it was even more important to the initiators to connect people who suffered from anorexia nervosa and their relations with others who shared their experiences, to foster and mentor mutual support groups, offer education and break the taboo on talking about anorexia nervosa.[70] In addition, it was essential to them to stop the blaming of parents for causing their child's problems.[71]

---

[67] Archive Vleeschdraager, zero issue *ANtenne* February 1979, Sieders, 'Openingstoespraak'; René Sieders, '20 jaar', *ANtenne* (1998) 107, 4-5.

[68] Archive Vleeschdraager, zero issue *ANtenne* February 1979, Sieders, 'Openingstoespraak'; René Sieders, '20 jaar', *ANtenne* (1998) 107, 4-5; R. Sieders, 'Bedankt en welkom!', *ANtenne* (1981) 13, 5; R. Sieders, 'Het lustrum van de stichting: vijf jaar wanhoop en hoop', *ANtenne* (1984) 24, 2-9, 2.

[69] Article 2 in the foundation's bylaws as printed in *ANtenne* (1979) 1, 7.

[70] Archive Vleeschdraager, zero issue *ANtenne* February 1979, Sieders, 'Openingstoespraak', 4, 7; interview Erik Vleeschdraager, 7 October 2020.

[71] Paulien Goettsch, 'Verslag Jubileumdag 8 juni 1991. Middaggedeelte', *ANtenne* (1991) 64, 21-23, 21.

The factors that enabled the family movement's predecessors of the 1970s to emerge

When Al-Anon and Pandora were born in the early 1960s, the world of Dutch mental health care had been neatly arranged: doctors and other professionals knew best, psychiatric hospitals were trusted places of healing, and mental illness was perhaps nothing to be ashamed about, but best kept inside the family. In the early 1970s, as we have seen, that world was quickly turned upside down. The discontent that had been brewing among progressive and young mental health care professionals since the 1960s had become public with the chaotic *Te gek om los te lopen* conference in 1970. It was mirrored in the discontent that had been brewing since the 1950s among young, intellectual, artistic people, and that became widespread in the late 1960s and early 1970s. One by one, hierarchies were challenged, taboos were broken, rights were claimed, and autonomy was conquered. To the budding movement of people with mental health problems and their relations, both the new climate in society and the new climate in psychiatry provided models, inspiration and courage.

A new climate in society

For a long time the 1960s were heralded in the public memory as a magical decade of creativity and change – especially by those who found themselves in the middle of the turmoil – while the 1970s were dismissed as the period in which that atmosphere quickly died.[72] But as historian Duco Hellema has shown, the 1970s and early 1980s were in fact the years when that spirit of reform blossomed and spread in waves of activism to all corners of Dutch society. Almost everywhere, marginalised people – women, homosexuals, peace and environmental activists, squatters – demanded an equal say instead of having to listen and to obey others put above them, the right to make their own decisions instead of others deciding for them, and an end to taboos and stigmas that kept them diminished, silent and burdened with shame.[73]

This even came with a new, typical Dutch vocabulary. *Bespreekbaarheid* (openness for discussion) referred to previously untouched subjects that should be discussed without religious restraints or social conventions standing in the way of free expression, in order to lift taboos and empower those who suffered from them. Since the 1960s, as historian James Kennedy has argued, it had become more than a vogue word, it had become a central value – not only to discuss difficult subjects, but also to make room for the social change that was suggested in those discussions.[74] *Mondigheid* (self-advocacy) was key in

---

[72] Hans Righart, *De eindeloze jaren zestig. Geschiedenis van een generatieconflict* (Amsterdam 1995) 266.

[73] Duco Hellema, *Nederland en de jaren zeventig* (Amsterdam 2012).

[74] James Kennedy, *Een weloverwogen dood. Euthanasie in Nederland* (Amsterdam 2002) 17-18.

that: the ability of all citizens to open their mouths, be assertive and question authorities, to form and offer their own opinions, and to make their own decisions.[75] Women's weekly *Margriet* devoted a whole series to the new phenomenon in 1974, explaining at length to the readers what this new attitude entailed:

> *"Mondigheid: het is een woord, dat helemaal bij onze tijd past; bij de veranderde mens, die zich in deze maatschappij niet meer zo slaafs wil opstellen als vorige generaties, maar méé wil beslissen, méé wil praten. Dus: mondig wil zijn."*[76]

> ("Self-advocacy: it is a word, that is perfectly suited for our time; that suits the changing human being, who no longer wants to take a subdued position in this society as previous generations did, but wants to be involved in the decision-making, in the conversation. In short: wants to self-advocate.")

When they emerged in the 1960s, these changes had caused a deeply painful conflict between the generations. People who had grown up before the Second World War had rebuilt the country in an atmosphere of discipline, frugality and 'everybody knowing their place'. Those who grew up after this had only experienced increasing affluence, enabling them to set themselves free from traditional authority. This conflict was expressed most of all in families, where from the mid-1960s onwards, sons with long hair and daughters with short skirts no longer accepted it when their father, as the head of the family, forbade them to listen to pop music, skip church, fool around with anyone they fancied, or try to smoke a joint.[77] Moreover, the traditional family seemed to represent all that was wrong in society at large: it used force and violence on its children to make them conform to traditional norms, and if they couldn't or didn't, they were victimised – the family, in particular the parents, made them 'mentally ill'.[78]

By the 1970s, the liberation and empowerment of young people, women and other previously voiceless groups was progressing, and their ideas about equality and society as well as their methods became widespread. The women's movement in particular became

---

[75] Stephen Snelders & Frans J. Meijman, in their book *De mondige patiënt. Historische kijk op een mythe* (Amsterdam 2009) do not define *mondigheid*, but seem to limit it to the ability to process information that is offered.

[76] 'Een recept alleen helpt niet', *Margriet* 37 (1974) 17, 99-104.

[77] Hellema, *Nederland en de jaren zeventig*, 25; Nelleke Bakker, Jan Noordman & Marjoke Rietveld-van Wingerden, *Vijf eeuwen opvoeden in Nederland. Idee en praktijk 1500-2000* (second revised edition; Assen 2010) 380-385.

[78] Gemma Blok, ' "Tall, Spanking People": The Idealisation of Adolescents in a Dutch Therapeutic Community', in: Marijke Gijswijt-Hofstra & Hilary Marland (eds.), *Cultures of Child Health in Britain and the Netherlands in the Twentieth Century* (Amsterdam 2003) 265-285, 267, 275-282.

the example for other marginalised groups to follow.[79] Not only did it demand equal rights for women, it also developed methods to educate and raise awareness, for example in *praatgroepen* (discussion groups), and it developed *vrouwenhulpverlening* – their own branch of mental health and welfare care, exclusively of and for women.[80] Here as in other movements, there were factions that radicalised in this period, but overall, a more moderate progressive spirit of reform prevailed, making it possible for those less inclined to revolution to join in, as the previous quote from *Margriet* – a weekly for housewives – shows. The new ideas had found their way in because, as historian James Kennedy has demonstrated, they found supporters in people of authority[81] – and now, they trickled down to other traditional parts of the population. And with the government supporting these developments, it seemed like the whole country was gripped by the new spirit.[82]

Part of the spirit of the 1970s was also how more and more people started paying attention and taking responsibility for their own emotional well-being. They were leaving the churches in increasingly large numbers and exploring ways to take care of their mental and spiritual well-being away from traditional Christianity. Instead of 'manning up' and suppressing difficult feelings and traumas, or confiding in a priest, the thing to do now was to talk about your innermost experiences without shying away from difficult confrontations with yourself or others. And if that was too difficult, or did not help, it became more and more acceptable to seek professional psychological help. This new attitude was also taught through popular self-help books. People were shown the way to liberate themselves from everything that suffocated them – feelings of guilt, shame and anxiety, pressures from traditional role patterns and the expectations of others – and become their own authentic self. That empowerment came with responsibility for their own actions and ideas, and the duty to be tolerant of the desires, behaviours and lifestyles of others. Psychologist Ruud Abma has traced the roots of this process of psychologisation back to the beginning of the twentieth century, but it was between 1950 and 1976 that the number of clients of mental health care multiplied tenfold.[83] This process was helped along by large investments in the sector from the government, including the *Algemene Wet Bijzondere Ziektekosten* (AWBZ, General Law on Exceptional Medical Expenses, 1968) under which many forms of mental health care became free for patients.[84]

---

[79] Hellema, *Nederland en de jaren zeventig*, 15, 61.

[80] Hunsche, *De strijdbare patiënt,* 71, 95-98; Janneke van Mens-Verhulst & Berteke Waaldijk (eds.), *Vrouwenhulpverlening 1975-2000. Beweging in en rond de gezondheidszorg* (Houten 2008).

[81] James Kennedy, *Nieuw Babylon in aanbouw. Nederland in de jaren zestig* (Amsterdam 1995).

[82] Hellema, *Nederland en de jaren zeventig,* 16; Vilan van de Loo, *De vrouw beslist. De tweede feministische golf in Nederland* (Wormer 2005) Chapter 4.

[83] Ruud Abma, 'De patiënt. De opkomst van de therapeutische samenleving', in: Jeroen Jansz & Peter van Drunen, *Met zachte hand. Opkomst en verbreiding van het psychologisch perspectief* (Maarssen 1997) 115-131.

[84] Harry Oosterhuis & Marijke Gijswijt-Hofstra, *Verward van geest en ander ongerief. Psychiatrie en geestelijke gezondheidszorg in Nederland (1870-2005), Band II* (Houten 2008) 798-799.

It is important to realise, however, that this marked only the progressive, mainly young and urban parts of the population. The mainstream preferred to hold on to their way of life. Many Dutch people of the 1970s frowned upon the undermining of traditional norms and values, and felt threatened by the way new ideas seemed to be promoted everywhere: the autonomy of women and young people, the disdain for conventions, the fierce criticism of the family and the church, sexual freedom, living together out of wedlock, divorce, liberal drug policies, the increased availability of pornography, and ultimately, a dangerous decline in public order and safety. Conservative people turned to the state pleading for the restoration of law and order, social discipline and community values.[85]

In some of the most outspoken conservatives, a politicised collective experience identity even awakened. A committee of conservative parents served in 1971 as the driving force behind the foundation of the Vereniging Algemene Bond van Ouders en Opvoeders (VABOO, Association General League of Parents and Educators). The concerns of the VABOO ranged from liberal attitudes towards drugs and sex to propagating progressive ideas in schools and adding fluoride to drinking water, and its purpose was to defend traditional values against those influences. Its first chairman was Piet Esser, the psychiatrist who had been instrumental in the start of AA and Al-Anon in the Netherlands (see Chapter 1). Motivated by the increasing number of young people with drug addiction problems whom he saw in his work for the municipal social psychiatric service in Haarlem, Esser and his companions voiced equal concern about all kinds of modern developments that were undermining the traditional moral upbringing of children and the institution of the family.[86]

In 1975, the original parents' committee seems to have re-established itself as an independent foundation (though closely connected to the VABOO) under the name Stichting Actie-comité Verontruste Ouders (SAVO, Foundation Action Committee Alarmed Parents).[87] The foundation united parents who had 'lost' their children to alternative youth welfare care organisations. The 'black book' the SAVO published that year presented five cases that suggested that the parents portrayed had legitimate reasons for their complaints. Even though their runaway children had been minors, the organisations that they had turned to had not contacted the parents. Instead, the welfare care workers had referred the children to squats or other sub-culture living arrangements where they had not been able to maintain themselves, bringing the children – all girls – into the company of 'bad men' and drugs. Some of the girls had ended up with a heroin addiction.[88]

But the SAVO protests remained an isolated phenomenon. The extremely aggressive attitude these parents adopted towards alternative youth workers and anyone who was

---

[85] Hellema, *Nederland en de jaren zeventig*, 296-297.

[86] 'Verontruste ouders op de bres voor het gezin', *De Tijd* 8 April 1971; Paul van Geest, 'Laat jeugd eerst volwassen worden', *De Tijd* 9 October 1971.

[87] Ferry Tromp & Maarten Nederhorst, *Ouders kinderen van de rekening* (Baarn 1977) 97.

[88] Stichting Actiecomité Verontruste Ouders, *Zwartboek alternatieve hulpverlening* ('s-Gravenhage [1975]).

too liberal for their taste will not have helped. But fundamentally it was their traditional, authoritarian opinions on raising children that were defeated by the new ideology that put an adolescent's autonomy first and took an empathetic approach instead of a patronising and disapproving one. Ignored by the government and even the police and the justice department – that had adopted a tolerant attitude that in no way resembled the rigidity of the 1950s and 60s – and ridiculed and marginalised in the media, the SAVO parents got hardly any traction.[89] The majority of formal and informal authorities were convinced that morals were inevitably modernising.[90] This broad support for reform also created room for those on the very margins of society and their allies to break a taboo like that on mental health issues, and to organise.

A new climate in psychiatry

All this turmoil in society had an impact on psychiatry, but in turn, developments in psychiatry marked the societal debate too, as around 1970, several events – and the media attention they attracted – catapulted psychiatry onto centre stage in public debates. We have already come across the conference *Te gek om los te lopen* of 1970, and Corrie van Eijk-Osterholt's book *Laten ze het maar voelen…* of 1972. Even more influential was the book *Wie is van hout…* (Not Made of Wood) by psychiatrist Jan Foudraine that hit the bestseller lists in 1971,[91] and the conflict over Dennendal, a residential facility for mentally handicapped people, that became highly publicised that same year.[92] Combined with the first initiatives of the budding countermovement in psychiatry, that was quickly joined by the clients' movement and in particular the Cliëntenbond, events like these ignited broad public interest in critical psychiatry. Over the 1970s that resulted in a 'national craze', in the words of historian Gemma Blok. In this craze, democratising the extremely hierarchical relationship between the expert and the lay person was the central issue.[93] Formulated from the perspective of the clients' movement, what was central was nothing less than a question of human rights.

Criticisms made by the clients' movement became to some extent embedded in the critiques that had already been brewing within mental health care itself. Progressive professionals were increasingly rejecting the way patients were treated in traditional

---

[89] Sophie Janssens, *Wegloper waarheen? Een sociaal-culturele geschiedenis van het wegloopfenomeen in Nederland, 1950-2000* (Master's thesis Universiteit van Amsterdam 2023) 62-65.

[90] Hellema, *Nederland en de jaren zeventig*, Chapter 5; Kennedy, *Nieuw Babylon in aanbouw*.

[91] Jan Foudraine, *Wie is van hout… Een gang door de psychiatrie* (Baarn 1971); Alex Rutten, *Jan Foudraine. Psychotherapeut, onderzoeker, schrijver* (Amsterdam 2021) Chapter 5.

[92] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 418; Evelien Tonkens, *Het zelfontplooiingsregime. De actualiteit van Dennendal en de jaren zestig* (Amsterdam 1999).

[93] Blok, *Baas in eigen brein*, 43.

psychiatric hospitals, that they saw as hierarchical, paternalistic, disciplining, undemocratic and intolerant systems. With that, they also took a stand against the biomedical explanatory model that had dominated mental health care for most of the century – the approach that informed Pandora and Al-Anon – but that had not delivered on its promises. Associated with that biomedical approach was the criticism that its institutions were used to lock away deviant, unwanted people, and that they had a debilitating effect on the 'patients' there.[94]

This perspective was put forward by the critical international movement in psychiatry that had become known under the name anti-psychiatry. American and Western European psychiatrists, sociologists and philosophers like R.D. Laing, David Cooper, Michel Foucault and many others laid its theoretical foundations. Society, not biology, was to blame for mental health issues, so it was not the individuals suffering from these issues who should change, but society. This perspective would permeate Dutch public debate both in the mental health care field and in society in general. Anti-psychiatry in the Netherlands was not embraced as quickly or radically as it was in the United Kingdom and Italy, where in the 1960s and 70s entire psychiatric hospitals were closed down – which is the reason why Blok puts the term in parentheses in her history of Dutch 'anti-psychiatry', and prefers the term critical psychiatry instead. But ideas from international anti-psychiatry gave direction to the Dutch mainstream of professionals who in the 1970s were desperate to find new ways forward.[95]

The approach to mental illness as a psychosocial rather than biomedical problem was not new to mental health care professionals – in fact, in practice, many psychiatrists combined biomedical, psychological, social and religious or spiritual approaches. But the radical social stand of anti-psychiatry was unheard of: it was not the patient who was ill, it was society, and that 'patient' was the canary in the coalmine. For many members of the Dutch public, including nurses-in-training and other (aspiring) mental health care professionals, it was Jan Foudraine's bestseller that opened their eyes to this perspective. *Wie is van hout…* (Not Made of Wood) was a personal account of how the psychiatrist had developed his own psychotherapeutic insights, particularly while working at the Chestnut Lodge. In this American clinic, treatment was inspired by the work of important predecessors of the anti-psychiatrists: psychoanalysts like Harry Stack-Sullivan, Frieda Fromm-Reichmann and John Rosen. Like them, Foudraine focused on patients with schizophrenia.[96]

Instead of as 'schizophrenia patients', Foudraine looked at those he treated as 'people with life problems'. Their problems, in his view, were usually rooted in the dramatic way

---

[94] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 775-776, 780-781, 794-796; P. Laurs, *Recht voor psychiatrische patiënten. Een onderzoek naar de rechtsbescherming voor in psychiatrische ziekenhuizen opgenomen patiënten* (PhD thesis Rijksuniversiteit Utrecht 1988) Chapter 2-4; J. Legemaate, *De rechtspositie van vrijwillig opgenomen psychiatrische patiënten* (PhD thesis Universiteit van Amsterdam 1990) Chapter 3.

[95] Laurs, *Recht voor psychiatrische patiënten,* 41-44; Hunsche, *De strijdbare patiënt,* 72-74.

[96] Foudraine, *Wie is van hout* (1971)*;* Rutten, *Jan Foudraine*, 61, 127-128.

they had grown up. Through psychotherapy sessions, in which he built up a close, warm, personal relationship with a person, the psychiatrist tried to help his patients understand where their problems stemmed from in order to help them heal. After his return to the Netherlands, however, he found that what he had learned did not much impress his Dutch colleagues, and his plan to write a dissertation fell through. But when instead he published *Wie is van hout…*, he made an impact that went beyond anything he could have imagined. The book instantly became a bestseller.[97]

Carel Muller was another Dutch pioneer who made it to the public podium, although under very different circumstances. This psychiatrist was set on opening up and democratising the institution he led, the Dennendal residential home in Den Dolder. Though a specialised facility for mentally handicapped people, Dennendal was part of the Willem Arntz Hoeve mental health care organisation, and that was how the conflict that erupted there in the early 1970s came to be associated with psychiatry. In the spirit of breaking taboos, ending stigma and promoting equality, Muller had erased all forms of hierarchy in Dennendal and allowed far-reaching freedom to everyone who lived or worked there. He had also invited other people to join their community, so that the Dennendal 'pupils' would no longer live their lives separated from the rest of society.[98]

When in 1971, a pupil drowned in a bath tub, that made headlines in *De Telegraaf.* The conservative newspaper took the opportunity to present everything that was happening at Dennendal as a scandal: not only the neglect of proper standards of care, but also 'free sex' and drug use. Behind the scenes, Muller had already found himself in conflict with his board over the path he had chosen, and now it escalated. Initially, things calmed back down, but when the conflict flared up again in 1974, Dennendal was evacuated and Muller fired.[99] Like the conflict between Sjef Teuns and the MOB board in Leiden, which also dragged on into 1974, Dennendal was a matter of great public interest that made headlines regularly for years.[100]

The critical debate on psychiatry that was now suddenly on full display to the average citizen became intrinsically connected to the larger spirit of change in society when increasing numbers of progressive Dutch citizens – particularly journalists, social workers, artists and social scientists – started identifying with psychiatric patients.[101] These patients were the ones with the sensitivity to see the world around them for the sickening

---

[97] Foudraine, *Wie is van hout* (1971); Rutten, *Jan Foudraine,* 51, 100, 109-110, 143. In 2021, on occasion of its fiftieth anniversary, the book was printed for the thirty-second time: Jan Foudraine, *Wie is van hout… Een gang door de psychiatrie* (thirty-second edition; Amsterdam 2021).

[98] Tonkens, *Het zelfontplooiingsregime*; Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 407.

[99] Tonkens, *Het zelfontplooiingsregime*; Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 407.

[100] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 405-406; Spruit, *Van wie zijn de kinderen?,* Chapter 6.

[101] Blok, *Baas in eigen brein,* 25.

place that it was, and their mental illness was a form of protest: a healthy reaction to an unhealthy society. Progressive people felt they suffered from something similar: *vervreemding* (alienation) from society. People were not in touch with their feelings, not in touch with each other, and their twisted communication patterns made them literally crazy – while all they did in response was consume, numbing themselves even more with what they purchased, particularly tobacco and alcohol. 'Consciousness-expansion' was the remedy, through psychotherapy, or, to some, through the use of psychedelic drugs like LSD. Some were convinced that people who experienced psychoses did not need such aids: their 'psychotic journey' could be a way to self-awareness, too. Psychiatric patients were regarded as the tragic heroes of critical psychiatry.[102]

These ideas reached the masses also through popular films. *Family Life* (1971, in Dutch cinemas 1972), told the story of how conflicts with her old-fashioned, controlling parents made a young British woman end up in a psychiatric hospital for life. *Toestanden* (Situations, 1976), based on a successful play by the experimental theatre company Het Werkteater, showed the pathological communication in Dutch families that made people crazy. And although *One Flew Over the Cuckoo's Nest* (1975, in Dutch cinemas 1976) portrayed poor practices and mistreatment in an American asylum in the 1950s, many people saw it as an illustration of the state of Dutch institutions in the present.[103]

In the two international movies, traditional psychiatry was presented as the domain of aloof doctors in white coats and tyrannical nurses in uniforms who used pills and electroshocks to get patients back in line, so that they could be returned to society as obedient citizens. Modern psychiatry, by contrast, was shown in *Family Life* as an egalitarian mini-society in which doctors and patients were hard to distinguish from one another, and talking therapies helped patients reconnect with themselves and liberate themselves from the societal and particularly the family restraints that had made them sick. Protesting the shortcomings of psychiatry thus became linked to the larger public debate around personal freedom, equality, and openness.[104]

When over the course of the 1970s, a range of action groups and initiatives emerged with the intention of forcing changes in mental health care, the participants in that movement ranged from critical mental health care workers, former patients and relations to progressive lawyers, social scientists, feminists and students from various disciplines. On one end of the spectrum, there were students and intellectuals who were inspired by Marxism and the way the radical German Sozialistische Patientenkollektiv (SPK, Socialist Patient Collective) applied these ideas to their anti-psychiatry actions. On the other end, there were those who had actually experienced mental health crises and mental

---

[102] Blok, *Baas in eigen brein,* 25-32.
[103] Blok, *Baas in eigen brein,* 174.
[104] Blok, *Baas in eigen brein,* 36-47.

health care, and wanted to address concrete issues that mattered to the lives of people who were going through such experiences. Although the voice of those clients and ex-clients grew stronger over the course of the 1970s, in the early years of the decade, the fight was largely fought by *zaakwaarnemers*, as they were called: people who had never been patients themselves, but wanted to reform psychiatry in their name.[105] Increasing numbers of supporters, as we have seen, were professionals.

This wave of reform-mindedness pushed professionals who insisted on a biomedical perspective or even a more multi-perspectival approach to the sidelines. Psychiatrists like Piet Stolk and Maarten Cohen Stuart wrote critical pieces pointing out the downsides of the psychosocial approach, but their views no longer dominated the mainstream.[106] Likewise, patients who did not care much for anti-psychiatry and simply wanted specialised care – whatever the theoretical approach, as long as it worked and was done in a manner that was respectful to them – organised less conspicuously. Instead of rejecting diagnoses, as anti-psychiatry prescribed, they united in diagnosis-oriented organisations, focusing on one particular category of mental health issues. The NVA and the Stichting Anorexia Nervosa were of such a different nature than the Cliëntenbond and the countermovement in psychiatry at large, that they are usually more associated with the diagnosis-oriented patient movement of the late 1980s and 90s, when anti-psychiatry was on its way out.[107] But as we have seen, the first clients' organisations of this kind actually developed simultaneously.

What became very apparent in the early 1970s was that everyone had the right to challenge psychiatry, including the clients of mental health care, who had no say in it up until that point. It was that vibrant atmosphere of change in psychiatry and society at large that helped them organise, whether in the Cliëntenbond, where people with all kinds of mental health issues were welcome, or in the diagnosis-oriented NVA and Stichting Anorexia Nervosa. It *was* possible to crack open the closed bulwark of psychiatry, clients had every right to demand improvements, and you were no longer alone if you did so.

A literary reflection: Keefman (1972)

In 1971, the year that Foudraine hit the bestseller lists and the Cliëntenbond was founded, the short story 'Keefman' by Jan Arends was published. Initially printed in *De Stethoscoop* (The Stethoscope), the in-house magazine of the Willem Arntz Stichting where Arends was hospitalised when he wrote it,[108] the next year it came out as the title piece in a

---

[105] Blok, *Baas in eigen brein,* 43.

[106] Laurs, *Recht voor psychiatrische patiënten,* 103-111.

[107] Hunsche, *De strijdbare patiënt,* 144-159.

[108] 'Jan Arends en de Bezige Bij', *De Engelbewaarder* 4 (1979) 15, 29-50, 36-37.

collection of short stories.[109] What was unprecedented was how, through Arends's work, readers experienced from within what it was like to have severe mental health issues. Arends gave the patient a voice and a humanity that had not previously surfaced in Dutch literature, illustrating how *mondigheid*, self-advocacy, was a possibility even for the most marginalised of people.

Arends, a difficult man who led a difficult life, had already acquired some fame in literary circles for his poems and short stories, but with this book he established himself firmly on the literary podium. The timing of the book was perfect: right when psychiatry became all the rage and anti-psychiatry ideals started spreading through mental health care and society.[110]

'Keefman' is a monologue consisting of seven letters, in which psychiatric patient Keefman ('caveman' written in phonetic Dutch) tells off his psychiatrist in an impressive rant. He is angry with the doctor for his inability to cure him, and for his denial that Keefman is deaf and could be a productive member of society if only he had the hearing aid he deserved. He is angry with the way he is excluded by the nurses and the other patients, whom he describes as disgusting, useless people. And, despite all of the above, he is mad at the doctor for intending to discharge him.

Addressing the psychiatrist with the informal *jij* instead of the formal *u* – which would have been unusual at the time, but precisely reflected the new 'democratic' conventions that were propagating in progressive circles – a central theme in 'Keefman' is power struggle. Keefman demands to be heard, despite the speech impairment and the deafness from which he suffers. He does not accept the subordinate position of the patient, challenges the authority of his psychiatrist, and accuses the doctor of blocking Keefman from moving up in society by his continued efforts to make his patient accept training for a menial job:

"Want je zit nou wel altijd de heilige te spelen die het allemaal zo goed bedoelt maar ik heb je door. Jij wilt een werkman van mij maken. Omdat het blijven moet zoals het is. Het mag niet anders worden. Mensen als ik moeten naar beneden getrapt worden. Dat is jullie enige kracht. Mij

("You're always playing the saint who means so well, but I've got you figured out. You want to make a workman out of me. Because things have to stay the way they are. They must not change. People like me need to be kicked down. That is your only power. Kicking me

---

[109] Jan Arends, *Keefman* (Amsterdam 1972).

[110] Margriet Westerhof, 'De boze taal van een eenzaam man. Over waanzin in de romanliteratuur en over de receptie van het verhaal *Keefman* van Jan Arends in het bijzonder', *Groniek* 23 (1990) 109, 105-117, 111-112; Nico Keuning, *Angst voor de winter. Jan Arends: leven en werk* (Amsterdam 2014) 240-246, 257-260.

naar beneden trappen. Want als je daarmee ophoudt is het allemaal niet meer waar en dan ben jij geen dokter meer. Dan kan jij niet langer de grote mijnheer uithangen."[111]

down. Because if you stop doing that, it's all no longer true and then you're no longer a doctor. Then you can no longer pose as the big man.")

The painful thing is that the further the story unfolds, the more Keefman's inability to survive outside the hospital shines through his angry words. After his discharge, he wanders the streets, hungry, cold and without money to pay for shelter. Soon, he returns to the psychiatric hospital, banging on the doors of the institution to be let in again. But that is no sign of defeat – quite the contrary:

"*En nou kan jij wel lullen van huisvredebreuk omdat ik er niet meer uit wou toen ik eenmaal binnen was maar dan had jij Keefman maar niet boos moeten maken. Keefman kwam midden in de nacht omdat het nooit te laat is om de waarheid te vertellen. Keefman kwam midden in de nacht omdat jullie overdag doof zijn. Omdat jullie de mensen dan van het kastje naar de muur sturen. Omdat jullie dan te druk bezig zijn met briefjes om te zeggen dat ik maar naar* [hulp voor] *onbehuisden moet.* [...] *Ja vriend, je hebt gelijk. Ik heb schandaal gemaakt. Ik heb midden in de nacht aan de bel van jouw gekkenhuis staan trekken. Nou ben jij kwaad omdat ik de waarheid in jouw oren heb gebeld en die er niet meer uit wil.*"[112]

("And now you can bullshit about trespassing all you want because I didn't want to leave once I got in, but then you shouldn't have pissed Keefman off. Keefman came in the middle of the night because it's never too late to tell the truth. Keefman came in the middle of the night because you people are deaf during the day. Because you are busy sending people from pillar to post. Because you are too busy with notes telling me to go to [help for] the homeless. [...] Yes pal, you are right. I made a scandal. I rang the bell of your madhouse in the middle of the night. Now you're angry because I've rung the truth in your ears and it doesn't want to go away anymore.")

The *Keefman* short story collection got its fair share of attention from critics and sold reasonably throughout 1972. Although by the end of the year, the interest was fading, Arends had definitely made an impression, and his new poetry collection was expected

---

[111] Jan Arends, 'Keefman', in: Jan Arends, *Keefman* (Amsterdam 1991 [1972]) 7-39, 10.

[112] Jan Arends, 'Keefman', 38-39.

with anticipation. But finally having things going well seems to have been difficult for him to handle. In January 1974, after having held the first copies of his new book in his hands, Arends ended his life.[113]

In reaction, interest in his work, in particular in 'Keefman', soared. Over the following years, the story was turned into a play, a film and a television series. Although the literary quality of Arends's work was largely uncontested, that continued interest became intertwined with his dramatic life and death, as well as with the trend for anti-psychiatry.[114] In fact, literary critic Ton Brouwers suspects that if it hadn't been for anti-psychiatry, 'Keefman' would have been long forgotten.[115]

The clients' movement organised a lecture series under the title *Keefman-lezingen* (Keefman Lectures) in 1987.[116] However, Arends's message, as literature student Margriet Westerhof has noted, was far more complicated than the movement's. Keefman calls out society as the cause of his madness, and critiques psychiatry's inability to heal him. At the same time, however, the psychiatric hospital is a refuge for him that he cannot do without.[117] In fact, the writer had warm memories of the time he had written 'Keefman' in the safe confinement of the Willem Arntz Huis in Utrecht.[118] And the feeling may have been mutual, we might conclude from the fact that the institution printed the story in its magazine. It came with a careful introduction, however, asking less progressive readers to give it a chance: *"Voor sommigen onder u zal dit wellicht een moeilijk te verteren brok betekenen, maar we hopen toch dat de meesten het op z'n minst boeiend zullen vinden om het mét de schrijver eens van een ongebruikelijke kant te zien."*[119] ("For some of you, this may be a difficult piece to digest, but we hope that most of you will at least find it fascinating to see it from an unusual side with the writer.")

Whether psychiatrists and nurses liked it or not, Keefman was speaking to them from the pages of the magazine of their own institution. He did that in a way that left the reader no other choice than to identify with him, identify with a psychiatric patient. This patient was not a voiceless object depending on the whims of the powerful mental health care worker, but a strong-willed individual demanding to be treated by them as a deserving member of society – as a client. 'Keefman' symbolised how the days of silenced patients were over and made it conceivable for all of them to raise their voices and be heard.

---

[113] Keuning, *Angst voor de winter,* 280-287, 316-340.

[114] Ton Brouwers, 'Jan Arends. Keefman', in: Ton Anbeek, Jaap Goedegebuure & Bart Vervaeck, *Lexicon van literaire werken* (Groningen 1989-2014; 1998) 1-14, 12; Westerhof, 'De boze taal', 111-115.

[115] Brouwers, 'Jan Arends. Keefman', 11.

[116] Stichting Kongres Psychiatrie in Werkelijkheid, *De Keefmanlezingen* (Amsterdam 1988).

[117] Westerhof, 'De boze taal', 114-115; 239-243.

[118] Keuning, *Angst voor de winter,* 226-228.

[119] 'Jan Arends en de Bezige Bij', *De Engelbewaarder* 4 (1979) 15, 29-50, 37.

The experiences that triggered the family movement's predecessors of the 1970s

In the 1960s, stigma and isolation were the main factors prompting the establishment of Al-Anon and Pandora. But in the sources on the origins of the three organisations that are central in this chapter, stigma is not very prominent as an explicit reason for organising, and combatting stigma is rarely mentioned in their goals. The fact that the organisations' members were there, openly identifying as people who had experienced mental health problems, been hospitalised, or were closely related to someone who had, was destigmatising in itself. And it was liberating, as Dunya Breur, one of the first and most prominent Cliëntenbond activists with a past in a psychiatric hospital, remembered: *"Dat je zomaar zonder blikken of blozen durfde te zeggen dat je in een inrichting had gezeten en dat je daar nog trots op was ook, was ongekend"* ("That you would dare say that you had been in an institution and that you were even proud of that, that was unprecedented").[120] The more people with personal experience as a patient or a relation were able to get rid of their public stigma as well as their self-stigma, the more it became possible to finally address the issues that had troubled them collectively for so long.[121]

The issues raised by relations and patients in the 1970s in their protests were doubtless connected with stigma. But instead of public stigma, they primarily addressed structural stigma: dilapidated hospitals, traumatising mistreatment, the poor legal position of patients, the lack of scientific knowledge on particular issues like autism and anorexia nervosa, the resulting lack of care and support facilities for those who suffered from these particular disorders, and the ideology that was so intensely damaging to relations – mother-blaming and family-blaming. These triggered the solidarity movement of the 1970s.

Dilapidated hospitals and traumatising mistreatment

Despite the feeling of crisis that loomed over Dutch psychiatry around 1970, there were nonetheless places where new ideas were put into practice, not just in outpatient care, but also in the psychiatric hospitals. Such innovations were not just about improving the poor circumstances that remained in many older institutions. Making the transition from a predominantly biomedical approach – where the accent, particularly on long-term wards, was on treatment with medication – to a stronger (psycho)social approach that revolved around individual and group psychotherapy, did not only mean introducing

---

[120] Hunsche, *De strijdbare patiënt,* 39.

[121] NL-HANA-CB inv. no. 241, 'De Cliëntenbond bestaat nu vijf jaar', anonymous typescript, dated by hand 14 November 1976.

new methods. Those methods demanded much smaller settings, and many more and better-trained staff, in a field where personnel had always been scarce to begin with.

The most outspoken example of such an innovation was the therapeutic community, where those who were admitted and the people who worked there formed a non-hierarchical mini-society, a new family, in which people with mental health issues were challenged to look deep inside themselves as well as to confront others in order to learn how to heal. Although addiction care had its own separate therapeutic communities,[122] those in general mental health care were open to people no matter what the nature of their problems. Traditional diagnoses were rejected – instead, labels such as 'identity crisis' were used, for example. Inspired by the rebelliousness and creativity of the young protest generation, the professionals here preferred young patients, who were not yet hospitalised and about whose chances of recovery the therapists were hopeful, like adolescents with a first psychotic episode.[123] Wil van der Laak remembers how, in the psychiatric hospital where he was a nurse, staff members of the therapeutic community came scouting suitable candidates in his ward, with a clear preference for pretty young girls.[124]

In 1972, student Bert Bakker admitted himself to Amstelland, the brand-new therapeutic community set up by psychiatrist Jan van de Lande at the Meerenberg psychiatric hospital in Bloemendaal, also known as 'Santpoort'. Looking back, Bakker had fond memories of the daily patient-staff meetings, unstructured group sessions that helped him get in touch with himself and others. But he also remembered the contrast of their new, brightly coloured pavilion with the destitute buildings around it:

"Ik dacht: ze steken in mij en andere jongeren geld. Een keer zag ik in paviljoen Wieringenland, ik moest daar zijn om mijn jas te repareren, een man masturberen in een hoek. Die werd daar toen gewoon uitgeramd, zo van: oprotten, zodat wij konden doorlopen. Mensen stijf onder de medicijnen, wat je later in de film One Flew Over the Cuckoo's Nest *zag."*[125]

("I thought: they are spending money on me and other young people. Once in the Wieringenland pavilion, where I went to have my coat repaired, I saw a man masturbating in the corner. He was just knocked to the side, like: piss off, so that we could pass through. People who were completely doped up, like you saw later in the film *One Flew Over the Cuckoo's Nest*.")

---

[122] Blok, *Ziek of zwak,* 89-195.

[123] Blok, ' "Tall, Spanking People" '; Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 903.

[124] Interview Wil van der Laak, 11 January 2023.

[125] Hunsche, *De strijdbare patiënt,* 64.

Bakker was right: in fact, the budget that had been allocated for renovations of Santpoort's chronic wards had been spent on Van de Lande's project instead.[126] And likewise, in many places, contrasts could be extreme, and especially for patients in long-term care, circumstances were often still harsh. Psychiatrist Willem Schudel reported in his 1976 dissertation that on average, Dutch psychiatric hospitals had less than one fulltime psychiatrist to every hundred patients, and that on three quarters of the wards of the four psychiatric hospitals that he surveyed, material circumstances were so out-of-date that many patients still slept on large wards with dozens of others, sanitary facilities were not up to standard, and people had no privacy to speak of.[127] Another indication of the backward circumstances was that the training programmes for nurses were so obsolete that in 1970, young nurses-in-training united in Aktie Willem (Action Willem, named after the Willem Arntz Hoeve hospital where it originated), and demanded to be taught modern methods, like therapeutic communication techniques and socio-therapy, instead of outdated nursing routines limited to medical and household tasks. To their surprise, their supervisors agreed with them.[128]

It was not that no one cared. Since its beginnings, psychiatry had been largely a matter of religious charities and independent foundations, and money had always been tight. It was a very recent development that the government was becoming more involved, making financial means available for material improvements and increases in staff.[129] And in some places, the results of that were already evident. In Voorburg psychiatric hospital in Vught (the same institution from which psychiatric nurse Wil van der Laak reported such backward circumstances of care), for example, the new ward Zilverlinden prompted a delegation of the Cliëntenbond to conclude after a 1975 visit that if all institutions were like that, a clients' league would no longer have to worry about mental health care.[130] But the backlog was immense, and that meant choices had to be made. Under pressure of having to deal with people in crisis while chronically overburdened, well-meaning professionals often lacked the power and the means for change.[131]

Certainly, many mental health care workers were able to create safe places for patients even where material circumstances were poor. Even the fiercest critics of mental health care made sure to mention them: Corrie van Eijk-Osterholt, for example, not only wrote appreciatively about the medical superintendent who undertook serious efforts to improve the psychiatric hospital her sister was in, she also supported the man when he

---

[126] Blok, ' "Tall, Spanking People" ', 271-275.

[127] W.J. Schudel, *Opgenomen..., opgegeven? Een exploratief onderzoek naar het gebruik van de bedden in psychiatrische ziekenhuizen* (Deventer 1976) 87, 141-142, 148.

[128] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 882-891; interview Wil van der Laak, 11 January 2023.

[129] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 797-800.

[130] 'Bezoek aan Huize Voorburg, afdeling Zilverlinden 3', *Bulletin van de Cliëntenbond* 3 (1975) 4, 9.

[131] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 857-858.

took legal action against his premature dismissal.[132] Some people who joined the clients' movement demanded room for positive stories to be told and heard as well, inspiring the editors of the *Gekkenkrant* (Newspaper of the Mad) to devote an entire issue to good experiences.[133] During an evaluation meeting, however, they concluded that the magazine should keep the number of positive articles to a bare minimum.[134] The editors of the *Bulletin van de Cliëntenbond* (Cliëntenbond Bulletin) also invited readers to report positive experiences they had in psychiatric hospitals, despite the reaction of a member who thought it was dangerous to encourage those who saw an admission as something 'fun', or a way to get rid of an unwanted family member.[135]

The Cliëntenbond had documented poor practices and mistreatments from its start. To substantiate the point that these were not incidental, they joined a countermovement-wide initiative to support a survey carried out in 1974 and 1975 by researchers from the University of Amsterdam, that became known as the 'Release survey'. In the survey, former patients who had been discharged between 1970 and 1975 reported both positive and negative experiences, but overall, the conclusions confirmed that most patients had no voice in decisions on hospitalisation, medication or treatment, were not informed about their rights or even their own test results, were pressured or forced to take medication, and were not very impressed with the quality of the other forms of therapy on offer. Overall, almost all institutions for which a representative number of ex-patients were interviewed, were characterised in the conclusions as bad, fair or a mix of good and bad.[136] Although it thus remained debatable whether these poor practices were representative of all psychiatric hospitals, the survey report that came out in 1977, confirmed that the experiences of individuals like Mies Osterholt and her twin sister Corrie van Eijk-Osterholt were not individual, but structural.[137]

Any remaining doubts about the extent of the poor practices in mental health care were eliminated when in 1977, another national survey was undertaken by an official government commission.[138] This Commissie Van Dijk (Van Dijk Commission) was established in 1975 to advise on the question of whether legislation guaranteeing patients' rights should be developed, and confirmed what the countermovement had

---

[132] Van Eijk-Osterholt, *Laten ze het maar voelen* (1972), 73-81.

[133] 'Positief nummer', *Gekkenkrant* 11 (1975) 2.

[134] 'De Gekkenkrant', *Bulletin van de Cliëntenbond* 3 (1975) 3, 8-9, 9.

[135] 'Reacties op het bulletin', *Bulletin van de Cliëntenbond* 8 (1980) 2, 3.

[136] Onderzoeksgroep Demokratisering in de Hulpverlening, *De positie van de psychiatrische patiënt in Nederland. Een onderzoeksverslag naar aanleiding van de enquête "De positie van de psychiatrische patiënt", Deel 2 Cijfermatige inzichten en overzichten* (Amsterdam 1977) 18-23.

[137] Laurs, *Recht voor psychiatrische patiënten*, 45-46.

[138] W.K. van Dijk, *Interimrapport van de Werkgroep rechtspositie patiënten in psychiatrische ziekenhuizen* ('s-Gravenhage 1977); Werkgroep rechtspositie patiënten in psychiatrische ziekenhuizen, *Rapportage resultaten enquête* ('s-Gravenhage 1979); Werkgroep rechtspositie patiënten in psychiatrische ziekenhuizen, *Rechtspositie patiënten in psychiatrische ziekenhuizen. Eindrapport* (['s-Gravenhage] 1980).

already exposed. Many hospital buildings were as good as uninhabitable and unliveable, which was all the more unacceptable as about two thirds of the patients in them had been there for more than two years, and almost half of them more than ten years.[139] The number of staff was only half of that in general hospitals of the same size, suggesting that care was inevitably inadequate.[140] But the commission was particularly indignant about the interpersonal treatment patients received from staff:

> *"Plagerijen, strafshocks en koudwaterbaden, een waardeloze registratie daarvan, medicijnen die als dwangmiddel werden toegediend zonder voldoende indicatie en in ongewenste combinaties, vrijwillig opgenomene patiënten die werden bedreigd met onvrijwillige opname, slordig invulde geneeskundige verklaringen."*[141]

> ("Bullying, shocks for punishment and cold-water baths, a worthless registration of all that, medication that was administered as a coercive measure without sufficient indications and in undesirable combinations, voluntarily admitted patients who were threatened with involuntary hospitalisation, carelessly filled out medical certificates.")

What was particularly remarkable in the report was the discrepancy between how hospital boards perceived the situation and how patient representatives saw it. When it came to informing patients on their treatment and their rights, or involving them in decisions on their treatment and care, the boards consistently reported figures that were two or three times more positive than those of patient representatives.[142] To the question asking whether patients were informed about their legal status – whether a person was a voluntary or an involuntary patient, and what consequences that had – 81% of hospital boards replied that this was the case, while only 33% of patients' representatives thought so.[143] Such a radically different view of psychiatric practice was not exclusive to the patient perspective, however. Critical psychiatrists like Peter Bierenbroodspot and Rudy van den Hoofdakker had already challenged their colleagues on their inaccessibility and unaccountability to the world outside their institutions, their authoritarian and aloof attitude towards their patients, and how they let patients' lives be determined by

---

[139] Werkgroep rechtspositie, *Rapportage,* 8. Various government inspections in the late 1970s confirmed the poor material conditions for at least half of all institutions in the country (Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 818-820).

[140] Werkgroep rechtspositie, *Rapportage,* 14.

[141] Quoted in Hunsche, *De strijdbare patiënt,* 30.

[142] Werkgroep rechtspositie, *Rapportage,* Chapter 3.

[143] Werkgroep rechtspositie, *Rapportage,* 19.

the arbitrary rule of head nurses.[144] The sector was increasingly becoming more self-critical, as we saw before. Now, it became entangled with the broad protest movement and counter-culture.[145]

The poor legal position of patients

Corrie van Eijk-Osterholt's account of the poor circumstances in which her twin sister Mies Osterholt and fellow patients spent their days in *Laten ze het maar voelen…,* the brutal ways they were often treated by nursing staff and the neglect they suffered from the doctors who were responsible for them, not only struck a chord with fellow clients and the general public. Criminology professor Peter Hoefnagels read the book with a legal eye, and deduced from the account that the doctors and nurses taking care of Osterholt had committed multiple infractions in five legal categories: *mishandeling, zware mishandeling, opzettelijke wederrechtelijke vrijheidsberoving, diefstal c.q. verduistering* and *oplichting* (assault, grievous bodily harm, unlawful detention, theft casu quo embezzlement and fraud).[146]

What also stood out in *Laten ze het maar voelen…,* was how it seemed to be impossible for these patients, and for relations who tried to advocate for them, to be taken seriously when they took up such issues or filed complaints with the authorities, from head nurses and doctors to medical superintendents and mental health inspectors. Almost every time Van Eijk-Osterholt approached those in charge to discuss worries over her sister's health and treatment, or complaints about the poor practices and abuses her sister had to endure, she was brushed off, misinformed, belittled or intimidated. Whenever she took up an issue with the mental health inspector, she was struck by his passive attitude. In her experience, a tacit agreement between doctors to always have each other's backs guaranteed that any complaint or suggestion they did not like was swept under the rug.[147]

The avalanche of reactions to her book and the talk show *Een klein uur U,* and the many cases the Cliëntenbond handled and documented strongly suggested that this was not an individual problem, but a collective and a structural one. The survey of the Commissie Van Dijk confirmed that in almost half of the institutions, there were no options for filing a complaint other than with the professionals who treated the patient or with the management.[148] Patients' rights became number one on the agenda of the Cliëntenbond as well of that of the broader countermovement in psychiatry.[149]

---

[144] Laurs, *Recht voor psychiatrische patiënten*, 41-42; P. Bierenbroodspot, *De therapeutische gemeenschap en het traditionele psychiatrisch ziekenhuis* (Meppel 1969); R.H. van den Hoofdakker, *Het bolwerk van de beterweters. Over de medische ethiek en de status quo* (Amsterdam 1971).

[145] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 775.

[146] G.P. Hoefnagels, 'Witte-jassen-criminaliteit', *De Gids* 136 (1973) 1, 590-598, 591.

[147] Van Eijk-Osterholt, *Laten ze het maar voelen* (1972).

[148] Werkgroep rechtspositie, *Rapportage,* 32.

[149] Hunsche, *De strijdbare patiënt,* 16-17, 23-25, 53-55.

Around 1970, patients had no rights to speak of, and were largely uninformed about such rights they did have. Dutch mental health care, or more precisely, the admission and discharge of involuntary patients in mental health care institutions, was still governed under the *Krankzinnigenwet* (Insanity Act) of 1884. Although the law had been extended and amended several times over the years, the need for a new, up-to-date law was widely felt.[150] But not only was the law outdated, it was also not respected in important aspects of daily practice. Municipal health services sometimes kept blank orders for involuntary commitment in a drawer, pre-signed by the mayor who was supposed to weigh such a request with careful consideration. The hospital stays of voluntary as well as involuntary patients could be extended time and time again by judges uncritically signing off a doctor's cursory requests, while patients were kept unaware of their right to be heard in the matter. And the legal requirement to register the use of coercive measures, that had made mental health care professionals accountable for the use of measures like restraint, isolation or involuntary treatments since the late 1930s, was hardly observed anywhere.[151]

Following the failure of an earlier proposal for a new law in 1955, in 1971, the government proposed another one, entitled *Wet Bijzondere Opnemingen in Psychiatrische Ziekenhuizen (Wet* BOPZ*,* Law on Special Admissions to Psychiatric Hospitals). Its fundamental difference with its predecessor the *Krankzinnigenwet* was that people could no longer be involuntarily committed to a psychiatric hospital on the grounds that the judge, advised by a doctor, decided that that was in the patient's best interest (the so-called *bestwilcriterium,* 'for-your-own-good' criterion). Instead, the *gevaarscriterium* (danger criterion) was introduced, making involuntary hospitalisation possible only when a person's mental state was considered a serious danger to themselves or to others. Although this sounded like an important improvement, the 1971 proposal came right in the middle of swelling public debate and the rise of the countermovement, and was widely criticised. The major objection was that the law hardly contained any rights for patients.[152]

Mother-blaming and family-blaming

It was the main subject of the opening speech that René Sieders, the founder of the Stichting Anorexia Nervosa, held on the first 'contact day' of the foundation in January, 1979: the *"bijzonder onaangename wijze"* ("particularly unpleasant manner") experts wrote about patients and their parents – about his daughter, her mother and himself. Anorexia patients were attention-seekers who wanted to dominate their parents but refused to grow up. They had a dominant mother who refused to let her daughter grow up. Or an emotionally absent father, who probably even committed incest with his child. The

---

[150] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 857-858.

[151] Laurs, *Recht voor psychiatrische patiënten,* 39; Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 863.

[152] Laurs, *Recht voor psychiatrische patiënten,* 48; Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 858.

parents stood in the way of the children's development, they took care of their daughter's body, but not of her, they trained their children to their own needs, not the needs of the children. And so the list went on and on.[153]

It is a sad fact that terrible things happen in families that can damage the mental health of children – with his criticism, Sieders did not intend to deny this. What he wanted to address was that when a person was diagnosed with anorexia nervosa, many mental health care professionals simply *assumed* this kind of abuse to be a fact, based on the causality that was set out in the scientific literature. From studying that literature himself, Sieders had concluded that over the years, dozens of explanations had been offered for anorexia nervosa, but that the prevailing one in the Netherlands since the 1960s was that a dominant mother was to blame. In his 1979 speech, Sieders blamed the endless repetition of this reasoning on Dutch psychiatrist Christien Lafeber, who had put forward this theory in her dissertation that was first published in 1963. The thesis then found its way to a broad medical audience in 1971 when it was republished in the series *Nederlandse Bibliotheek der Geneeskunde* (Dutch Library of Medicine).[154] But blaming the mother, the father or the family for having caused or sustained anorexia nervosa was not a particularly Dutch trait, and nor was it recent. In addition, such reasoning was not exclusive to anorexia nervosa: over the course of the twentieth century, almost all kinds of severe mental health issues would, sooner or later, be blamed on close relations.

Feminist writers and historians have used the term 'mother-blaming' for this phenomenon since the 1960s.[155] Loosely quoting Denise Sommerfeld's definition, this is the tendency to hold mothers accountable for problems with their offspring's physical and psychological well-being.[156] Fathers, and in due course also partners and entire family units, met the same fate. Such a judgement did not rest on an assessment of an individual patient's problems and family dynamics, but was based on theoretical notions with brittle foundations.

Although ideas on child-rearing have led to mother-blaming ideas in Western societies since ancient times,[157] this kind of 'scientific justification' for them originated

---

[153] Archive Vleeschdraager, zero issue *ANtenne* February 1979, Sieders, 'Openingstoespraak', 8-9.

[154] Archive Vleeschdraager, zero issue *ANtenne* February 1979, Sieders, 'Openingstoespraak', 5-6.

[155] For example: Barbara Ehrenreich & Deirdre English, *For Her Own Good: 150 Years of Experts' Advice to Women* (New York 1978); Susan Contratto, 'Psychology Views Mothers and Mothering: 1897-1980', in: Vivian Patraka & Louise A. Tilly, *Feminist Re-Visions: What Has Been and Might Be* (Ann Arbor 1983) 149-178; Molly Ladd-Taylor & Lauri Umansky (eds.), *"Bad" Mothers: The Politics of Blame in Twentieth-Century America* (New York 1998); Carol Eadie Hartwell, 'The Schizophrenogenic Mother Concept in American Psychiatry', *Psychiatry* 59 (1996) 3, 274-297; see also classics such as Betty Friedan, *The Feminine Mystique* (Harmondsworth 1963) and Elisabeth Badinter, *L'amour en plus: histoire de l'amour maternel (XVIIe-XXe siècle)* (Paris 1980).

[156] Denise P. Sommerfeld, 'The origins of mother-blaming: Historical perspectives on childhood and motherhood', *Infant Mental Health Journal* 10 (1989) 1, 14-24, 15.

[157] Sommerfeld, 'The origins of mother-blaming', 15-16.

in the early twentieth century with Sigmund Freud's psychoanalytical theories.[158] From the psychoanalytic viewpoint, the cause of any psychological or psychiatric problem in a person lies hidden in their earliest experiences, buried in their unconscious.[159] "And so the question became," Molly Ladd-Taylor and Lauri Umansky wrote, "What kind of mother led to this person's problems? The answers stretched as far as the variations on the bad-mother theme could go."[160]

Although Freud warned readers not to take his theories too far, and especially not to use psychoanalysis to treat people with schizophrenia,[161] many of his followers tried his ideas and methods on patients with all kinds of severe mental health issues, hoping to find a way to cure them. An important vehicle for these ideas was the international mental health movement (see Chapter 1). With its focus on mental health instead of mental illness, the healthy raising of children and adolescents inevitably became a central concern.[162] When, in the aftermath of the Second World War, worries about the moral degradation of young people ran high, the movement's ideas boomed in the Netherlands as elsewhere in the Western World.[163]

The work of the British child psychiatrist and psychoanalyst John Bowlby was central here. From his studies of orphaned and delinquent children, Bowlby concluded that in order for a child to become a socially and emotionally healthy human being, it must spend its earliest years in close, continuous, physical proximity to the mother and form a balanced attachment to her:

> *"It is submitted that the evidence is now such that it leaves no room for doubt regarding the general proposition – that the prolonged deprivation of the young child of maternal care may have grave and far-reaching effects on his character and so on the whole of his future life. Although it is a proposition exactly similar in form to those regarding the evil after-effects of rubella in foetal life or deprivation of vitamin d in infancy, there is a curious resistance to accepting it."*[164]

Although Bowlby's work was criticised for its poor methodology, psychoanalytic determinism and uncritical affirmation for traditional roles of men and women, it

---

[158] Ladd-Taylor & Umansky, *"Bad" Mothers,* 13.

[159] Edward Dolnick, *Madness on the Couch: Blaming the Victim in the Heyday of Psychoanalysis* (New York 1998) 14.

[160] Ladd-Taylor & Umansky, *"Bad" Mothers,* 13.

[161] Dolnick, *Madness on the Couch,* 39.

[162] Anne Harrington, 'Mother Love and Mental Illness: An Emotional History', *Osiris* 31 (2016) 1, 94-115, 100.

[163] De Goei, *De psychohygiënisten,* 49-163.

[164] John Bowlby, *Maternal Care and Mental Health: A Report Prepared on Behalf of the World Health Organization as a Contribution to the United States Programme for the Welfare of Homeless Children* (New York 1967 [1951]) 46.

became very influential.[165] Having been developed in close consultation with leading Dutch child psychiatrists, Bowlby's ideas reached the Netherlands early on.[166] Not only professionals, but the Dutch public at large as well. A popular child care handbook from 1966, for example, stated:

> *"Elke moeder die van haar kind houdt* [...] *zal zich inspannen om haar plichten zo goed mogelijk na te komen. Er rust een grote verantwoordelijkheid op haar, want het kind krijgt de gevolgen te dragen van al wat zij verkeerd zou doen."*[167]

> ("Every mother who loves her child [...] will strive to fulfil her duties to the best of her ability. There is a great responsibility on her, because the child has to bear the consequences of everything she could do wrong.")

One of the most powerful examples of a field that was shaped by mother-blaming was autism. In his first article on autism, published in 1943, the Austrian-American child psychiatrist Leo Kanner suggested that autism might be caused by a cold parenting style and family atmosphere.[168] In 1948, in an interview with the American magazine *Time*, the way he spoke about autistic children was quoted as "children who were kept neatly in refrigerators which did not defrost",[169] a phrase he repeated in a scientific paper published the following year.[170] In the wake of these articles, mothers of autistic children came to be called 'refrigerator mothers'. Kanner was not the first to link autism to a faulty upbringing – as a matter of fact, the theoretical roots of mother-blaming in autism go back to the 1910s,[171] when it was seen as a symptom of schizophrenia. But the interview in *Time* launched the phenomenon onto the public stage, first in the United States, subsequently finding its way all over the Western world.[172]

---

[165] Jeroen Jansz, 'Het kind. Deskundige opvoedingsadviezen en -interventies', in: Jeroen Jansz & Peter van Drunen, *Met zachte hand. Opkomst en verbreiding van het psychologisch perspectief* (Maarssen 1997) 37-55, 48.

[166] Frank C.P. van der Horst, 'John Bowlby's ontmoeting met de Nederlandse kinder- en jeugdpsychiatrie: verslag van een werkbezoek in 1950', *Kind en Adolescent* 35 (2014) 4, 255-267; Leonie de Goei, *In de kinderschoenen. Ontstaan en ontwikkeling van de universitaire kinderpsychiatrie in Nederland, 1936-1978* (Utrecht 1992) 66.

[167] Quoted from Anneke Ribberink, *Leidsvrouwen en zaakwaarnemers. Een geschiedenis van de aktiegroep Man Vrouw Maatschappij (MVM) 1968-1973* (Hilversum 1998) 36.

[168] Leo Kanner, 'Autistic Disturbances of Affective Contact', *Nervous Child* 2 (1943) 3, 217-250, 250.

[169] Dolnick, *Madness on the Couch,* 178; Christopher Sterwald & Jeffrey Baker, 'Frosted Intellectuals: How Dr. Leo Kanner Constructed the Autistic Family', *Perspectives in Biology and Medicine* 62 (2019) 4, 690-709, 691.

[170] Leo Kanner, 'Problems of Nosology and Psychodynamics of Early Infantile Autism', *The American Journal of Orthopsychiatry* 19 (1949) 3, 416-426.

[171] Dolnick, *Madness on the Couch,* 92.

[172] Sterwald & Baker, 'Frosted Intellectuals', 694-695.

Over the years, psychoanalytically inclined researchers came up with an array of variations on the theme. The mother of an autistic child was compulsive, perfectionist, narcissistic, unripe, rigid, emotionally detached, afraid of physical contact, insensitive. And the fathers did not escape: they were described as obsessive, detached, humourless and extremely perfectionist.[173] Edward Dolnick calls it a 'chorus' of 'antiparent messages'[174] that sounded from the mid-1940s to at least the mid-1960s. The strongest and most radical voice was that of the Austrian-American child psychologist Bruno Bettelheim. His 1967 book on autism, entitled *The Empty Fortress,* made him an international celebrity. Drawing on his personal experiences as a victim of the Dachau and Buchenwald concentration camps during the Second World War, Bettelheim compared children with autism to concentration camp prisoners in that they felt "deprived of hope, and totally at the mercy of destructive irrational forces bent on using him for their goals, irrespective of his".[175] Central to his book, he wrote, was his "belief that the precipitating factor in infantile autism is the parent's wish that his child should not exist".[176] Even more than Kanner, Bettelheim was able to spread his message to a large international audience.[177]

Although the mother-blaming chorus was loud and overwhelming, there were a few scientists who questioned it or offered evidence supporting a 'nature' thesis instead of a 'nurture' one. The American psychologist Bernard Rimland, who had a young autistic son himself, published the book *Infantile Autism* in 1964, in which he questioned the mother-blaming theories, but it was barely noticed.[178] When Bettelheim's *The Empty Fortress* appeared, Rimland reacted furiously in the *New York Times*: "Parents of mentally ill children have anguish enough already [...]. To heap guilt, based on disproven, circumstantial evidence, on these parents, is an act of irresponsible cruelty."[179] Another 'parent-of' and psychiatrist, John Kysar, saw the deepening of the trenches as detrimental to the children, their parents, their schools and everyone who worked with them, and pleaded for reconciliation in 1968.[180]

Although these voices were initially ignored, the confrontation with these colleagues and other parents made Kanner acquit them of blame in a speech he gave in 1969 for the American parents association.[181] But the 'refrigerator mother' was not easily wiped out, as Bettelheim and other experts continued on this track. When the American child

---

[173] Ina van Berckelaer-Onnes, 'Ouders van kinderen met ASS door de jaren heen. The hand that rocks the cradle', *Kind en Adolescent* 36 (2015) 4, 229-240, 231.

[174] Dolnick, *Madness on the Couch,* 184.

[175] Quoted in Dolnick, *Madness on the Couch,* 183.

[176] Quoted in Dolnick, *Madness on the Couch,* 184.

[177] Dolnick, *Madness on the Couch,* 179-184.

[178] Van Berckelaer-Onnes, 'Ouders van kinderen met ASS', 232-233.

[179] Quoted in Dolnick, *Madness on the Couch,* 218.

[180] Van Berckelaer-Onnes, 'Ouders van kinderen met ASS', 233.

[181] Van Berckelaer-Onnes, 'Ouders van kinderen met ASS', 232-233; Dolnick, *Madness on the Couch,* 206-207.

psychiatrist Marian DeMyer tested the refrigerator mother hypothesis in controlled trials in the first half of the 1970s and proved it wrong, she also noticed that even parents had internalised the theory, making them come across as aloof in the doctor’s office because they knew the experts had already decided on their guilt. “They’d heard that there was something wrong with them, and they were frozen with fear when they first came to be interviewed.”[182] The theory had become a self-fulfilling prophecy.

In the sources of the Dutch autism organisations that arose in the 1970s, there is no mention of ‘refrigerator mothers’ or ‘mother-blaming’ – apart from a rare reference to such reasoning as something from the past.[183] That is because the organising parents were supported from the start by experts who belonged to an independent Dutch tradition of autism research. Experts like Dirk van Krevelen, Frits Grewel, Sjef Teuns, Lucas Kamp, Nan Snijders-Oomen and Ina van Berckelaer-Onnes, some of whom were even psychoanalysts, rejected the idea that autism was caused by the parents. But their expertise would remain confined to expert circles for a long time.[184] That meant that parents who did not find these specialists or the parent organisations they supported – which was something that could easily happen in the opaque Dutch mental health care system of the time – could still be confronted with parent-blaming. Grewel fulminated repeatedly against what he called widespread ‘dilettantism’: *“een leek die psychiatrisch klinkende termen hanteert, bij voorkeur modetermen zoals ‘emotionele verwaarlozing door de moeder’ ”* (“A lay person using psychiatric sounding terms, preferably fashionable terms such as ‘emotional neglect by the mother’.”)[185] In addition, the ‘refrigerator mother’ was such a remarkable phenomenon that it would continue to circulate in professional readings as well as popular magazines. Van Berckelaer-Onnes, who started working as a clinical child specialist in the early 1960s, remembered:

“Ik heb heel veel huilende ouders gehad, echt helemaal in alle staten. En dat zijn de meest liefhebbende ouders die je je maar kunt voorstellen hè? En die lezen dan in

(“I have seen many crying parents, really bouncing off the walls. And those are the most loving parents you can imagine, right? And then they read

---

[182] Quoted in Dolnick, *Madness on the Couch,* 226.

[183] See for example Fred van der Meulen, ‘Een vorm van bijval’, *Engagement* 2 (1975) 9, 26-27; C. Rümke, ‘Enkele bedenkingen, van de pionierstijd tot heden’, *Engagement* 2 (1975) 16-19, 19; Eric Schopler, ‘Behandeling van autistische kinderen in een historisch perspectief’, *Engagement* 4 (1977) 6, 2-12.

[184] De Goei, *In de kinderschoenen,* 120-122; Edo Nieweg, ‘De mythe van de koele moeder herzien. Over vooruitgang en vooroordeel in de psychiatrie’, *Maandblad Geestelijke Volksgezondheid* 57 (2002) 9, 854-860.

[185] De Goei, *In de kinderschoenen,* 118.

een tijdschrift, want het was natuurlijk heel bekend op een gegeven moment, zelfs de Libelle *wist dat nog te doen hè, dat ja, dat het echt wel aan die ouders lag. Dus dat is heel kwetsend voor ouders en maakt je dus ook heel erg onzeker in je opvoedingscompetentie.*"[186]

in a magazine, because at some point it was of course very well known, even [women's weekly] *Libelle* still managed to do that, that yes, that those parents really were the problem. So that is very hurtful for parents and it also makes you very insecure in your parenting abilities.")

From the mid-1970s onwards, the Nederlandse Vereniging voor Autisme and its predecessors would be increasingly instrumental in spreading scientific information that *was* supportive to parents, children, and entire families – new scientific insights that they had helped their expert allies develop. Families that suffered from anorexia nervosa, however, were not so lucky. For twenty years, founder René Sieders would publish critical reviews of the latest scientific and popular literature on the subject in every issue of *ANtenne*, the Stichting Anorexia Nervosa newsletter, consistently debunking old and new mother-, father- and family-blaming theories.

Sieders's criticism was not only based on how incompatible these theories seemed to be with his personal experience with his daughter and the stories he heard from other patients and parents. Time and time again he noted that different researchers linked opposing observations to the causes of anorexia nervosa in a person – one might state, for example, that mothers of patients were dominant characters, whereas another maintained that dominant women were not found among mothers of people who suffered from anorexia nervosa. A university graduate himself, Sieders also judged the studies he read from a methodological point of view, focusing in particular on the way they dealt with causality. All sorts of personal traits that experts identified in parents as causing anorexia nervosa in their children, could just as readily be found in parents of healthy offspring, he concluded: *"Mij is opgevallen dat alle vaders van anorexia's een neus hebben, dat zal dus wel de oorzaak van de AN zijn"* (I have noticed that all fathers of anorexia's have a nose, therefore that must be the cause of the *AN*).[187]

The roots of mother-blaming associated with anorexia nervosa go back to the 1930s. After a period in which biological explanations of the disorder's origins first gained dominance and then subsided,[188] psychoanalysts started to focus on the subconscious

---

[186] 'IJskastmoeders. Over onbegrepen autisme', *Andere Tijden* (television documentary 14 October 2017) at 22:54, https://www.anderetijden.nl/aflevering/720/IJskastmoeders accessed 29 December 2023.

[187] René Sieders, 'Boekbespreking. Titel: Een strijd om het bestaan', *ANtenne* (1980) 7, 13.

[188] Ron van Deth & Walter Vandereycken, *Van vastenwonder tot magerzucht. Anorexia nervosa in historisch perspectief* (Meppel 1988) 203-204.

symbolic motivation behind the refusal to eat.[189] An array of explanations came to the light, connecting the phenomenon with classical Freudian, suppressed, unconscious feelings about sexuality – it could for instance be an expression of a girl's unwillingness to be orally penetrated by the father.[190] But it was the mother who was blamed most of all: her ineffective and emotionally abusive parenting was why her child stopped eating. An anorexic girl, for example, suppressed her sexual feelings and the development of her body, because her mother had raised her with puritanical ideas about sex.[191]

From the 1950s onwards, mother-blaming may have subsided somewhat as hope was pinned on behaviour therapy – punishment and reward depending on whether a patient gained weight or not – and on medication.[192] In the 1960s, psychoanalytic approaches returned, now focusing on poor communication between mother and daughter. Psychiatrists like the German-American Hilde Bruch and the Italian Mara Selvini-Palazolli reasoned that anorexia nervosa started with feeding problems in infancy: that was when a girl must have learned already that it was her mother who controlled her needs. The British psychiatrist A.C. Crisp widened this kind of mother-blaming to family-blaming: overprotected by her family, the daughter was not allowed to develop a sense of self and the skills that she needed to face the world in adolescence.[193]

When the Stichting Anorexia Nervosa was founded in 1978, the most influential authority in the international anorexia nervosa field was the Argentinian child psychiatrist Salvador Minuchin. Minuchin coined the term 'anorexogenic family' – a family that produces children with anorexia nervosa. He looked at the issue from a systems theoretical perspective: the family was seen as a system in which the psychiatric disorder is caused and maintained. As a consequence, the therapist should not focus on the patient, but on the whole family. Families in which anorexia nervosa occurs, he maintained, were families that did not allow children to develop their autonomy and identity, instead overemphasising loyalty and protection. Such families were rigid and lacked problem-solving skills. In such families, a child could develop anorexia nervosa as a physiological way to defer conflicts between the parents: instead of fighting, they

---

[189] Joan Jacobs Brumberg, *Fasting Girls: The History of Anorexia Nervosa* (Cambridge 1988), 212-217; Thomas Vander Ven & Marikay Vander Ven, 'Exploring Patterns of Mother-Blaming in Anorexia Scholarship: A Study in the Sociology of Knowledge', *Human Studies* (2003) 26, 97-119, 102-103; Paulien Goettsch, 'Verslag van de landelijke contactdag op 31 maart 1990', *ANtenne* 56 (1990) 14-16, 14.

[190] Liliana Dell'Osso et al., 'Historical Evolution of the Concept of Anorexia Nervosa and Relationships with Orthorexia Nervosa, Autism, and Obsessive-Compulsive Spectrum', *Neuropsychiatric Disease and Treatment* (2016) 12, 1651-1660, 1655; Paulien Goettsch, 'Verslag van de landelijke contactdag op 31 maart 1990', *ANtenne* 56 (1990) 14-16, 14.

[191] Vander Ven & Vander Ven, 'Exploring Patterns', 102-103.

[192] Paulien Goettsch, 'Verslag van de landelijke contactdag op 31 maart 1990', *ANtenne* 56 (1990) 14-16, 14.

[193] Vander Ven & Vander Ven, 'Exploring Patterns', 104-106.

come together over their concern for the child, who is thus rewarded for her symptoms. Minuchin reported spectacular results for the family treatment that he developed based on this theory, and although his publications were never peer-reviewed and lacked solid scientific data, his approach became very popular in the 1970s and 80s, including in the Netherlands. In contrast to autism, there was no alternative school of thought at the time that exculpated parents from the assumption that they had caused their child's anorexia nervosa.[194]

How these theories impacted Dutch parents is seen in the experiences participants shared during a contact day of the Stichting Anorexia Nervosa in 1984. Many parents felt insufficiently informed, belittled, not taken seriously, ignored, left to their own devices and made to feel guilty about causing their child's eating issues. They questioned themselves initially about what they might have done wrong, and those feelings were made worse by the attitudes of professionals towards them.[195] Many people with anorexia nervosa wrote lovingly about their parents in *ANtenne*, despite the unavoidable frictions between them as a result of their distorted eating habits, while others addressed problems with their family without referring to blame theory. But sometimes a letter clearly bore the marks of the psychiatric line of thinking that was *en vogue*. A young man complained about *"een zeer zwakke vader op de achtergrond en een dominante moeder die alle touwtjes in handen heeft"* ("a very weak father in the background and a dominant mother who holds the reins").[196] And two parents who told their daughter that they would not let themselves be talked into feeling guilty, received the reaction from her: *"... en juist omdat jullie geen schuldgevoelens hebben, heb ik A.N."* (... and precisely because you don't feel guilty, I have A.N.").[197]

The theories weighed heavily on the parents' shoulders, adding to the burden that already came with dealing with anorexia nervosa. *"Als de andere kinderen er niet waren geweest,"* a Mrs. V. concluded, *"zou ik nu zelf in een inrichting zitten"* ("If the other children had not been there, I would be in an institution now myself").[198] They did not understand why the complicated dynamics in their families, that in their experience had developed *after* their child had stopped eating normally, were taken as proof of its cause. A Dutch mother whose anorexic daughter committed suicide in 1973 put it like this:

---

[194] Vander Ven & Vander Ven, 'Exploring Patterns', 104-109; Daniel Le Grange et al., 'Academy for Eating Disorders Position Paper: The Role of the Family in Eating Disorders', *International Journal of Eating Disorders* 43 (2010) 1, 1-5, 1-2; Eric van Furth, *Eetstoornissen in context* (Inaugural lecture Universiteit Leiden 2013), 6-8; Paulien Goettsch, 'Verslag van de landelijke contactdag op 31 maart 1990', *ANtenne* 56 (1990) 14-16, 14.

[195] Mieke Coenen, 'Verslag groep V', *ANtenne* (1984) 25, 30-35; 'Verslag groep VI', *ANtenne* (1984) 25, 36-37.

[196] Radboud Hartendorp, 'Ik ben Radboud', *ANtenne* (1981) 11, 28.

[197] Mieke Coenen, 'Verslag groep V', *ANtenne* (1984) 25, 30-35, 34-35.

[198] Mieke Coenen, 'Verslag groep V', *ANtenne* (1984) 25, 30-35, 34.

"Is het niet verschrikkelijk, dat bij alle verdriet en normale zelfverwijten, die ouders na zo'n intens tragisch verdriet te dragen krijgen, zij zich nu ook geconfronteerd zien met 'psychologische verklaringen', dat het aan de ouders en het gezin zou liggen? Ik wil niet uitsluiten, dat er zulke gevallen misschien zijn. Evenmin als er volmaakte mensen zijn, bestaan er volmaakte gezinnen. Maar alle liefhebbende ouders trachten al hun kinderen evenveel aandacht en liefde te geven, aangepast aan hun karakters. En het tot een goede oplossing brengen van problemen, in harmonie met het hele gezin, kan een extra warme gezinsband geven. Is het gezamenlijk vinden van oplossingen niet de sport van het leven? Een psychiater ziet de patiënt pas als deze ziek is. En dat beeld is een vertekend beeld van de echte persoon. Uit ervaring weet ik, dat hun karakters onherkenbare veranderingen ondergaan. Hun problemen van nu zijn gehéél andere dan voorheen. Hoe wil een buitenstaander daarover oordelen?"[199]

("Isn't it horrible that with all the grief and normal self-reproach that parents have to bear after such an intensely tragic grief, they are now also confronted with 'psychological explanations' that it is the fault of the parents and the family? I do not want to rule out the possibility that there may be cases like that. Just like there are no perfect people, there are no perfect families. But all loving parents try to give all their children the same amount of attention and love, tailored to their characters. And bringing problems to a good solution, in harmony with the whole family, can give an extra warm family bond. Isn't finding solutions together the sport of life? A psychiatrist does not see the patient until they are ill. And that image is a distorted image of the real person. I know from experience that their characters undergo unrecognisable changes. Their problems today are very different from before. How does an outsider want to judge that?")

Considering the history of mother-blaming, it is not easy to resist the urge to start blaming professionals in turn. However, we must keep in mind how difficult severe mental health issues were and are to deal with for all involved: for the person who is burdened with them, the relations, as well as the professionals whose help is sought. Historian Anne Harrington has stressed that these theories were not developed out of misogyny;[200] while science journalist Edward Dolnick, overlooking his historical study of mother- and family-blaming in autism, schizophrenia and obsessive-compulsive disorder, could only blame two influential international experts for having been downright malevolent.[201] In fact, many early proponents of such theories, like

---

[199] Een ontgoochelde moeder, 'Zondebok', *ANtenne* (1981) 11, 20.

[200] Harrington, 'Mother Love', 96.

[201] Dolnick, *Madness on the Couch*, 278.

psychoanalysts Frieda Fromm-Reichmann and Anna Freud, came from "a positive interest in the psychology of women and what one might even consider a pro-mother sensibility" and a deep empathy for struggling mothers.[202] Compared to traumatising and invalidating treatments for severe mental health issues, like electro-convulsive therapy or lobotomy, or drugs with limited positive effect and severe 'side' effects, the talking cures of the psychoanalysts and family therapists held the promise of a humane solution.[203]

Unfortunately, however, psychoanalytic theories grew increasingly accusatory in tone, radicalising as they developed further.[204] Even though it was not the intention of the experts to blame anyone, the compassion and loyalty of professionals lay with their patients in the first place, even if they realised that their theories were crushing to parents.[205] Many influential publications advised not holding such ideas on the origins of mental illness against the parents, for they did not purposely act the way they did.[206] From the pages of *Wie is van hout...*, Jan Foudraine's compassion for parents is obvious:

"Geen vader en moeder zorgen er bewust voor dat hun kind de psychiatrische inrichting indraait. Zij zijn mensen met enorme innerlijke conflicten, die ze vaak via hun kinderen tot oplossing trachten te brengen. Zeker – de 'battle' is meestal tussen de ouders (en schoon- en grootouders!) en de kinderen vormen vaak de 'battlefield'. Maar de psychotherapeut, die zich met alle gezinsleden diepgaand bezighoudt verliest (terecht) ieder gevoel om een 'schuldige partij' aan te wijzen, ook al valt hem dat bij ouders die hun kind op grove wijze verwerpen en geestelijk (en vaak ook lichamelijk) continu kwetsen wel eens moeilijk."[207]

("No father and mother consciously cause their child's hospitalisation in the psychiatric institution. They are people with enormous inner conflicts, which they often try to resolve through their children. Surely – the 'battle' is usually between the parents (and in-laws and grandparents!) and the children often form the 'battlefield'. But the psychotherapist, who deals intensely with all family members, (rightly) loses all sense of pointing to a 'guilty party', even though he sometimes finds it difficult to do so with parents who rudely reject their child and constantly hurt them mentally (and often physically).")

---

[202] Harrington, 'Mother Love', 96, 100-101.

[203] Harrington, 'Mother Love', 104-105.

[204] Harrington, 'Mother Love', 101.

[205] Dolnick, *Madness on the Couch,* 204.

[206] Dolnick, *Madness on the Couch,* 204; about Kanner: Sterwald & Baker, 'Frosted Intellectuals'.

[207] Foudraine, *Wie is van hout* (1971), 52.

But in practice, this was quite the challenge. As a Dutch addiction care worker put it: *"Het is nogal verwarrend dat ouders geen schuld aan de verslaving van hun kind mag worden verweten maar dat zij door de hulpverlening wel in therapie worden genomen, omdat de oorzaak binnen het gezin gezocht wordt."*[208] ("It is quite confusing that parents cannot be blamed for the addiction in their child, but that they are still taken into therapy by mental health care, because the cause is sought within the family.") And even Foudraine seemed to agree that collateral damage was unavoidable here, as he wrote in *Bunkerbouwers* (1997):

"Hoe voorkom je dat je de indruk wekt ouders, een moeder of vader 'de schuld te geven', ze als vreemde, verwarrende of angstwekkende figuren af te schilderen? [...] *Hoe voorkom je de kritiek dat je ouders nog meer ellende bezorgt dan ze in hun leven al moeten doormaken? Het is onmogelijk om dat te voorkomen."*[209]

("How do you avoid giving the impression of 'blaming' parents, a mother or father, portraying them as strange, confusing or frightening characters? [...] How do you avoid the criticism that you are causing parents even more misery than they already have to go through in their lives? It is impossible to prevent that.")

The theories were translated into therapeutic practice in various ways. In family therapy, introduced to the Netherlands halfway the 1960s,[210] patients were challenged to express their deepest feelings, find their own individuality and break away from relations who did not give them space to be their own person.[211] Therapeutic communities, the new form of intramural psychiatry that emerged around the same time, were set up as alternative families, where a person could heal by projecting their feelings towards their relations onto group members, who could help them work through those feelings and grow up the right way.[212]

This development resulted in an increasingly negative attitude towards relations in psychoanalytically and psychosocially oriented professionals, whose numbers

---

[208] S. Boerdam, 'Oudergroepenwerk drugteam Haarlem', in: *Ouders en verslaving. Verslag van een tweede themadag op 8 oktober 1983* (Bilthoven 1983) 40-45, 43.

[209] Jan Foudraine, *Bunkerbouwers. Ontmoetingen met afgeslotenen* (Amsterdam 1997) 88; see also Rutten, *Jan Foudraine,* 61, 143, 253, 280.

[210] Blok, *Baas in eigen brein,* 62-63, 66-89, 121, 156-166.

[211] Blok, *Baas in eigen brein,* 15.

[212] Hartwell, 'The Schizophrenogenic Mother Concept', 281-282; Mary V. Seeman, 'Forty-five years of schizophrenia: personal reflections', *History of Psychiatry* 17 (2006) 3, 363-373, 365-366; Blok, ' "Tall, Spanking People" '.

increased quickly in the 1970s. These were not only psychiatrists, but also psychologists, psychiatric nurses, occupational therapists and so on, who were increasingly educating themselves in order to work therapeutically with patients. Even social workers, who had traditionally been the appointed contacts for the family in mental health care, made this shift, now exclusively siding with patients. As journalist Arend Jan Heerma van Voss would sarcastically summarise, looking back in 1986: *“Vanuit een onverbiddelijke solidariteit met iedereen die adolescent was of daar op leek, werden ouders door het personeel bejegend als (op zijn best ‘onbewuste’) bron van het kwaad – het ging om katharsis, separatie en individuatie, de drie moeilijkste woorden van het stencil waar het allemaal op stond.”*[213] (“Out of an unrelenting solidarity with everyone who was an adolescent or looked like one, parents were treated by the staff as a (at best an ‘unconscious’) source of evil – it was about catharsis, separation and individuation, the three most difficult words of the stencil that held all the information.”)

This way of looking at relations was reinforced by the way the family as an institution was criticised in the 1970s for standing in the way of ideals like freedom for the individual, equality, democratisation and emotional openness.[214] Paternalistic and emotionally detached parents were seen as harmful for children’s personal growth. In hindsight, some professionals admitted that it was the aggression they felt towards their own mother and father that they sublimated in their work with patients and their families.[215] Professionals who disagreed with the mother- and family-blaming approach and the methods that resulted from it were regarded as old-fashioned, a social worker recalled:

‘Je ongelukkige jeugd had het gedaan. Je was niet begrepen door je vader of moeder. Ik vond altijd dat je vanaf je achttiende zelf verantwoordelijk bent voor de glimlach op je eigen gezicht. Maar met dat soort ouderwetse ideeën hoefde je toen niet aan te komen.’[216]

(“It was your unhappy childhood that had caused everything. You were not understood by your father or mother. I always thought that from the age of eighteen you are responsible for the smile on your own face. But you couldn’t suggest that kind of old-fashioned idea back then.”)

---

[213] A.J. H. v. V. [A.J. Heerma van Voss], untitled foreword to *Maandblad Geestelijke Volksgezondheid* 41 (1986) 7/8, 689-690, 689.

[214] Blok, *Baas in eigen brein,* 156.

[215] Blok, *Baas in eigen brein,* 170.

[216] Gemma Blok, ‘Van “zedelijke verheffing” tot “harm reduction”. Verslavingszorg in Arnhem en Nijmegen, 1900-2000’, in: J. Vijselaar et al., *Van streek. 100 jaar geestelijke gezondheidszorg in Zuid-West Gelderland* (Utrecht 2007) 152-191, 177.

A lack of scientific knowledge and practices in support of families

The scientific research that was presented in the previous section reveals only the tip of the iceberg of 'mother-blaming' literature on autism and anorexia nervosa. And the more the cause of severe mental health problems was pinned on relations, the less attention was paid to figuring out how to support relations in caring for their loved one. Neither were specialised treatment possibilities and facilities developed in the Netherlands of the 1970s. That is how autistic children ended up in homes for the 'mentally retarded', and how anorexic girls spent months in general hospitals under pressure to eat. In a mental health care sector that tended to focus more on psychoses (associated in particular with schizophrenia and manic depression), and that was now, under the influence of anti-psychiatry, rejecting such medical diagnoses but at the same time concentrating even stronger on what used to be called schizophrenia,[217] researchers and practitioners seemed to have little interest in other severe mental health issues such as autism and anorexia nervosa.

In the early Cliëntenbond, complaints about psychiatry's lack of expertise referred to the general level of professionalism in mental health care workers and organisations. With the turn the league took in 1973, away from outpatient care and towards institutional care, it also drifted away from its initial focus on support for families and stopped demanding more medical research – they hardly thought in terms of diagnoses anyway.[218] By contrast, for the Nederlandse Vereniging voor Autisme and the Stichting Anorexia Nervosa, diagnosis was the focal point in advocating for what they desperately needed: more research into that diagnosis, so that help for patient and family could finally be envisaged.

Despite the longstanding Dutch tradition in autism research, in the early 1970s, only a handful of specialists in the Netherlands had knowledge of autism, and even they had little more to offer than a respectful attitude aimed at figuring out together what might work. In the eyes of child psychiatrist Nan Snijders-Oomen, who started working with the NOVA parents in 1973, nobody was an autism expert then. Arend G. Benner has suggested that disinterest due to 'treatment pessimism' was why it would remain a marginal field until the 1980s – there were a lot of theories about what might cause autism, but not much on offer in the way of treatment or support.[219]

As a result, appropriate care for autistic children was extremely hard to find. Most family doctors and other (mental) health care professionals were unfamiliar with it. Many parents consequently lived in uncertainty for years, desperately trying to find out what was the matter with their child, whose behaviour was so bewildering. Parents

---

[217] Blok, *Baas in eigen brein,* 48-52; Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 903.

[218] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 407-411; 'Op welke weg is de Cliëntenbond', *Bulletin* 7 (1979) 6, 23-25.

[219] Benner, *Streven naar limonade,* 39, 43.

were usually advised to put their little ones in an institution for mentally handicapped children, as taking care of them at home could be extremely challenging. Although many families found that those homes did not fit their child's needs, they had hardly any other options if the situation outweighed their coping capacity. In 1973, the parents of eleven-year-old Cor were among those who shared their story in *Nieuwsblad van het Noorden*. They raised their autistic son, the fourth of their nine children, at home. Because the boy needed the fulltime attention of his father, the man quit his job. Having no other source of income, the family saw no other solution but to sell their house and live off those funds, but after a year, their bank account was nearly empty.[220]

People who suffered from anorexia nervosa and their parents found themselves in a similar situation. Although anorexia nervosa had been known as a self-contained (mental) health issue for much longer than autism, doctors often approached a low body weight as a physical problem. If the underlying mechanisms that made such patients avoid eating were addressed, this was done in a family-blaming way that many patients and relations felt to be disrespectful and hurtful. Whenever a patient's body weight became dangerously low, she would be admitted to a general or psychiatric hospital, where she was pushed to eat under a reward-and-punishment regime, and force-fed if she didn't respond. Relapse soon after a patient was discharged from the hospital was often the result.[221]

In the arena

The atmosphere in the Dutch mental health care arena was quite volatile, as we have seen, when in 1971 the Cliëntenbond entered the scene. Not only were established and junior mental health care professionals looking for new ways to make a difference, the circle of people outside mental health care who wanted to engage critically with psychiatry was widening, too. This was the backdrop to the young clients' movement's early dealings with the other players in the arena: the media, the public, the mental health care sector, the government and the movements' predecessors from the 1960s that were presented in Chapter 1.

Through news media coverage, especially of the long-drawn-out Dennendal conflict, a growing public became aware of what was going on in psychiatry, and came to identify with one of the parties. Readers of right-wing newspaper *De Telegraaf* would probably agree with its strong criticism of Carel Muller's 'hippie' management, while readers of

---

[220] Harm van den Berg, 'Ook Cor moet maar weg van huis...', *Nieuwsblad van het Noorden* 21 August 1973.

[221] Untitled interviews with psychiatrist Miep Heins van de Bruinhorst, clinical psychologist H. van Agteren and child psychiatrist Christien Lafeber, *ANtenne* (1998) 107, 10-13, 16-17; René Sieders, '20 jaar', *ANtenne* (1998) 107; interview Erik Vleeschdraager, 7 October 2020.

the leftist *de Volkskrant* may have been more likely to support such innovations.[222] The sector itself showed two faces, too: progressive professionals embraced the Cliëntenbond and the NVA so enthusiastically that the organisations had to protect themselves from being overpowered by them, while conservative institutions preferred to keep the new meddlers at bay. The Stichting Anorexia Nervosa had to make do without professional allies from either side for many years.

How the clients' movement was received by the government shows that the latter was beginning to educate itself on the subject, and to become more involved in the sector. And while the multifaceted countermovement in psychiatry, of which the Cliëntenbond was one of the main components, was preparing to set the tone for the 1970s, Pandora, so rooted in the optimistic 1960s view of psychiatry challenged by the later movement, was on its way to an intense identity crisis.

The media and the public

For the NVA and the Stichting Anorexia Nervosa, it was clear what message they wanted to spread to the public. In the much more diverse and extremely democratically governed Cliëntenbond, it was much harder to agree. As the public interest in mental health care and mental health activism was booming, the Cliëntenbond regularly featured in the press. Not only did it attract attention by exposing mistreatment in psychiatric hospitals and taking hospital boards to court when they were unwilling to release a patient who was unlawfully detained, soon journalists also approached it whenever issues in mental health care were debated.[223] Protest actions in which the league participated were covered extensively by the news, and paralleled by a growth in membership. That leapt almost overnight from a handful of people to a hundred after the talk show *Een klein uur U* aired in January 1973, and continued to grow to about 1,300 in 1978.[224]

Generating that kind of attention was a lot more difficult for the diagnosis-oriented organisations, which found themselves outside the mainstream of the countermovement. Despite the involvement of the *Nieuwsblad van het Noorden* and all of Willem Momma's experience as a newspaper director, it was harder for the early autism associations NOVA and BBAKO to attract members. When the two merged to form the NVA in 1978, they counted about two hundred members, and they grew only very slowly to a thousand around 1990. This had to do with how unknown autism was, but also with the fact that milder forms of autism were not yet recognised – the idea that there was such a thing as

---

[222] Blok, *Baas in eigen brein*, 28-29.

[223] Impression based on entering the query 'Cliëntenbond' in digital newspaper archive Delpher.nl, accessed 10 October 2023.

[224] Pim Stoel, 'Ergens met je problemen heen kunnen', *Het Parool* 27 October 1973; Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 419.

an autism spectrum would not be developed until the 1990s – making the NVA's initial target group much smaller than it is today.

In contrast, the media were not only instrumental in the birth of the Stichting Anorexia Nervosa, but the number of people on the foundation's address list also jumped from two hundred fifty to a thousand almost overnight after the 1979 television broadcast of the documentary *Bang om groter te groeien* (Scared to grow bigger), which featured an anorexia patient and her partner who were both active members of the foundation.[225] Looking back in 1998, founder René Sieders concluded, however, that each year *ANtenne* welcomed a hundred new subscribers, but that equal numbers of people cancelled, most of them because they or their relation had recovered enough to move on.[226]

For everyone who recognised themselves in the membership of these organisations, it must have been an entirely new experience. In all three organisations, mutual support was the central activity: through correspondence, telephone calls, visits and regional and national meetings. As diagnosis-oriented organisations, the NVA and the Stichting Anorexia Nervosa concentrated on organising opportunities to exchange experiences, on educating people about the diagnosis and where to find professional help, and on promoting scientific and therapeutic innovations.[227] The Cliëntenbond of the 1970s was mainly focused on educating, empowering and liberating people with mental health problems through helping individual patients in dire straits and offering them local groups where they could develop their activism together, and on improving their circumstances, treatment and (legal and social) position.[228] The Cliëntenbond did not think in diagnoses, it was there for everybody, although that had the consequence, as the autism parents had quickly concluded, that little opportunity was left to fight for better care tailored to specific groups.

Of course, the people who came together in these organisations, who had just discovered their *mondigheid,* their self-advocacy, as consumers, were going to display that newfound attitude as members of those organisations too. Often, internal frictions had to do with a board or another limited group of volunteers working extremely hard to set things up, without time and energy to spare for communication with the rank and file. That resulted in reproaches of being untransparent and undemocratic. During the merger between BBAKO and NOVA, for example, members complained that the interim board was moving forward without allowing others a say.[229]

---

[225] 'De Stichting AN in 1979', *ANtenne* (1980) 6, 3-5.

[226] René Sieders, '20 jaar', *ANtenne* (1998) 107, 4.

[227] Personal archive Willem Momma, undated early brochure Nederlandse Vereniging voor Autisme, *Autisme*; Stichting Anorexia Nervosa, *Anorexia nervosa. Informatiebrochure* (1980).

[228] NL-HANA-CB inv. no. 241, 'De Cliëntenbond bestaat nu vijf jaar', anonymous typescript, dated by hand 14 November 1976.

[229] B. v.d. Werff, 'Bijeenkomsten van distrikt II', *Engagement* 3 (1977) 7, 19-21, 21; Het bestuur, 'Een korte aantekening', *Engagement* 3 (1977) 7, 26-28.

Such conflicts are of course typical for associations, but in this movement, they could escalate as a consequence of the divergent characters who needed to work together. Former board member of the Stichting Anorexia en Boulimia Nervosa (as the Stichting Anorexia Nervosa would be renamed in 1996) Erik Vleeschdraager found that the problem was aggravated by the low self-esteem that anorexia patients tend to suffer from – a trait he recognised from his own late wife Marijke.[230] In the Cliëntenbond, that was seen in a different light. When an accumulation of complaints and backstabbing actions directed against the board led the entire board – including some of the original MOB parents – to step down in 1975, member Patricia Bolderhey asked for their understanding along similar lines:

"Wantrouwen [...] *is een verminking ons door de psychiatrie aangedaan. Het is een mager excuus, maar misschien kunnen jullie op dit gebied geduld met ons hebben."*[231]	("Distrust [...] is a mutilation inflicted on us by psychiatry. It's a poor excuse, but perhaps you can bear with us in this respect.")

Despite the fact that these frictions were more than just incidents, especially in the Cliëntenbond, in the 1970s they did not play out along dividing lines between people with mental health issues and their relatives. In fact, it is the unity of those with mental health problems and the relations that ultimately stands out. In a period when the only autism known was severe autism, the early family organisations in this field were naturally focused on families with severely autistic children and were largely the domain of parents automatically advocating in their name too. But the lack of dividing lines between patients and relations in the other organisations is something to consider. Although Cliëntenbond founder Doortje de Graaf-Sherston regretted it, the MOB parents in the Cliëntenbond gracefully accepted in 1973 that their original goal of improving outpatient care would take a backseat to improving the situation in psychiatric hospitals.[232] And even though MOB father Arie Groot only accepted the position of chairman temporarily in 1974, he stayed on for five years because there was no one else who wanted to or could do it.[233] Negative and positive stories about people's relationship with their relations were printed in the Cliëntenbond's *Bulletin* without it

---

[230] Interview Erik Vleeschdraager, 7 October 2020.

[231] NL-HANA-CB inv. no. 25, 'Notulen Algemene Ledenvergadering Cliëntenbond d.d. 14 juni 1975', 6.

[232] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 411; 'Bestuursberichten', *Bulletin van de Cliëntenbond* 2 (1974) 5, 17-22, 21; Marijke Groot-Kingma, 'Ontstaan en eerste jaren van de Cliëntenbond', *Bulletin van de Cliëntenbond* 15 (1987) 1, 2-3, 3.

[233] NL-HANA-CB inv. no. 25, 'Notulen Algemene Ledenvergadering Cliëntenbond d.d. 14 juni 1975', 3; 'Afscheidsrede van voorzitter Arie Groot', *Bulletin* 7 (1979) 6, 30-34.

taking sides.[234] Most of the volunteers who built up the Stichting Anorexia Nervosa, were 'parents-of' and 'partners-of', together with patients who had recovered.[235] In their activities, relations did not present themselves as a separate interest group either – it was not until the late 1980s to early 1990s that the first activities and groups were set up in support of them.[236]

The mental health care field

Whereas the organisations that relations had set up in the 1960s, Al-Anon and Pandora, had to deal with professionals and institutions whose authority and methods could not be contested by them as lay people, the turmoil around 1970 shook up the situation. The number of professionals who were critical of their own methods and institutions was growing, and the anti-psychiatry ideas that inspired them were easily connected with left-wing ideas of liberation that were increasingly popular in intellectual circles. In this atmosphere, an alternative welfare care circuit, which to a certain extent overlapped with mental health care, was set up: the walk-in centres of the Sosjale Joenit (Social Unit, 1968), the Jongeren Advies Centrum (JAC, Youth Advice Centre, 1970) and Release (1970), where even lay people counselled the young, dotted the country. With these, room was created for a positive reception of critical initiatives from below, at least by progressive mental health care and social workers.

When the Cliëntenbond entered the stage in the early 1970s, indeed, progressive mental health care workers enthusiastically joined their ranks. But most of the clients in the league did not perceive this as helpful; to them, the professionals were a threat. Not only did many members associate them with personal traumatic experiences in mental health care in the past, the risk that they would come to dominate the organisation and stand in the way of the clients' liberties – the whole aim of the league – was also considered real. Although there were some members who argued that the league could profit from the knowledge, networks and energy of (mental) health care professionals, it was decided in 1974 that they could not be members of the Cliëntenbond, so that they would not have a vote or be eligible for a place on the board.[237]

That did not mean that the Cliëntenbond did not want to have anything to do with them. They were invited to join the league as donors, and were called on regularly whenever

---

[234] See for example M. Groot-Kingma, 'Aktiviteiten van de werkgroep ambulante g.g.z.', *Bulletin* 1 (1973) 5, 12-14; Door de Graaf, 'Ik wil leven', *Bulletin* 3 (1976) 5, 22-28, 23.

[235] 'Onderling contact', *ANtenne* (1979) 1, 7; interview Erik Vleeschdraager, 7 October 2020.

[236] 'Oproep III', *ANtenne* (1989) 49, 17; 'Ontstaan en werkzaamheden van de "Werkgroep Ouders"', *ANtenne* (2000) 120, 23.

[237] 'Gesloten lidmaatschap', *Bulletin van de Cliëntenbond* 2 (1974) 1, 4; Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 416-417.

they were needed. General practitioner and Cliëntenbond donor Titia Feldmann, for example, recalls that she was regularly asked to lend a helping hand.[238] But structural collaborations in one of the national organisation's working groups, were taboo. The ban resulted in the league's most prominent working group, the one on the legal position of patients, leaving the organisation in 1974 and moving forward independently. It also resulted in the suggestion that a vital member such as Corrie van Eijk-Osterholt should step back and become an advisor to the organisation. Van Eijk-Osterholt moved on as an independent activist, even though her ties with the league remained strong.[239]

When BBAKO started that same year, 1974, it proposed a similar construction right away: professionals could not join the organisation as members, because if the parent organisation wanted to be critical, distance was needed. But as advisors, the professionals were very welcome, making it possible for the parents to continue working with allies such as child psychiatrist Sjef Teuns. This was a divisive element in the preparation of the merger with NOVA: the 'northern' parents of the NSA foundation had since 1973 collaborated much more closely with professionals. With the aim of merging, both sides eventually agreed on a model in which the future NVA would function as an advocacy association for relations and patients, and a national foundation in support of scientific research would be set up separately. As former BBAKO chairman Willem Martinot explained when the merger was final: *"... wetenschappers en ouders zijn elk op hun eigen terrein deskundig, ze hebben elkaar nodig maar dan wel elk naast elkaar met eigen verantwoordelijkheid en eigen perspectief, vandaar een vereniging en stichting"* ("... scientists and parents are each experts on their own terrain, they need each other but should stay apart, alongside each other, each with their own responsibility and their own perspective, hence an association and a foundation").[240] The idea of setting up a national research foundation was neglected soon afterward, and such collaborations taken on from inside the NVA anyway, but membership of the association would remain exclusive to non-professionals.[241]

The Stichting Anorexia Nervosa did not have the luxury of excluding professional allies: it had none. When it started in 1978, the few anorexia nervosa specialists in the Netherlands were closely associated with the mother- and family-blaming ideology. And whereas the NSA had been able to involve child psychologist Nan Snijders-Oomen because she agreed with them that the lack of autism experts in the Netherlands meant that child specialists like herself should get on board, the Stichting Anorexia Nervosa was unable to find a similar engagement in the field. There was very little that professionals at the time had to offer to people with anorexia and their families. Pessimism in the face of a very difficult and

---

[238] Interview Titia Feldmann, 20 February 2020.

[239] Hunsche, *De strijdbare patiënt,* 23.

[240] W.J.J. Martinot, 'Een beetje weemoed mag', *Engagement* 5 (1978) 5/6, 16-18, 17.

[241] Benner, *Streven naar limonade,* 52-54.

complicated mental health issue was probably a strong element of that. And that pessimism easily translated into outright rejection: *"Wie wil zich nou inzetten voor die rotmeiden?!"* ("Who would want to devote themselves to those nasty girls?!"), later chairwoman of the foundation Liesbeth Libbers remembered a professional saying in the late 1970s.[242]

In addition, the popularity of the idea that mothers, fathers and families were responsible for causing anorexia nervosa may very well have been a factor in why professionals stayed away from the Stichting Anorexia Nervosa, since it so strongly rejected that approach. In the book on anorexia written by the principal Dutch authority in the field, Christien Lafeber, as we have seen, this mother-blaming phenomenon was central, and that surely stood in the way of any alliance. The only expert the foundation was able to ally with after a few years was the Belgian psychiatrist Walter Vandereycken, who had debunked mother-blaming theories for anorexia nervosa ever since his dissertation of 1980.[243] It was not until 1987 that anorexia experts in the Netherlands started setting up the first specialist treatment facility that came with, as Sieders emphasised, a respectful attitude towards patients and their families.[244]

That the Cliëntenbond and the NVA were able to find professional allies and collaborate with them did not mean that the organisations were automatically received positively by the entire professional community. Improving the knowledge of autism in (mental) health professionals was quite the challenge for the NVA. But the Cliëntenbond had to resort to outright confrontations with medical authorities, since it dealt with institutions of which the worst were the least open to their interference. The league supported individuals in taking their case to court, particularly in cases where patients were held in an institution without proper legal grounds. The most famous patient they helped in such a situation was Frits Winterwerp, who was involuntarily hospitalised in 1968, and between 1972 and 1979 took his case all the way to the European Court of Human Rights. When he was vindicated, that created important case law that would contribute to the protection of the legal rights of patients in Dutch courts, despite the shortcomings of the outdated *Krankzinnigenwet*.[245] A side effect of this case, however,

---

[242] Liesbeth Libbers, 'Het jubileum van een patiënten-vereniging, of het jubileum van de hulpverlening aan eetstoornissen?', *ANtenne* (1998) 108, 4.

[243] Walter Vandereycken, *Tussen mythen en feiten. Diagnose en behandeling van het zogenaamde anorexia nervosa gezin* (PhD thesis Katholieke Universiteit Leuven 1980). In 2012, Vandereycken would be discredited for having sexually abused several of his patients since the 1990s (Pieter Huyberechts & Kaatje De Coninck, 'Ik had twintig jaar seksuele relaties met patiënten', *Nieuwsblad* 10 October 20212, https://www.nieuwsblad.be/cnt/dmf20121009_00328704 accessed 3 October 2023.

[244] René Sieders & Karla Verhallen, 'Gelezen', *ANtenne* (1988) 48, 11-23, 21; René Sieders, '20 jaar', *ANtenne* (1998) 107, 5.

[245] Karel Kraan, 'Europees Hof geeft patiënt gelijk. Krankzinnigenwet biedt te weinig waarborgen', *de Volkskrant* 30 October 1979; 'Afscheidsrede van voorzitter Arie Groot', *Bulletin van de Cliëntenbond* 7 (1979) 30-34, 33; Laurs, *Recht voor psychiatrische patiënten*, 59-60.

was that the villains in Winterwerp's story included his own family, who had requested his involuntary commitment in the first place.[246] That foreshadowed a changing attitude in the Cliëntenbond towards relations, to which we will return in Chapter 3.

The Ministry and the government

Traditionally, the state had not been involved much in matters of mental health care. Institutions were run by independent foundations, often religious charities or Catholic orders, whose sisters and brethren served as nurses, with a doctor here and there to prescribe medication or shock treatment. The expanding web of consultation bureaus and other outpatient mental health care facilities also largely ran themselves. All that (local) governments had to do was pay the fee when people who could not afford mental health care were involuntarily committed. Since the 1960s, the national government began taking up matters of mental health care more actively, for example by making it available free of charge to all Dutch citizens through the national AWBZ law of 1968, greatly enlarging the accessibility of mental health care.[247]

Members of parliament were quick to support the new clients' organisations in the 1970s, and their founders all reported how they had been received with interest in The Hague: not only by individual members of parliament, but also by a chief inspector, a state secretary or a sympathetic, helpful key civil servant.[248] But getting the Ministry of Health and Environmental Hygiene to start developing policies, laws and regulations to relieve the needs of people with mental health problems and their relations was another matter. As there was hardly any research on the topic, nobody really knew the extent of the problems the organisations addressed. Taking matters into their own hands, the organisations started generating those data themselves. BBAKO, NOVA/NSA and the NVA each set up surveys charting the problems their members had encountered to get a proper diagnosis and help for their autistic children. The Cliëntenbond documented cases of how individuals became stuck and were mistreated in the mental health care system, and in 1977 it joined the initiative of several organisations in the countermovement to run a thorough scientific survey.[249] The Stichting Anorexia Nervosa did not have the means for a survey of their own to prove how the system fell short in taking care of their specific patient group and their families, but managed to convince the government to commission one through the Gezondheidsraad (Health Council), which was given the official assignment in 1984.[250]

---

[246] 'Een patiënt met machtiging moet worden gehoord', *Bulletin van de Cliëntenbond* 6 (1978) 2, 18.

[247] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 798-799.

[248] Hunsche, *De strijdbare patiënt,* 39; N.M. van Leeuwen, 'Bij het eerste lustrum van de N.V.A.', *Engagement* 10 (1983) 6, 2-6, 5; René Sieders, '20 jaar', *ANtenne* (1998) 107, 5.

[249] Onderzoeksgroep Demokratisering in de Hulpverlening, *De positie van de psychiatrische patiënt in Nederland.*

[250] René Sieders, '20 jaar', *ANtenne* (1998) 107, 5.

In terms of subsidies for the budding organisations, the Ministry was equally hesitant, but the organisations also do not seem to have asked much in that regard initially. A report on the Cliëntenbond's first general meeting in March 1974 shows that money was an unpopular subject – people were more important.[251] It was not until 1977 that the league received its first *waarderingssubsidie* (appreciation subsidy) from The Hague.[252] In BBAKO and the NVA, a more businesslike atmosphere made it possible for early chairmen Willem Martinot and Willem Momma to mobilise their professional networks, giving these organisations a flying start through large donations from charities. Combining these with the revenue from a puzzle competition in the newspaper concern where Momma worked, the NVA was able to open a modest office in 1978 and hire its first parttime employee.[253] René Sieders, as we saw, used his Rotary friends and their financial support to start up the Stichting Anorexia Nervosa, but soon, money would be tight for them. The earliest government subsidies would be local or provincial or earmarked for projects – structural financing from the national level, however modest, would not provide financial relief until 1987.[254]

While the priority of the diagnosis-oriented organisations was for the Ministry to do something about the lack of specialised care, patients' rights were the focus for the Cliëntenbond and the rest of the countermovement in psychiatry in their relationship with the government in the 1970s. The first proposal for the *Wet BOPZ,* the law that was going to replace the *Krankzinnigenwet*, was put on the agenda right when the Cliëntenbond was born in 1971. The making of the new law became a long-drawn-out process that would dominate the actions of the countermovement towards the government through the 1970s and 80s. This may have had the benefit, however, of perhaps helping to open governmental doors to the new organisations.

The reason the 1971 proposal was rejected was that it did not formulate any rights for patients, whether voluntary or involuntary. In response, ex-patients, mental health care professionals, sociologists and lawyers who were active in the Cliëntenbond set up a working group on the subject of the legal position of patients. A lot of the initial issues the Cliëntenbond had wanted to address were now re-formulated in legal terms. The lack of information available to clients, for example, became the demand for the right to information (on the legal rights of patients in the first place), and the protest against traumatising methods, such as various forms of restraint, electroshock treatment and the isolation cell, became the demand to ban these methods in law. After mental health care professionals

---

[251] 'Eerste algemene ledenvergadering', *Bulletin van de Cliëntenbond* 2 (1974) 1, 5-6.

[252] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 419.

[253] M. Hoffman-Keizer, 'Beknopt verslag van de oprichtingsvergadering van de Nederlandse Vereniging Autisme 17 juni 1978 – Jaarbeursgebouw, Utrecht', *Engagement* 5 (1978) 7/8, 3-15, 5-8.

[254] R. Sieders, 'Het lustrum van de stichting: vijf jaar wanhoop en hoop', *ANtenne* (1984) 24, 2-9, 7; R. Sieders, 'Het tweede lustrum van de stichting: tien jaar wanhoop en hoop', *ANtenne* (1989) 48, 7-11, 8.

were excluded from the league in 1974, the working group proceeded independently. Elsewhere in the countermovement, other groups had also taken up the issue. In 1974, they came together in the Landelijke Werkgroep Krankzinnigenwet (National Working Group Insanity Law). This gave the countermovement its definite primary focus: patients' rights.[255]

In reaction to all the criticism, in 1975 State Secretary Jo Hendriks of Health and Environmental Hygiene set up the Werkgroep Rechtspositie Patiënten in Psychiatrische Ziekenhuizen (Working Group Legal Position Patients in Psychiatric Hospitals) that became known under the name Commissie Van Dijk (Van Dijk Commission), after its chairman, psychiatry professor Kuno van Dijk. The commission's task was to compile a report to provide insight into the legal position of patients in psychiatric hospitals, and evaluate whether laws to strengthen that position and complaints committees should be developed.[256] It was a novelty that a number of patients and relations were invited to take part in the commission. However, Evelien Paull, Fried Hehemann and Corrie van Eijk-Osterholt, who were all prominent members of the movement, did so in a personal capacity, which set them apart from the movement they helped form.[257]

First, the commission compiled a survey into the state of psychiatric hospitals and how patients were treated, as mentioned in the previous section.[258] The poor practices that were listed in its preliminary report from 1977 were confirmed, which led to great turmoil in parliament and to the whole debate on patients' rights shifting gear. The Landelijke Werkgroep Krankzinnigenwet meanwhile continued to bring together the various action groups with their divergent opinions on how the law should be changed. They ran public hearings where (ex-)patients were heard, and followed the commission with eagle eyes. Eventually, they severed all ties with the three representatives of the movement. Shortly after, these representatives resigned, as a result of irreconcilable conflicts with the conservative psychiatrists on the commission, before the final report came out in 1979. Despite the disagreements, the commission's overall conclusion was that legal measures to strengthen the patients' legal position were an absolute necessity. By then, parliament had already set the government on that course.[259]

The clients' movement

When the Cliëntenbond entered the mental health care arena in the early 1970s, the countermovement in Dutch psychiatry had just started to take shape. It was a heterogeneous

---

[255] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 420; Hunsche, *De strijdbare patiënt,* 30-31, 53-55.

[256] Laurs, *Recht voor psychiatrische patiënten,* 51.

[257] Hunsche, *De strijdbare patiënt,* 30-31.

[258] Werkgroep rechtspositie, *Rapportage.*

[259] Van Eijk-Osterholt, *Laten ze het maar voelen* (1981), 174-207; Laurs, *Recht voor psychiatrische patiënten,* 51-54; Hunsche, *De strijdbare patiënt,* 30-31.

field in which people with widely diverging motivations and interests took part.[260] In the Bond voor Wetenschappelijke Arbeiders (BWA, Scientific Workers' League), for example, set up in 1969 for critical scientists who wanted to put their work to the benefit of the people instead of the political system, those interested in psychiatry organised in the Sectie Welzijnszorg (Section Welfare Care). Similar to other intellectual initiatives in the 1970s, they took inspiration from the radical German SPK (Sozialistische Patientenkollektiv, Socialist Patient Collective), which saw mental illness as the consequence of capitalist repression, but also as an act of resistance against that system. Another initiative was that of De Beurs, a series of conferences between 1971 and 1973 where critical minds met, mostly psychiatric nurses, but also members of the public.[261]

Although the initiators of the Cliëntenbond certainly shared a social perspective on mental health problems,[262] the radical Marxist opinions that prevailed in the early countermovement were not their cup of tea. Dunya Breur, whose personal experiences at the Meerenberg psychiatric hospital in Santpoort in 1972 had been traumatising, had first tried to find an outlet for her protest in the BWA. But the gap between her and the BWA activists was unbridgeable – she found them elitist hotheads, many of whom only had a theoretical notion of the poor practices and mistreatment in psychiatry.[263] When she first heard the pragmatic Marijke Groot-Kingma and Doortje de Graaf-Sherston of the Cliëntenbond speak at a De Beurs meeting, that was a relief:

> *"Twee dames die schuchter opstonden en aarzelend zeiden: 'U praat nou wel zoveel over de patiënt, maar het gaat helemaal niet over de patiënten'. Eindelijk, dacht ik. Eindelijk mensen die die opgewonden taal van al die linkse actievoerders eens doorprikken en uit eigen ervaring spreken.* [...] *Ik vloog ze zo ongeveer om hun hals."*[264]

> ("Two ladies who stood up timidly and hesitantly said: 'You talk so much about the patient, but it's not about the patients at all'. Finally, I thought. Finally, there are people who pop the excited language of all those left-wing activists and speak from their own experience. [...] I just about fell on their necks.")

Around the Cliëntenbond, the countermovement in Dutch psychiatry mushroomed in the early 1970s with a wide variety of initiatives. Some were active nationwide, but there

---

[260] Becky Fox, *Psychiatrische tegenbeweging in Nederland* (Amsterdam 1983).

[261] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 408-410; Hunsche, *De strijdbare patiënt,* 76-77.

[262] NL-HANA-CB inv. no. 241, 'De Cliëntenbond bestaat nu vijf jaar', anonymous typescript, dated by hand 14 November 1976, 2.

[263] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 413-414; Hunsche, *De strijdbare patiënt,* 36-37.

[264] Hunsche, *De strijdbare patiënt,* 37.

were also dozens of local and regional groups that tried to improve psychiatry on that level. Some were rooted in practice, like the Opiniegroep Wolfheze (Opinion Group Wolfheze, 1972), an activist initiative of psychiatric nurses in training; others very ideology driven, like the Marxist SPK Solidariteitskomitee (SPK Solidarity Committee, 1972) and the Psychiatrisch Kollektief Utrecht (Utrecht Psychiatric Collective, 1973). There were large, public conferences, like *Psychiatrische patiënt vogelvrij?* (Psychiatric patient outlawed?, 1973) in Breda, and other events, like the annual *Week van de Psychiatrie* (Psychiatry Week).[265]

Another organisation that was already in place was, of course, Pandora. While trying to find its way into the closed bulwark of mental health care, and even securing structural ties with and funding from the Nationale Ziekenhuisraad (NZR, National Hospital Council),[266] Treeske Blase had also taken a radical step towards empowering ex-patients. In 1970, she had placed an advertisement asking 'former psychiatric patients' to volunteer as educators for the foundation. Former patients, the advertisement said, were best suited for the job: *"Zij hebben tenslotte persoonlijk beleefd hoe de maatschappij geestelijk zieken accepteert"* ("They, indeed, have experienced personally how unaccepting society is of the mentally ill").[267]

Although Pandora initially undermined its own ideal of recognising expertise-by-experience by demanding that applicants for a volunteer position included the name and address of their psychiatrist in their letter, Blase's decision to present former patients as experts was groundbreaking. The volunteers visited schools where they educated young people by sharing their – positive – experiences with mental health problems and treatment. In addition, they showed the Pandora campaign film *Waarom gek? Omdat-ie anders is?* (Why crazy? Because he's different?), shot at a shiny new psychiatric hospital in Venray, and answered questions.[268]

As a result, Pandora might have seemed a natural ally of the Cliëntenbond, but nothing was further from the truth. In the eyes of the Cliëntenbond, the excursions to psychiatric hospitals that Pandora was also still organising came down to shameless *aapjes kijken* (monkey watching), and *Waarom gek?* was a promotional film for mental health care instead of a realistic rendition of the general state of Dutch institutions.[269] Treeske Blase's idea that presenting mental health care in the most flattering light would help destigmatise mental health problems was now definitively rejected by the very people she wanted to help. And the same institutions she had tried so hard to ally with and promote in order to destigmatise psychiatry, were now being criticised in public debate, even by increasing numbers of their own staff.[270]

---

[265] Hunsche, *De strijdbare patiënt*, 76-80.
[266] Van der Kroef, *25 jaar*, 57-58.
[267] Van der Kroef, *25 jaar*, 51.
[268] Van der Kroef, *25 jaar*, 52-56.
[269] 'Aapjes kijken', *Bulletin van de Cliëntenbond* 1 (1973) 2, 7.
[270] Van der Kroef, *25 jaar*, 43, 59-60.

Confusing enough as that was, the friction went even deeper. Times had changed so quickly that the two organisations seemed to come from different planets. Although Pandora was very modern in certain aspects, like the graphic designs of its materials, its use of modern means of communication and the inclusion of experts-by-experience in its activities, its board and director operated in a paternalistic way that was reminiscent of charities of the past.[271] Despite Blase's empowering idea to engage ex-patients as volunteers, the volunteers were not supposed to participate actively in the organisation.[272] Typical of Pandora's attitude was that the first 'expert-by-experience' who was sent to a school was not an ex-patient, but psychiatric nurse Wil van der Laak, who had also volunteered. He remembers how he was struck by the combination of paternalism and ignorance that director Treeske Blase and her assistant P.A.M. Cornelissen displayed. Watched like a hawk by Cornelissen during that first presentation, Van der Laak was later asked to put what he told the students on paper, as it was considered very useful to the organisation.[273]

The situation grew increasingly complicated for Pandora as the attacks on psychiatry by other organisations and critical individuals exposed a very different reality in institutions than what Pandora wanted to portray. In facing those critical voices, the board and Blase insisted on holding on to the 'neutral', 'objective' and 'nuanced' position of Pandora. But that position was increasingly challenged as books like *Wie is van hout...* and *Laten ze het maar voelen...* found their way to the public. Volunteers were confronted with critical students who did not accept stories couched in medical, rather than political, terms. A media campaign in which Pandora wanted to point out that Corrie van Eijk-Osterholt's book *Laten ze het maar voelen...* portrayed the exception to the rule and thus wrongfully painted the whole sector in a negative light, was called off. But siding with the countermovement and adopting a critical position towards mental health care, was deemed too risky for the anti-stigma organisation: it feared a backlash from the more conservative parts of the sector, on which it had become financially dependent.[274]

As a tiny remnant of the cancelled campaign, Van Eijk-Osterholt was sent a critical personal letter. She replied that she hoped they could work together, but also criticised Pandora for its aloof and elitist attitude. Blase and Van Eijk-Osterholt only met once, the latter remembered:

"[Blase] *ontpopte zich als iemand die mijn boek verre van gunstig gezind was. U mag*

("[Blase] turned out to be someone who was far from sympathetic to my book.

---

271 Van der Kroef, *25 jaar*, 48-49.
272 Van der Kroef, *25 jaar*, 50-52.
273 Interview Wil van der Laak, 11 January 2023.
274 Van der Kroef, *25 jaar*, 60-65.

> *alle brieven zien, heb ik toen gezegd, maar dat hoefde niet. Ze werd wel een beetje stil van de foto's uit de inrichting van mijn zus.*[...] *Omdat Pandora zich aankondigde als vereniging van ex-patiënten, ben ik alle namen van het briefhoofd* [van Pandora] *met haar afgelopen – om te vragen of mr. Klaasesz ex-patiënt was; of jonkheer mr. Van der Does, of Baron van Dedem, of prof. dr. De Kock van Leeuwen. Er zat geen enkele ex-patiënt in het hele bestuur."*[275]

> You can see all the letters, I said, but I need not show them. She did get a bit quiet looking at the photos of my sister's asylum. [...] Because Pandora announced itself as an association of ex-patients, I went through all the names of the [Pandora] letterhead with her – to ask if Mr. Klaasesz, Esq. was an ex-patient; or squire Van der Does Esq., or Baron van Dedem, or Prof. Dr. De Kock van Leeuwen. There was not a single ex-patient on the entire board.")

With the wind of the countermovement at their back, the experts-by-experience that Blase had recruited as Pandora volunteers were also becoming critical, and soon enough she was faced with their demands for internal democratisation. This ushered in an intense and painful period of re-orientation between 1973 and 1977. Not only the volunteers' position within Pandora was at stake, its foundations – goals, target groups, message, strategy – were all up for drastic reconsideration.[276] Despite endless, intense debates in true 1970s, 'the-personal-is-political' style, the gap between volunteers and staff only widened, resulting in one of the ex-patients saying: *"Velen van ons vinden dat Pandora medewerkers intern dezelfde fouten maken, die de stichting naar buiten toe bestrijdt"* ("Many of us feel that Pandora employees make the same mistakes internally that the foundation fights in the outside world").[277] In the middle of all the turmoil, Pandora would present some of its best-known media productions: the film *Kind van de zon* (Child of the Sun, 1975) and the campaign *'Ooit 'n normaal mens ontmoet? En..., beviel 't?'* (Ever Met a Normal Person? And..., Did You Like It?, 1973), with its slogan printed on mirror paper.[278] Instead of making an appeal to 'normal' people to accept those who were different, the message was now that drawing that line was the worst kind of discrimination.[279]

Meanwhile, many initiatives in the countermovement came together in 1976 in the action week *Te gek om vast te zitten* (Too Crazy To Be Incarcerated), which protested

---

[275] Quoted in Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 415.

[276] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 414-415; Van der Kroef, *25 jaar,* 68-90; Hunsche, *De strijdbare patiënt,* 44-59.

[277] Van der Kroef, *25 jaar,* 80.

[278] Van der Kroef, *25 jaar,* 80-83.

[279] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 416.

against the continuing political immobility regarding patient's rights.[280] Within Pandora, by contrast, the action week resulted in decisive escalation. Volunteers accused the organisation of having distanced itself from the protest – which was not true – or at least of having displayed an aloof attitude, and Blase became the target of that fierce criticism. That year, she stepped back and Hans van der Wilk, one of the volunteers, became the new Pandora director. With his extensive patient experience, combined with the qualities he had developed as a social worker and a local politician, he established Pandora in the heart of the countermovement in psychiatry of the mid-1970s.[281]

By that point in time, the countermovement had developed into a vibrant, multi-coloured phenomenon. The most legendary initiative was the *Gekkenkrant*, a magazine for and by psychiatric patients begun in 1973 by a small group of recent university graduates, a few of whom had patient experience in mental health care. It attracted a lot of attention in the 1970s, not only as a democratic, taboo-breaking magazine, but also for the playful protests the group organised. *"Je liet een scheet en je had drie journalisten op de stoep staan"* ("You farted and three journalists were on your doorstep"), Flip Schrameijer, one of the founders, recalled.[282] Many actual patients and ex-patients, however, did not appreciate the magazine's name, and found such actions too radical.[283]

Quietly advocating for the day-to-day interests of patients in psychiatric hospitals, were the patient councils. The first, founded by a progressive board of directors in psychiatric hospital Coudewater in Rosmalen in 1970, had preceded the Cliëntenbond. But the league's support contributed greatly to the subsequent development of councils in many more institutions, and seven years later, the Netherlands counted thirty-five of them. Through their representatives on these councils, institutionalised patients took up practical issues with the management or board of their hospital – perhaps the bravest activism of all, as in the early 1970s even more than today, these patients were in a very vulnerable position and not at all used to being heard by, let alone speaking up to those placed above them. From 1975 onwards, council members from all over the country gathered annually, and in 1981, they would form the Stichting Landelijke Patiëntenraden (LPR, Foundation National Patient Councils). Meanwhile, experiments with ombudsmen for patients in institutions were so successful that in that same year, the LPR, the Cliëntenbond and the NZR set up an independent national foundation, the Stichting Patiëntenvertrouwenspersoon (PVP, Foundation Patient Advocate) to guarantee their independence.[284]

---

[280] Hunsche, *De strijdbare patiënt,* 76-79.

[281] Van der Kroef, *25 jaar,* 68-90; Hunsche, *De strijdbare patiënt,* 44-59.

[282] Quoted in Hunsche, *De strijdbare patiënt,* 63.

[283] Heerma van Voss, 'De geschiedenis van de gekkenbeweging', 412-413, 421-422; Van der Kroef, *25 jaar,* 46; Hunsche, *De strijdbare patiënt,* 78.

[284] Van der Kroef, *25 jaar,* 46-48; Hunsche, *De strijdbare patiënt,* 192-193; Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 857; Stichting Patiëntenvertrouwenspersoon Geestelijke Gezondheidszorg, *Verslag 1981-83* (Utrecht 1983) 7-8.

While the Cliëntenbond, Pandora and the LPR came to occupy a central position in the countermovement in Dutch psychiatry during the 1970s,[285] the diagnosis-oriented organisations developed largely outside of it, which illustrates that not all activists in mental health care in the 1970s viewed mental health problems from the social perspective. To the autism organisations, it was difficult to find their place to begin with, as autism was not even clearly defined and debates about what it was raged on, both among professionals and among parents.[286] The autism organisations connected with other parents' organisations that were mainly setting up autism care facilities.[287] The Stichting Anorexia Nervosa, the first in this field, was joined over the years by other initiatives in the widening domain of eating disorders.[288] Al-Anon, the diagnosis-oriented organisation we met in Chapter 1, kept to itself as always, but its model was increasingly copied over the 1970s, for example by the Anonieme Families (Anonymous Families), mutual support organisations for relations of users of hard drugs. The question is, however, to what extent these organisations would have been considered part of the clients' movement back then. It is telling that Petra Hunsche, in her history of the Dutch clients' movement, portrays the Nederlandse Stichting voor Manisch Depressieven (NSMD, Dutch Foundation for the Manically Depressed) of 1987 as the first diagnosis-oriented organisation in mental health, even though her book also mentions the Fobieclub (1969) and the Stichting Anorexia Nervosa (1978).[289]

Conclusion

In the early 1970s, people with severe mental health issues and their relations – 'clients' – began to protest against the stigma and powerlessness they experienced in society and psychiatry. Parents of children and adolescents in mental health care lit the fire: for their severely autistic children in the NVA and its predecessors, for their anorexic teenagers in the Stichting Anorexia Nervosa, and for any loved one in the Cliëntenbond. Together with the patients and ex-patients who joined them, they fuelled their organisations on the long road to become equal stakeholders in psychiatry. They were all clients of mental health care: in these early years, any difference in the interests of patients and families was hardly perceptible. Although it was suggested to Corrie van Eijk-Osterholt, as a 'sister-of', that she exchange her membership in the Cliëntenbond for an advisory position, the MOB

---

[285] Hunsche, *De strijdbare patiënt*, 39.

[286] W.J.J. Martinot, 'Om het geluk van het autistische kind', *Engagement* 2 (1975) 5, 1-15, 3-5.

[287] Besides the NSA, there were already a few other autism foundations that were striving for care facilities, like SHAKA. Five of them would form the Landelijk Overleg Autisme (National Council Autism) in 1982 (Benner, *Streven naar limonade*, 54).

[288] An address list in *ANtenne* 26 (1984) 34 shows three organisations in the field of binge eating disorder and obesity.

[289] Hunsche, *De strijdbare patiënt*, 144-159.

parents who had laid the groundwork with her remained in vital positions for years, and they all operated in great solidarity.

After the first relations and ex-patients had come out with their personal stories about what they had experienced in mental health care, the response from their fellow-sufferers was overwhelming. Many of them had felt isolated, convinced that nobody knew what they were going through. Meeting others in the same situation was not only a relief and a comfort, but it also came with the awareness that the problems they had were not incidental, they were signs of what was structurally wrong in Dutch mental health care. That realisation gave the initial spark to their organisations, their politicised collective experience identity.

It was no coincidence that this happened in the 1970s. This was the decade in which all kinds of groups in the Netherlands sought to become empowered, serving as an example to others on the margins of society. This was the decade in which society was turned upside down, with those who had been at the bottom pressuring those who had been above them to grant them an equal say. Psychiatry served progressive people as the perfect example of how society should change, despite the efforts of more conservative counterparts who preferred to hold on to what they knew. And other activist groups in society in turn provided the clients of mental health care with inspiration and examples that showed them how they could fight for change.

The diagnosis-oriented organisations had the huge task of educating professionals and lay people about the particularities of autism and anorexia nervosa in order to end mother-blaming and family-blaming, and of making sure that care arrangements and scientific research in these fields were pursued. They in fact held on to the biomedical explanatory model, while the Cliëntenbond was part of the countermovement that, in contrast, promoted the social explanatory model, rejected diagnoses and other illness terminology, and tended to speak in terms of life problems instead. Whereas the NVA and the Stichting Anorexia Nervosa wanted more and more specialised mental health care, the Cliëntenbond demanded radically different mental health care, in which legal rights would safeguard patients from being denied information, from being excluded from decisions about their own health and autonomy, from poor practices and mistreatment. The league's choice of the word *cliënt* said it all: it wanted to radically change the extremely unequal relationship between mental health care professionals on the one hand, and patients and relations on the other. Although unlike its predecessors from the 1960s, stigma was rarely explicitly on its agenda, combatting structural, public and self-stigma was central in everything it did.

§

In 1978, Willy Brill's daughter Josephine took her own life at the age of seventeen, in desperation over her (lack of) treatment in the psychiatric hospital where she was admitted. A year later, her mother published a fierce indictment of those who had been responsible for her child there.[290] Brill's article also attested to how desperate parents had been scared into silence when faced with professionals:

"Het is met ons gegaan zoals het waarschijnlijk met de meeste relaties van patiënten gaat: door de hele gang van zaken word je geïntimideerd, verlamd. Het is die mengeling van angst om als lastig beschouwd te worden, van eerbied voor deskundigheid, van onzekerheid en valse hoop, die je er van weerhouden openlijk te protesteren op een moment dat nog niet alles verloren is. De vrees dat een krachtig optreden op de patiënt verhaald zou kunnen worden houdt je bedaard en braaf. Dingen die we ons in andere omstandigheden nooit zouden laten welgevallen hebben we zwijgend getolereerd, in de hoop ons kind daar een dienst mee te bewijzen."[291]

("It happened to us as it probably does to most relations of patients: you are intimidated by the whole course of events, paralysed. It is this mixture of fear of being seen as troublesome, of respect for expertise, of uncertainty and false hope, that prevents you from openly protesting at a time when all is not yet lost. The fear that stepping in forcefully could lead to repercussions for the patient keeps you restrained and well-behaved. Things that we would never put up with in other circumstances, we have silently tolerated, hoping to do our child a favour.")

Psychiatrists Lou van Eck and Jan van de Lande rejected Brill's criticism in a most eloquent and offensive manner. Responding to her from their positions as board members of the psychiatric hospital in question, Meerenberg in Bloemendaal ('Santpoort'), they lectured her on separation issues and loyalty conflicts in young people, and singled her out as a mother who should take a long hard look at herself.[292] This was a sign of how, over the course of the 1970s, the natural solidarity between people with mental health issues and their relations was increasingly undermined, in mental health care as well as in the clients' movement. But Brill's public protest also heralded the change coming around 1980, when the first relations who shouldered the burden of care for a loved one with severe mental health issues would no longer put up with being marginalised.

---

[290] Willy Brill, 'Mijn dochter en de psychiatrie', *Maandblad Geestelijke Volksgezondheid* 34 (1979) 11, 738-744.

[291] Brill, 'Mijn dochter en de psychiatrie', 743-744.

[292] L.A.J.M. van Eck & J.L. van de Lande, 'Behandelde, familie, behandelaar', *Maandblad Geestelijke Volksgezondheid* 34 (1979) 11, 746-751.

Chapter 3

The assertive years:
The birth of the family movement in the early 1980s

Around 1980, the world around relations of people with severe mental health problems was changing profoundly. Even though many issues regarding mental health care were still hotly debated, on the whole, the combination of insights from anti-psychiatry, demands of the clients' movement and financial concerns of policy makers were already changing the general course of mental health care. While new laws regulating the (mental) health sector were under development, the first new patients' rights were being enshrined in the Dutch Constitution that, from 1983 onwards, would guarantee the inviolability of the body and every citizen's right to privacy. In mental health care policy, deinstitutionalisation and substitution became the buzz words: the first steps were taken towards the reduction of 'beds' in the abhorred institutions and the replacement of long-term institutional care by care in the community. Patients were discharged from psychiatric hospitals sooner than before, and – even though the new *Wet Bijzondere Opnemingen in Psychiatrische Ziekenhuizen* (*Wet* BOPZ*,* Law on Special Admissions to Psychiatric Hospitals) was not yet finalised – the danger criterion became a leading factor in decisions on involuntary commitment.[1]

All this came with consequences for the relations. Rights guaranteed the autonomy and privacy of people with mental health issues even when they were in very bad shape, which could put their family members in a tight spot, for example when trying to get help for someone in crisis who rejected any involvement by mental health care professionals. With the restrictions on involuntary commitment and treatment, for example, people with severe mental health issues became better protected against arbitrary, far-reaching and harmful infringements on their autonomy, but at the same time a last resort for relations at their wits' end was now virtually unattainable. Family members thus came to realise that their interests and the interests of their loved one with severe mental health issues did not always align. That new self-awareness was also a result of 1970s

---

[1] Petra Hunsche, *De strijdbare patiënt. Van gekkenbeweging tot cliëntenbewustzijn. Portretten 1970-2000* (Amsterdam 2008) 83; Harry Oosterhuis & Marijke Gijswijt-Hofstra, *Verward van geest en ander ongerief. Psychiatrie en geestelijke gezondheidszorg in Nederland (1870-2005) Band II* (Houten 2008) 858-860; P. Laurs, *Recht voor psychiatrische patiënten. Een onderzoek naar de rechtsbescherming voor in psychiatrische ziekenhuizen opgenomen patiënten* (PhD thesis Rijksuniversiteit Utrecht 1988) 59-66.

ideals of liberation and empowerment that had trickled down and reached broad layers of the population. Like other marginalised groups in society, relations were learning to be more assertive and make their own demands.[2]

The result was that in the early 1980s, one after another, organisations were founded that explicitly addressed the problems encountered by relations. This started in 1980, with the Landelijke Stichting Ouders van Drugsverslaafden (LSOVD, National Foundation Parents of Drug Addicts). In 1982, the Algemeen Diakonaal Bureau van de Gereformeerde Kerken in Nederland (ADB, General Diaconal Bureau of the Reformed Churches in the Netherlands) set up its working group of and for Christian relations, an initiative that would later be named In Perspektief (In Perspective). In 1983, the Pandora foundation (see Chapter 1 and 2) also started bringing relations together, laying the groundwork for the Labyrint foundation (1985). Meanwhile, in Rotterdam in 1984, parents registered the Vereniging Ouders van Chronische Psychotici (VOCP, Association Parents of the Chronically Psychotic), the starting point for the association that would become known as Ypsilon. These are the organisations I will focus on in this chapter.

Why all these initiatives were suddenly taken in quick succession, and why relations had not risen in protest much sooner, is not only of interest to the historian – it puzzled some of the founders of the organisations too. Labyrint founder Linda Horn suggested that the larger demands the new developments made on the family might be part of the explanation, but she did not allow herself time to dwell on the question.[3] Neither did Ria van der Heijden, the initiator of Ypsilon:

"We moeten verder, de tijd dringt. Den Haag moet weten, wat er aan de hand is binnen de psychiatrie. Omdat we daar achterlopen op andere disciplines in de gezondheidszorg, omdat daar het beleid niet goed functionneert [sic], *omdat ze niet wéten. En dat is onze eigen schuld. We hebben té lang onze mond gehouden. We hebben het verstopt, we zijn niet in de publiciteit gegaan."*[4]

("We have to move on, time is running out. The Hague needs to know what is going on in psychiatry. Because we are lagging behind other disciplines in health care, because the policy there is not working well, because they do not know. And that is our own fault. We have kept our mouths shut for too long. We have hidden it, we did not seek publicity.")

---

[2] Linda Horn, 'Tussen twee grenzen van het eigen belang', *Welzijnsmaandblad* 40 (1986) 9, 11-16; Linda Horn, 'Een vergeten groep: familieleden van psychiatrische patienten', *Maandblad Geestelijke Volksgezondheid* 41 (1986) 9/10, 878-889; Jan van Vlodrop & Mary Thewissen-van Velzen, *Onze schizofreniepatiënten, wat er met hen gebeurt. Noodkreet, zwartboek, eisenpakket* ([Rotterdam] [1989]).

[3] Horn, 'Een vergeten groep', 879.

[4] Ria van der Heijden, 'Impressie', *Nieuwsbrief Ypsilon* (1986) 7, 4.

What all the new family organisations had in common was their insistence that relations should no longer be shut out of mental health care matters, but acknowledged as partners in care. They wanted recognition for *their* burden, *their* needs and *their* desire for autonomy, and accordingly to have a say in psychiatry debates. This radical focus on the struggle of parents, partners, brothers and sisters, children and close friends of people with severe mental health problems separates the family organisations of the early 1980s from all previous activism by relations, which had made no distinction between the interests of patients and their relations. Despite that common cause, however, there were dynamics at work that divided the family organisations of the early 1980s even before they were established.

This chapter will uncover the origins of the LSOVD, In Perspektief, Ypsilon and Labyrint. In addition, it will tell the story of the simultaneous beginnings of the Alzheimerstichting (Alzheimer's Foundation) of 1984, when the specialised field of psycho-geriatrics was increasingly taking over the care for people with dementia from mainstream psychiatry. Just like the organisations of parents of mentally handicapped children in Chapter 1, the rise of the Alzheimerstichting offers more insight into the marginalised position of relations of people with severe mental health issues who were heavily burdened with care. Their need for information, understanding and support was reflected in the unexpectedly enthusiastic reception of the novel *Hersenschimmen* (Out of Mind, 1984) by J. Bernlef, the literary source in this chapter. An overview of the factors that triggered the relations' activism in the early 1980s follows: how they were ignored and stigmatised, how they were treated by mental health care professionals, how they still had to fight mother-blaming and family-blaming theories and practices, how their worries over the quality of care for their loved one were prolonged and how the new patients' rights had consequences for them.

Awakenings of the family organisations of the 1980s

The Landelijke Stichting Ouders van Drugsverslaafden (1980)

"Wij, de ouders, zijn nog een vergeten groep in de samenleving [...]. *Bijna niemand weet, welke ellende we hebben meegemaakt. Men kent de verhalen van de alcoholist, die de boel wel eens kort en klein slaat, maar heeft nauwelijks weet van de razernijen van een verslaafde. Men weet niet, hoe vaak we beduveld, bestolen en bedreigd zijn door ons eigen kind, dat weer geld voor een shot nodig had. Hoe we gehuild en gejankt hebben met dat kind, totdat er eigenlijk geen contact meer mogelijk was. Omdat niets hielp."*[5]

("We, the parents, are still a forgotten group in society [...]. Hardly anyone knows about the misery we have experienced. People are familiar with the stories of the alcoholic, who sometimes smashes things up, but hardly know about the rages of an addict. We don't know how many times we have been duped, robbed and threatened by our own child, in need of money for a shot again. How we cried and wailed with that child, until no contact was possible anymore. Because nothing helped.")

When in the autumn of 1980, chairman Q.A. Jansen of the LSOVD (Landelijke Stichting Ouders van Drugsverslaafden, National Foundation Parents of Drug Addicts) gave a journalist this explanation of what parents of children with a heroin addiction went through, he had just taken the lead in the organisation.[6] In March of that year, a group of parents had launched the initiative by presenting a manifesto to State Secretary of Health and Environmental Hygiene Els Veder-Smit. They demanded a drug policy that put prevention of addiction first, through educating the public, the police and medical professionals unequivocally about the dangers of drug use. They demanded the expansion of addiction care, including new specialised clinics and a procedure for involuntary commitment in a rehabilitation facility. They demanded more active prosecution of and longer sentences for drug dealers. And they demanded that they, as parents, no longer be blamed for their child's addiction. Instead, they wanted to be supported in dealing with the hardships they suffered as a consequence of their child's addiction, and become involved in matters of drug policy.[7]

---

[5] Henny Korver, 'Door drugsprobleem geteisterde ouders verenigen zich, hun waarschuwing: "Verslaafd kind moet de deur uit" ', *De Telegraaf* 20 September 1980. In the article, the LSOVD chairman interviewed remained anonymous, but as the next reference shows, at the time that was Q.A. Jansen.

[6] Q.A. Jansen, 'Openingsspeech', *Info* (1984) 9, 3-5, 3.

[7] 'Ouders komen in actie tegen "falend drugbeleid" overheid', *Nederlands Dagblad* 29 March 1980.

Heroin was unknown in the Netherlands until, around 1972, it was probably young tourists and American soldiers stationed in the country who introduced it as the latest fad. It quickly spread among youths who used it as a way to explore their minds and to rebel. From the mid-1970s, however, it started to show its ugly face in the increasing numbers of young people becoming heavily addicted, and the appearance of public heroin scenes in many cities. The estimated number of intensive users rose from about five thousand in 1975 to thirty thousand in 1983, and the number of heroin-related fatalities increased accordingly. And as the substance was very expensive, drug-related street crime and street prostitution soared too, resulting in increasing demands from the public to put a stop to it.[8]

The question was how. In the 1970s, the debate on how to approach the heroin problem was marked by a 'tribal war', as historian Gemma Blok calls it,[9] between traditional, abstinence-focused experts and supporters of alternative addiction care for whom support and care for the user were the main concern. Over the 1980s, the latter view would gain the upper hand, and 'harm reduction', as their approach became known, motivated by the wish to reduce public nuisance, would become the central tenets of Dutch drug policy.[10] But in 1980, when the LSOVD was founded, the drug debate had not yet resulted in any clear vision in addiction care and government circles, leaving desperate parents at a loss.

Sources on the earliest beginnings of the LSOVD are so scarce that I have only been able to find names of three of its initiators – those of M.J. Gerritsen, whose background is unknown to me,[11] and of Charles and Len Langeveld, the parents of two young people who were addicted to heroin for many years and the 'motors' behind a parent group in The Hague.[12] The story of Q.A. Jansen, who became the first chairman of the foundation formed in the summer of 1980 out of the original initiative, is unknown; even though he and his wife H. Jansen-van der Vlerk served on the board of the LSOVD for five years,[13] it is only clear that they were 'parents-of' from Alkmaar. In a country that was confronted with a sharp rise in heroin use and accompanying misery and public nuisance, the stigma

---

[8] Gemma Blok, *Ziek of zwak, Geschiedenis van de verslavingszorg in Nederland* (Amsterdam 2011) Chapter 6; Gemma Blok, ' "We the Avant-Garde": A History from Below of Dutch Heroin Use in the 1970s', *BMGN – Low Countries Historical Review* 132 (2017) 1, 104-125; Arjan Nuijten, *Regulating Paradise: The Local Origins of Harm Reduction in the Netherlands* (PhD thesis University of Amsterdam 2024) Chapter 2, 3.

[9] Blok, *Ziek of zwak,* 181.

[10] Blok, *Ziek of zwak,* Chapter 6; Nuijten, *Regulating Paradise,* Chapter 2, 3; Jasper Bongers, 'Harm Reduction as a Citizenship Movement: The Case of Hoog Catharijne, Utrecht (1973-2001)', *The Social History of Alcohol and Drugs* 37 (2023) 1, https://doi.org/10.1086/723361.

[11] Q.A. Jansen, 'Openingsspeech', *Info* (1984) 9, 3-5, 3.

[12] Marjo van der Meulen, 'Ouders kunnen drugsverslaafde kind niet helpen', *Het Parool* 14 October 1980; Charles Langeveld, 'We zijn moe, maar wel strijdlustig', *FZA Kwartaalberichten* 6 (1981) 4, 11-12. Main character Len in Yvonne Keuls's novel *De moeder van David S., geb. 3 juli 1959* (see Chapter 4) was modelled after Len Langeveld.

[13] Letter from D.S.J. Bartstra, secretary of the LSOVD, to the foundation's membership, 12 November 1985 and letter from Q.A. Jansen to the LSOVD board, undated, both printed in *Info* (1985) 15, 2-4.

of heroin addiction was enormous, and relations of people with a heroin addiction were reluctant to step forward and share their experiences openly.

A 'father-of' who was a driving force behind the LSOVD in a different way is better remembered. Bob van Amerongen had tragically lost his stepson in 1973. After having struggled with drug addiction for years, the young man seemed well on his way to recovery when he passed away unexpectedly due to health complications resulting from his earlier drug use. The experience was so devastating to Van Amerongen that he quit his job as the principal of a prestigious Haarlem grammar school, and devoted the rest of his career to drug education and prevention at the Federatie van Instellingen voor Alcohol en Drugs (FZA, Federation of Institutions for Alcohol and Drugs).[14] Van Amerongen supported the LSOVD from his position in this umbrella organisation of the independent Consultatiebureaus voor Alcohol en Drugs (CADs, Clinics for Alcohol and Drugs) until he retired, and in 1989 took a seat on the foundation's board.[15]

Just like family members of alcoholics had been encouraged by psychiatrists back in the 1950s to support each other in Al-Anon, something similar had happened in response to the rising numbers of people addicted to drugs. The first family groups were organised for parents of patients in therapeutic communities in the mid-1970s,[16] and the former director of the Amsterdam Consultatiebureau voor Alcohol en Drugs (CAD, Clinic for Alcohol and Drugs) who introduced AA to the Netherlands, Henk Krauweel, seems to have been of great help to parents of young people who were in treatment there in forming the first mutual support group under the name Anonieme Families (Anonymous Families) in 1977.[17] Like Al-Anon, Anonieme Families was inspired by an American example – Families Anonymous – that was based on the model of the Alcoholics Anonymous. The idea was soon picked up in other cities, like Rotterdam and The Hague.[18]

A conference in 1977 promoted the idea that CADs all over the country should start working together with local parent groups, or set up new groups if there were none. Addiction care worker Cobie Bos gave a presentation about the parent meetings that she organised at the Emiliehoeve, a therapeutic rehabilitation community in The Hague. In her talk, Bos envisioned a future in which parents would not only support each other, but would also become activists *"om de stad drugvrij te krijgen"* ("to get the city drug-free").[19]

---

[14] Ischa Meijer, 'Een heros', *Vrij Nederland* 4 August 1984; Jan Tromp, 'Homerus had het al over drank en drugs', *de Volkskrant* 14 November 1992.

[15] 'Bestuursmededelingen', *Info* (1989) 30, 4-5, 4.

[16] Bob van Amerongen, 'Ouders van drugsverslaafden: van schuld naar verantwoordelijkheid. Een terugblik op tien jaar', *Maandblad Geestelijke Volksgezondheid* 44 (1989) 2, 115-124, 115.

[17] Marjo van der Meulen, ' "Anonieme Families", zelfhelpgroep voor ouders / familie / vrienden van aan drugs verslaafden', *Het Parool* 22 September 1977.

[18] Q.A. Jansen, 'De driehoek verslaafde-ouder-hulpverlener', *FZA Kwartaalberichten* 6 (1981) 4, 8-10, 9.

[19] Cobie Bos, 'Ouders voor ouders, een plan van de Emiliehoeve', *FZA Kwartaalberichten* 3 (1977) 1, 22-26, 26.

A year or two later, a committee of Amsterdam parents took up that challenge when they initiated a national association called Ouders van Drugsverslaafden (OVD, Ouders van Drugsverslaafden). Internal conflicts stood in the way of the democratic association organising effectively, so in July 1980, under the leadership of Q.A. Jansen, they officially became a foundation, the Landelijke Stichting Ouders van Drugsverslaafden (LSOVD, National Foundation Parents of Drug Addicts). Bringing together many existing parent groups – eventually, almost all Anonieme Families groups would be absorbed – the organisation aimed at more than just offering mutual support. It was time for them to take political action against the impotence of the authorities and the mental health sector in dealing with the drug that was devouring these parents' children.[20]

In Perspektief (1981) and Labyrint (1985)

"Toen mijn man na twee jaar opgenomen werd, was ik aan de beurt om in te klappen. Al die tijd had ik me met hem beziggehouden en ik was helemaal niet meer toegekomen aan mezelf. Dat schoof ik toen opzij, dat vond ik toen niet tellen. [...] *Heel langzaam ben ik* [...] *meer gaan doen wat ik leuk vond. Eindelijk weer eens een beetje plezier maken en kletsen en de stad ingaan. Ik voelde me daar ook schuldig door, maar dat is nu wel aan het veranderen.* [...] *Ik weet ook niet wat er gaat gebeuren als hij weer thuiskomt, maar dat zien we dán wel weer.* [...] *ik voel dat het verschrikkelijk belangrijk is, dat ik dan tenminste weer een beetje stevig in mijn schoenen sta en dat ik een beetje een eigen leven heb. Voor mezelf, voor hem en voor de kinderen."*[21]

("When my husband was admitted after two years, it was my turn to break down. All this time I had been busy with him and I hadn't gotten around to myself at all. At the time, I put that aside, I didn't feel that was important then. [...] Very slowly I started [...] doing more of what I liked. Finally having a bit of fun again, and chatting and going into town. I felt guilty about that, but that is changing now. [...] I don't know what is going to happen when he comes home, but we'll cross that bridge when we come to it. [...] I feel that it is terribly important that at least I am a bit stronger again then and that I have a bit of a life of my own. For myself, for him and for the children.")

---

[20] Q.A. Jansen, 'De driehoek verslaafde-ouder-hulpverlener', *FZA Kwartaalberichten* 6 (1981) 4, 8-10, 9; Van Amerongen, 'Ouders van drugsverslaafden', 115-124. Both abbrevations, OVD and LSOVD, stayed in use; I will refer to the organisation as the LSOVD.

[21] Museum of the Mind, Haarlem, Pandora Library, inv. no. 1036, Linda Horn, 'Van lotgenoot tot bondgenoot. Over de positie en de zorgen van direct betrokkenen van z.g. psychiatrische patiënten', June 1985, appendix, *Eigendruk* (June 1984) [1], [3-4], 'Een ervaring'.

Stories like this anonymous one from a 'wife-of' were very familiar to Christien le Clerq. For many years, Le Clerq had worked as a holiday organiser for Christians in difficult home situations at the ADB (Algemeen Diakonaal Bureau van de Gereformeerde Kerken in Nederland, the General Diaconal Bureau of the Reformed Churches in the Netherlands).[22] The ADB was an executive agency of these churches that organised activities in support of marginalised groups in society. Their archives from the early 1980s show an ecumenical approach as well as a progressive choice of target groups: not only did they support the ill, the handicapped and their families, but also struggling singles and homosexuals.[23]

With her retirement from the ADB approaching, Le Clerq's intense wish was to devote her last working years to helping people who suffered from the burden of care for a loved one with mental health problems and, more importantly, from the way they were ignored or shunned in their church community. Her personal life had been marked by decades of care for her brother and sister, who both suffered from severe mental health issues, and for the children her sister was no longer able to raise. Le Clerq knew that she was no exception: in her job, she had met many people in similar circumstances and taken their stories to heart. But she also knew how derogatory colleagues spoke about mental health issues and the people suffering from them:

> "... *ook in mijn* [...] *werk-omgeving was voor velen psychische ziekte nog een onbekend en bedreigend gegeven. Reacties bijvoorbeeld: 'Wat zijn dat toch vreemde dingen! Gelukkig komen in mijn familie zulke ziektes niet voor...' Of, nog moeilijker te verteren: 'Heb jij er zelf ook niet wat van meegekregen? Soms een tikje manisch, soms een tikje depressief...' Begrijpt U? Dapper doorwerken op je postje, om de ander én jezelf te doen ervaren dat je genoeg gezondheid bezat om een goed stuk werk te leveren."*[24] [onderstreping in origineel]

> ("... Even in my [...] work environment, mental illness was still an unknown and threatening fact for many. Reactions, for example: "How strange those things are! Fortunately, in my family no such illnesses occur..." Or, even harder to digest: "Don't you have a touch of it yourself? Sometimes a little manic, sometimes a little depressed..." Do you understand? Bravely continuing to work in your modest position, trying to show the other person and yourself that you were healthy enough to do a good job.") [emphasis in original]

---

22 Personal archive Daisy Smith [hereafter Archive Smith], Christien C. le Clerq, 'Ontstaans- en wordingsgeschiedenis van de Interkerkelijke Stichting "IN PERSPEKTIEF", 17 mei 1990', 1.

23 Het Utrechts Archief, Utrecht, Archive Deputaten Gemeenteopbouw van de Gereformeerde Kerken in Nederland (aanvulling) (1859) 1962-1999, access no. 1492, 'Familie en vrienden van psychisch zieke mensen' [hereafter UA-GKN-F], inv. no. 1465-1491.

24 Archive Smith, Christien C. le Clerq, 'Ontstaans- en wordingsgeschiedenis van de Interkerkelijke Stichting "IN PERSPEKTIEF", 17 mei 1990', 2-3.

In September 1981, two years away from retiring, Le Clerq mustered the courage to present to her employers at the ADB her long-harboured plan to extend the diaconal labour of the bureau to Christian family members of people with mental health issues. Her plan was to create three working groups: one to organise education for church officials (almost like a Reformed-Church version of Pandora); one to develop initiatives for assisted living for people with mental health issues; and last, but definitely not least, one to advocate for the interests of family members. At first glance, these actions fit neatly into the diaconal work, which was all about caring for those who were suffering. What made the family work of the ADB different, however, and what made it part of the new family movement, was that Le Clerq, with the third working group in particular, set a course towards a mutual support organisation that was run largely *by* family members instead of *for* them.[25]

The majority of the volunteers that she gathered around her in the working group had first-hand experience with mental health issues in a loved one, and with negative reactions from the church community. Reina van Mourik, a social worker from psychiatric hospital Veldwijk who was invited to join the group for her professional experience, remembers how in the early years, their meetings were in fact mutual support groups:

> *"… ze hadden zelf een heleboel te verwerken. Ik denk dat ik die eerste jaren heel veel alleen maar geluisterd heb.* […] *Want ze konden pas eigenlijk zelf wat gaan doen, toen zij de stap konden maken. Dus het was echt ontzettend,* […] *ontzettend veel spuien.* […] *En ze hadden natuurlijk over het algemeen allemaal nog een ziek familielid. Dus het blééf aan de orde. Alleen zij gingen merken, doordat ze die lotverwantschap hadden en meer kennis, dat ze inderdaad daar anders mee om konden gaan."*[26]

> ("… they had a lot to deal with themselves. I think I spent a lot of those first years just listening. […] Because they could only really do something themselves when they could take the step. So, it was really, […] really an awful lot of unloading. […] And of course, generally, they all still had an ill loved one. So, it remained an issue. Only they started to feel, because they had that fellowship and more knowledge, that they could indeed deal with it differently.")

Early in 1983, Le Clerq found out that the ADB was not the only organisation with an initiative like this – Pandora was also exploring the possibility of setting up something in support of the relations. Linda Horn had only worked there as a volunteer coordinator

---

[25] Archive Smith, Christien C. le Clerq, 'Ontstaans- en wordingsgeschiedenis van de Interkerkelijke Stichting "IN PERSPEKTIEF", 17 mei 1990', 2-5.

[26] Interview Reina van Mourik, 12 May 2021.

for a year or so when, listening to the conversations between activists from the clients' movement gathered around the big table in the Pandora library, she noticed that many of them struggled when taking care of a friend in crisis, and had difficulties trying to get help when the situation became too hard for them to handle. It was an experience she could relate to. More importantly, she saw it reflected in the telephone conversations the foundation's hotline operators had with relations asking for advice. Struck by heartbreaking stories of distress, Horn and her colleagues started to plan the establishment of a mutual support organisation of close bystanders.[27]

They were already in touch with the Humanistisch Verbond (Humanist Union), that ran a mutual support group for relations in Amsterdam, when ADB's Christien le Clerq approached Pandora.[28] On 23 June 1983, representatives of the three organisations met for the first time to exchange experiences and ideas.[29] Recognising the same issues and concerns, they set a course towards founding a joint mutual support and advocacy organisation. Pandora took the lead, educating the ADB representatives on how to talk and think about mental health issues from the social perspective. And the ADB seemed eager to learn: Le Clerq even initiated and prepared a discussion on the causal connection between mental health issues and family relationships.[30]

If they energetically set up mutual support groups, meetings for relations and a newsletter, reaching consensus on the essence of the organisation they envisioned took more time. In September 1983, the three parties agreed on a first formulation of their main goal: creating possibilities for mutual contact and support, improving the relations' resilience, and breaking prejudice and taboos associated with psychiatric problems.[31] Le Clerq even came up with a suggestion for a name: F.L.O.X., short for FamilieLedenOrganizatieX – Family Members Organisation X, the X standing for *"het met taboes en geheimzinnigheid omgeven gebied van psychisch zieke mensen"* ("the area of mentally ill people that is clad in taboos and secrecy").[32]

---

[27] Jan van Lieshout, 'Wie A zegt, wil ook B zeggen, maar waar begint het eigen alfabet?', *Welzijnsmaandblad* 39 (1985) 2, 26-29, 29; Museum of the Mind, Haarlem, Pandora Library, inv. no. 1036, Linda Horn, 'Van lotgenoot tot bondgenoot', 3; interview Linda Horn & Lineke Marseille, 28 May 2021.

[28] Van Lieshout, 'Wie A zegt, wil ook B zeggen', 29; Archive Smith, Le Clerq, 'Ontstaans- en wordingsgeschiedenis'; Christien le Clerq & Daisy Smith, 'Over In Perspektief', in: Christien le Clerq, Daisy Smith & Olda van den Burg-Wigboldus (eds.), *Verdriet zoekt onderdak. Over pastoraat aan familieleden van (ex-)psychisch zieke mensen* (Zoetermeer 1994) 59-66.

[29] UA-GKN-F, inv. no. 1492-1487, Bart van Vliet, 'Aantekeningen van het gesprek te Utrecht, Gebouw Humanitas, donderdag 23 juni 1983, betreffende belangen familie-leden van (ex-)psychiatrische patiënten'.

[30] UA-GKN-F, inv. no. 1492-1487, 'Behoeften familie-leden' and Lineke Marseille, 'Verslag van de "familipraatgroep-bijeenkomst" [sic] dd. 25 augustus 1983'.

[31] UA-GKN-F, inv. no. 1492-1487, Linda Horn, 'Notulen van 14-9-1983 Praatgroep Familieleden'.

[32] UA-GKN-F, inv. no. 1492-1487, Lineke Marseille, 'Verslag van de "familipraatgroep-bijeenkomst" [sic] dd. 25 augustus 1983'.

But F.L.O.X. would never blossom. After a year of working intensely together, the ADB broke off the collaboration in September 1984 and decided to move on by itself. Despite the good intentions of the other two organisations, to which it was self-evident that a family organisation would welcome people of all religious orientations, Le Clerq and her colleague Bart van Vliet felt that their partners did not understand the specific, deeply felt needs and conflicts of Christian family members, and they feared that the essence of what they wanted to offer would be lost.[33] And they had good reason for that fear, as they had received not only gracious and obliging responses to their pleas, but also heard dismissive or even ridiculing comments in the widening circle of the initiative group.[34] With secularisation permeating all aspects of Dutch society, it was increasingly hard for believers to find true understanding outside their own circles. As long as the churches would allow the work for family members of people with mental health issues to continue under the ADB umbrella, it was safer there. Initially Le Clerq's initiative was simply called the 'working group family members'.[35] A few years later it would be christened In Perspektief,[36] the name that I will use from here on.

To the other two partners, the ADB suddenly pulling out and going ahead on its own came as a complete shock.[37] The Humanistisch Verbond, not willing to be the principal motor but unyielding in its support, remained involved through the individual efforts of people like Marianne Moussault, who took a seat on the first board, and Ad Goudswaard, who built up the family work in the northern provinces of the country.[38] It was left to Pandora to set up the organisation. Half a year after the departure of the ADB, on 22 March 1985, they founded Labyrint.[39] That name referred to the feeling of being lost in a maze, a feeling that many relations experienced when dealing with psychiatry:

---

[33] UA-GKN-F, inv. no. 1492-1469, 'Verslag van de vergadering van de werkgroepen, betrokken bij de aktiviteiten rond (ex-) psychisch zieke mensen en hun familieleden en vrienden, gehouden op 18 september 1984, in het Dienstencentrum te Leusden' and 'Familieleden/vrienden bijeenkomst d.d. 19 september 1984'.

[34] UA-GKN-F, inv. no. 1492-1471, 'Verslag van de vergadering van In Perspektief Interkerkelijke Werkgroep Familieleden en Vrienden van (ex-)psychisch zieke mensen gehouden op 25 mei 1989 te Leusden'.

[35] See for example UA-GKN-F, inv. no. 1492-1469, Rick Geukema, 'Enkele notities vergadering werkgroep familieleden maandag 17 december 1984 in Leusden'.

[36] UA-GKN-F, inv. no. 1492-1490, *Informatiebulletin* (1988) 6, 1, 'Groen licht voor samenwerking Labyrint-In Perspektief'.

[37] UA-GKN-F, inv. no. 1492-1487, letter from Egbert van der Poel to the board of the Algemeen Diakonaal Bureau, 31 October 1984.

[38] UA-GKN-F, inv. no. 1492-1490, *Eigendruk* (November 1986) 4, 1, 'Het bestuur van Labyrint'; interview Linda Horn & Lineke Marseille, 28 May 2021.

[39] Personal archive Inge van Ooijen, photocopy of 'Labyrint. Een organisatie van betrokkenen bij mensen met psychische problemen', *AHA!* (March 1986) 14-15.

"Het is een lange weg, het zoeken naar goede hulp en naar een manier om zelf om te gaan met de problemen. Eerst moet je een doolhof door en voor velen blijft het een doolhof waarin ze terecht gekomen zijn. [...] *Vandaar een initiatiefgroep die probeert mensen te helpen de weg te vinden, door informatie te verschaffen en steun te geven. Want daaraan ontbreekt het familie en vrienden van psychiatrische patiënten meestal bitter hard."*[40]	("It's a long road, trying to find good help and a way to deal with the problems yourself. First you have to go through a maze and for many it remains a maze in which they have ended up. [...] Hence an initiative group that tries to help people find their way, by providing information and support. Because that is what family and friends of psychiatric patients usually sorely miss.")

Ypsilon (1984)

"... wat het betekent om de hele zorg te moeten dragen voor een psychotische zoon of dochter, voor een kind dat gaat zwerven, in de drug-scene terechtkomt of voor een junk gehouden wordt. Een kind dat z'n geld of z'n spullen kwijtraakt of weggeeft, dat ten onrechte met politie of justitie in aanraking komt. Een kind tegen wiens plotse agressiviteit je machteloos bent."[41]	("... what it means to have to shoulder the entire burden of care for a psychotic son or daughter, a child who goes wandering, ends up in the drug scene or is thought to be a junkie. A child who loses or gives away his money or his belongings, who wrongly comes into contact with the police or the justice system. A child against whose sudden aggressiveness you are powerless.")

A comment like this, made by a relative during a study day for professionals, summarised the experiences of a parent confronted with their child's psychosis in a nutshell. Ria van der Heijden was one of those parents. In the mid-1970s, one of her five sons had developed severe mental health problems. The Rotterdam family had experienced very difficult years trying to deal with the situation at home, trying to find him the best possible care. Eventually, they had to come to terms with having their son and brother diagnosed with chronic psychosis and living permanently in an institution.[42]

After regaining some sort of balance in her life, Van der Heijden had become active in the local Vrouwenhuis (Women's Centre), in particular in their VIDO groups (Vrouwen

---

[40] Museum of the Mind, Haarlem, Pandora Library, inv. no. 1036, Linda Horn, 'Van lotgenoot tot bondgenoot', appendix, *Eigendruk* 2 [late 1984 or early 1985], 1; interview Inge van Ooijen, 12 January 2021.

[41] 'Open oor voor Ypsilon op Utrechtse studiedag', *Nieuwsbrief Ypsilon* (1987) 9/10, 3-4, 3.

[42] Interview Bas van Raaij, 21 June 2018.

In De Overgang, Women Going Through Menopause). On 17 January 1984, the VIDO women organised a 'listening afternoon': an open house at the public library in the centre of Rotterdam, inviting all women to come in for a cup of coffee and a chat. They were welcomed by volunteers who lent a willing ear to any emotional problems they might want to share: unemployment of their husbands and children, loneliness, money troubles, tranquiliser addiction, marriage problems, empty nest syndrome, the burden of care for elderly parents… Strategically held on a market day, as many as four hundred women showed up for the event. But what struck Van der Heijden most was that there were more mothers who had a child with problems like hers.[43]

The mothers decided to set up their own mutual support group, Moeders van Chronisch Psychotische Kinderen (Mothers of Chronically Psychotic Children). They had all experienced how hard it was to try to deal with a son or daughter who displayed increasingly bewildering behaviour, to be confronted with vague, dismissive or accusatory reactions when reaching out to mental health care in order to find help, and, when a psychiatric hospital was the last resort, how shocking the quality of care could be.[44]

After one of the participants, Wil van Atten, told her family psychiatrist about the group, he started referring other mothers to them. Halfway through 1984, in a conversation between Van der Heijden, Van Atten and this psychiatrist, the plan was made to found an association for all parents of children dealing with these problems. That autumn, they met with Pandora's Linda Horn, but the sources keep suspiciously silent on whether they discussed working together – already sensing that each group was very different in outlook, both sides just left matters at making each other's acquaintance.[45] On 26 November 1984, the Vereniging Ouders van Chronisch Psychotici (VOCP, Association Parents of the Chronically Psychotic) took official form.[46] One of Van der Heijden's other sons, psychology student Bas van Raaij, became a driving force.[47] In 1986, the organisation's name changed to Ypsilon. Looking for something that was more inspiring than the abbreviation VOCP, they chose one of the least used letters in the Dutch language as their symbol: the letter Y. Like the letter Y, they felt, the problems of the members of the association were ignored, or at least little known.[48]

---

[43] 'Vrouwen werklozen vinden open oor', *Het Vrije Volk* 16 January 1984; '45-plus vrouwen dinsdag in de bieb', *Het Vrije Volk* 4 February 1984; Jan-Hein de Groot, ' "Wat vrouwen nodig hebben is 'n oor…" ', *Het Vrije Volk* 21 September 1984; interview Bas van Raaij, 21 June 2018.

[44] UA-GKN-F, inv. no. 1492-1487, 'Notulen familie/vrienden d.d. 8 oktober [1984]'; Bert Paauw, '"Schizofrenie is een ware beproeving". Ypsilon helpt verwanten en familieleden van patienten', *Leeuwarder Courant* 31 May 1986.

[45] UA-GKN-F, inv. no. 1492-1487, 'Notulen familie/vrienden d.d. 8 oktober [1984]'.

[46] Jan van Atten, 'Hoe is Ypsilon ontstaan?', *Nieuwsbrief Ypsilon* (1987) 9/10, 21.

[47] Interview Bas van Raaij, 21 June 2018.

[48] UA-GKN-F, inv. no. 1492-1488, untitled Ypsilon newsletter [1986], 1, 'Redactioneel'.

The Alzheimerstichting (1984)

"Ik heb vele tergende jaren in onzekerheid doorgebracht en voelde me af en toe zo verloren. Een hele lange tijd wist ik niet dat m'n man aan de ziekte van Alzheimer leed. Ik herkende de verschijnselen niet en kon daardoor in het begin ook niet goed reageren op zijn karakterveranderingen. En om juist die onzekerheden èn spanningen bij andere mensen weg te nemen, heb ik me aangesloten bij de lezingengroep van de Alzheimerstichting."[49]

("I have spent many agonising years in uncertainty and felt so lost at times. For a very long time, I didn't know that my husband was suffering from Alzheimer's disease. I didn't recognise the symptoms and therefore couldn't react well to his character changes in the beginning. And to take away those insecurities and tensions from other people, that is why I joined the lecture group of the Alzheimer's Foundation.")

Many relations of people with dementia could relate to these experiences that 'wife-of' Netty van Doorn in 1987 shared in the newsletter of the Alzheimerstichting (Alzheimer's Foundation). In the mid-1980s, relations of people with dementia came together in this organisation that would play an important role in the development of psycho-geriatric care as a sector apart from mainstream psychiatry. In January 1984, dementia was the theme of the television talk show *Koos in gesprek met* (Koos in Conversation With), hosted by that same Koos Postema who had presented the talk show *Een klein uur U* in 1973 that launched the Cliëntenbond in de Welzijnszorg (Clients' League in Welfare Care). Afterwards, twenty thousand people called the aftercare hotline of the Stichting Korrelatie (Korrelation Foundation) – a number that shocked both the producers of the show and the doctors who had been on the panel.[50]

Later that year, the talk show team read an interview with Jan Ringoir, in which the mental health care inspector pleaded for support for people who were taking care of a person with dementia at home. On a study trip to Canada, he had made the acquaintance of the Alzheimer Society, active there since 1977, and he knew that similar organisations had been set up in the United States, Australia and the United Kingdom. Ringoir felt that there was also a need for such an organisation in the Netherlands. That summer, he found allies in clinical geriatrician Henk ter Haar and medical superintendent Johan Trommel. When Ringoir was approached by *Koos in gesprek met* producer Magda Berman and family doctor Wiebe Braam, who had been on the panel of the talk show, they all joined forces. On 28 December 1984, they founded the Alzheimerstichting.[51]

---

[49] Magda Berman, 'Een lezing over dementie kan onzekerheid wegnemen', *Alzheimer Nieuwsbrief* 2 (1987) 4, 1-2, 1.

[50] Jan Lakeman, *Toevlucht en thuisbasis. 15 jaar Alzheimerstichting* ([Bunnik] 1999) 11-14.

[51] Lakeman, *Toevlucht en thuisbasis,* 14-18.

For the position of chair, they set out to find someone with a wide network that would be helpful to raise funds. When Berman approached Thea van Veldhuyzen van Zanten-Roest van Limburg, this renowned business woman turned out to have first-hand experience as a relation of someone with dementia. Through Van Zanten, the foundation got a major boost to become the organisation they envisioned: not only *for* family members, but also driven *by* family members, in close collaboration with professionals.[52] In the pool of volunteers that travelled the country to give lectures educating the public about dementia, expertise-by-experience was considered as valuable as expertise-by-training, and equal numbers of relations and professionals participated. In addition, relations were encouraged to found their own local and regional Alzheimer's associations to spread information, raise funds, organise mutual support groups, and take on advocacy at the local and regional level.[53]

The factors that enabled the family organisations of the early 1980s to emerge

Seeing all these organisations pop up over a period of only a few years made some of their initiators wonder why that had not happened sooner. They all agreed that feelings of shame and guilt, fuelled by prejudiced reactions from their environment and the family-blaming attitudes they encountered in psychiatry, had kept them silent and isolated.[54] The question is, then, what it was that set them free and enabled them to start organising in the early 1980s. Contrary to what psychiatrists Aart Schene and Bob van Wijngaarden have suggested, neither the archival sources, nor the interviews show the influence of concrete examples of other relations organising in the (mental) health field, whether in the Netherlands or abroad, with the exception of the Alzheimerstichting.[55]

What the sources do show, is how the pioneers were helped to overcome their shame and guilt by what they picked up from the examples of other marginalised groups in the Netherlands in the 1970s, in particular the women's movement and the clients' movement. By the turn of the decade, the spirit of liberation of the preceding years had spread self-awareness and individualism widely in society, enabling relations to gain confidence, but also to see that their interests were not necessarily identical to those of their loved ones, and that they were entitled to advocate for themselves. This coincided with the winds of change in the mental health care arena that not only triggered relations to organise, but also created space for their particular perspective. On the one hand, that insight dawned in the

---

[52] Th.J. Veldhuijzen van Zanten [sic], 'Ten geleide', *Alzheimer Nieuwsbrief* 1 (1985) 1, 1.

[53] Lakeman, *Toevlucht en thuisbasis,* 20, 22; interview Jos van der Poel, 11 August 2022.

[54] Horn, 'Tussen twee grenzen', 12; Horn, 'Een vergeten groep', 879; Archive Smith, Christien C. le Clerq, 'Ontstaans- en wordingsgeschiedenis van de Interkerkelijke Stichting "IN PERSPEKTIEF", 17 mei 1990'; Jet Bruinsma, 'Ouders schizofrenen steunen elkaar in Ypsilon', *de Volkskrant* 17 July 1986.

[55] Aart Schene & Bob van Wijngaarden, *Familieleden van mensen met een psychotische stoornis. Een onderzoek onder Ypsilonleden* (Utrecht, Amsterdam 1993) 83.

clients' movement when activists took care of each other in times of relapse. On the other hand, space appeared in psychiatry as the social model with its family-blaming approach was challenged by a renewed biomedical model that took blame away from the relations.

In addition, the movements that had preceded the family organisations handed them important tools for building their organisations, from the mutual support methods of the women's movement to the expertise and resources that the clients' movement had made available. The novel *Hersenschimmen* (Out of Mind) by J. Bernlef serves as a reflection of how the nation was educated about dementia – one of the many mental health issues it needed to learn about – through literature.

A new climate in society

In the early 1970s, progressive Dutch people had hopes and dreams of a tolerant, democratic society with a strong sense of community, in which everybody could make their own life choices and flourish. By the end of the decade, journalist John Jansen van Galen concluded that the ideals had not come true, and resulted instead in individualism: far-reaching autonomy, personal choices and individual interests as the guiding lines of people's lives. Following his American colleague Tom Wolfe, he dubbed the 1970s *het ik-tijdperk,* the Me-Decade.[56] This development also had repercussions for the extent to which people were willing to care for each other in communities and families.[57] The positive side of individualism, however, was that a newfound self-awareness and self-assertiveness enabled more and more people to empower themselves – including relations of people with severe mental health issues.

The change was also tangible in the demise of activism, or at least that is how historian Duco Hellema sees it. Those organisations and individuals that remained active in the women's movement for example, either isolated themselves by radicalising, or were swallowed by professionalisation, exchanging protest for participation and volunteering in independent organisations for paid jobs inside the system.[58] The clients' movement, in particular the Cliëntenbond, was marked by both in the 1980s: increasingly radical in its style and very vocal in its fear of *inkapseling* (assimilation), while at the same time reaping the fruits of a decade of activism and being part of the changes the authorities were working towards.[59] In the eyes of historian Jouke Turpijn, by contrast, activism in the 1980s did not vanish, but merely changed its face, becoming less political, more practical

---

[56] John Jansen van Galen, *Het ik-tijdperk* ([Amsterdam] 1980); Duco Hellema, *Nederland en de jaren zeventig* (Amsterdam 2012) 12.

[57] Henny Oosterbaan, *Omgaan met gekte. Hoe familieleden de zorg voor psychiatrische patiënten volhouden* (Utrecht 1990) 10-12.

[58] Hellema, *Nederland en de jaren zeventig,* 284-286.

[59] Hunsche, *De strijdbare patiënt,* 83; interview Paul van Trigt, 30 November 2021.

and more individualistic.[60] His characterisation is more fitting for the family movement, where ideologies, though still at work below the surface, took the backseat to working towards practical ways to improve the lives of relations.

In addition, elements of the progressive, young activism of the 1970s became normalised in the sense that by the 1980s, they had spread to average citizens of all ages and beliefs who started using them actively. In many churches, in particular Protestant ones, an activist spirit was nothing new; in an effort to stem their loss of membership that followed from the ongoing secularisation in the Netherlands, already since the late 1950s they had become increasingly involved in social movements that reached out beyond their own constituencies, just like Christien le Clerq's ADB.[61] But the greatest example was the women's movement, which set the standard for many to follow.[62] All organisations in the family movement, for example, set up mutual support groups that were strongly inspired by the various kinds of discussion groups that had been developed in feminist circles. In fact, they usually had members who had been trained in such methods: Ypsilon's Ria van der Heijden used the experience she had gained in organising the Rotterdam VIDO groups and setting up the association of middle aged women WOUW (Wijze Oude Wijven, Wise Old Women),[63] while Inge van Ooijen, the first chairwoman of Labyrint, applied what she had learned in her cultural work studies to set up its mutual support groups.[64] How Van der Heijden spoke of her early activities is illustrative of how the feminist ideology was replaced by a pragmatic approach:

> *"We zijn dol op mannen. De 45+-groepen komen ook niet voort uit de feministische beweging, al zitten er heus wel feministen in. Maar het accent ligt niet op het feminisme. Wij hebben geen zendelingenfunctie. Wij helpen alleen maar...."*[65]

> ("We love men. The 45+ groups do not originate from the feminist movement, even though there are feminists in them. But the emphasis is not on feminism. We do not serve as missionaries. We're only helping....")

---

[60] Jouke Turpijn, *80's dilemma. Nederland in de jaren tachtig* (Amsterdam 2011) 16-17, 203.

[61] Jan Willem Duyvendak & Ruud Koopmans, 'Protest in een pacificatiedemocratie. Nieuwe sociale bewegingen en het Nederlandse politieke systeem', in: Jan Willem Duyvendak et al. (eds.), *Tussen verbeelding en macht. 25 jaar nieuwe sociale bewegingen in Nederland* (Amsterdam 1992) 39-57, 53-54; James Kennedy, *Stad op een berg. De publieke rol van protestantse kerken* (Zoetermeer 2010) 58-63, 74, 81-82, 91-93.

[62] Hellema, *Nederland en de jaren zeventig,* 61.

[63] 'Middag vol emoties in Vrouwenhuis', *Het Vrije Volk* 11 November 1984; Riet Diemer, ' "Oudere vrouw is geen last" ', *Trouw* 1 May 1990.

[64] Interview Inge van Ooijen, 12 January 2021.

[65] Jan-Hein de Groot, ' "Wat vrouwen nodig hebben is 'n oor..." ', *Het Vrije Volk* 21 September 1984.

A changing climate in mental health care and its clients' movement

It was not just leading opinion makers who were disappointed with how the ideals of the 1970s had worked out in practice. In the early 1980s, the mood in the mainstream of the clients' movement was gloomy as well. Taking stock of ten years of activism, the conclusion was that the results were disillusioning. Although new laws and policies were being developed and circumstances in institutions had improved somewhat, the fundamental changes that they strove for had not come any closer. People were still being scarred for life when they were involuntarily committed, put in isolation cells and treated with electroshocks. But there was a crucial accomplishment that seemed to get lost in the analyses: in only ten years, they had taken their place in the psychiatry arena.[66] In that development, Pandora and the Cliëntenbond had played an important part.

From an initiative promoting the merits of modern psychiatric hospitals, Pandora had developed into one of the central organisations in the Dutch clients' movement – despite continuing criticism of the fact that they were not a clients' organisation (see Chapter 1).[67] The turnaround came after Hans van der Wilk succeeded Treeske Blase as its director in 1977.[68] An expert-by-experience if ever there was one, Van der Wilk's focus was on creating a strong clients' movement. As Pandora was the only organisation in the movement with a paid staff and office, he offered the Cliëntenbond and other groups the use of its services and spaces. In addition, Van der Wilk joined the Landelijke Werkgroep Krankzinnigenwet (National Working Group Insanity Law), the heart of the movement at that point in time, accepted the position of chairman of the Cliëntenbond (succeeding 'father-of' Arie Groot) and travelled non-stop across the country advocating for the causes of the clients' movement.[69]

Despite the internal disputes and clashes, the clients' movement had grown into a movement to be reckoned with, putting one issue after another on the agenda, organising protests, setting up campaigns, writing critical reports and increasingly taking part in commissions and consultative bodies. It had contributed to moving the debate about mental health issues into the Dutch mainstream, making them *bespreekbaar* (open for discussion) and turning psychiatry and social work into popular fields to study or work in.[70]

---

[66] Hunsche, *De strijdbare patiënt,* 83-84; Oosterhuis & Gijswijt-Hofstra, *Verward van geest*, 1249.

[67] Corinne Kersbergen, *De psychiatrische tegenbeweging in de jaren 80. Van het inrichtingsbed naar de stoel van de beleidsmaker* (Master's thesis Universiteit van Amsterdam 1989) 108.

[68] Reinhilde van der Kroef, *25 jaar en nog steeds geen normaal mens ontmoet. Pandora, psychiatrie en beeldvorming* (Baarn 1990).

[69] Van der Kroef, *25 jaar*, 88-90, 104-117; Hunsche, *De strijdbare patiënt,* 45-59.

[70] Kersbergen, *De psychiatrische tegenbeweging*, 108-109; Hunsche, *De strijdbare patiënt,* 83.

And its influence was beginning to show results. Not only in the prolonged process of legal changes, but also sometimes in quicker political successes. In 1982, a coalition of Van der Wilk, prominent social psychiatry professors Kees Trimbos and Marius Romme and social physician Egbert van der Poel (who would succeed Van der Wilk as Pandora director the following year), convinced parliament to put a complete halt to all building plans for psychiatric hospitals – a decision that would become known as the Moratorium. The idea behind this was that these institutions damaged rather than helped people and therefore should vanish altogether. Instead, small facilities and intensified care in the community were the future, and all means should be targeted in that direction.[71] Under the same energetic leadership of Van der Wilk, in the early 1980s the Cliëntenbond no longer focused exclusively on everything that it was against. It also started a successful process formulating democratically how it wanted the system to change, culminating in the *Manifest Patiëntenrecht* (Patients' Rights Manifesto, 1980) and the *Denk- en Doeplan* (Think and Do Plan, 1982).[72]

Outside the scope of the mainstream clients' movement that the Cliëntenbond and Pandora belonged to, the diagnosis-oriented Nederlandse Vereniging voor Autisme (NVA, Dutch Association for Autism, see Chapter 2) was also making headway in convincing the government of its ideas on the development of specialised autism care. The *Nota Autisme* (Autism Memorandum) of 1984 marked the start of concrete improvements for their families. For Pandora and the Cliëntenbond the results were not yet quite so satisfying, but they had most certainly made headway. They had broken the taboo and made mental health issues something that could be talked about more openly than before. They had developed a large body of patient-centred knowledge on mental health issues, on stigma and on the Dutch mental health care system. By contrast with the situation ten years earlier, that meant that a lot of information, expertise and experience was at the fingertips of the family initiatives of the 1980s.

Around 1980, however, the Cliëntenbond was becoming more and more ambivalent in its attitude towards the relations. On the one hand, it was increasingly trying to purge itself of members who did not themselves have experience as a patient, now including family members – a position that was reinforced by the case of Frits Winterwerp (see Chapter 2), whose family was seen as the culprit behind his unwarranted hospitalisation. On the other hand, there were members of the league who started to appreciate the predicament that many relations were in. To Patricia Bolderhey, for example, reading

---

[71] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 820-823.

[72] NL-HaNA-CB, inv. no. 269, 'Manifest Patiëntenrecht in de Geestelijke Gezondheidszorg' (1980); 'Denk en Doeplan. De beleidsnota van de Cliëntenbond', supplement to *Bulletin van de Cliëntenbond* 10 (1982) 1.

Willy Brill's story about the events that led to the suicide of her daughter Josephine (see the end of Chapter 2) was eye-opening:

"Door het lezen van dit artikel is het voor het eerst in mijn leven pas tot mij doorgedrongen wat mijn moeder gedurende mijn suïcidale adolescentie doorgemaakt heeft. Immers, behalve haar bezorgdheid om mijn welzijn en mijn regelmatige afwijzingen, hatelijke, stekelige en beschuldigende op- en aanmerkingen, heeft zij ook de steun van enige hulp, begeleiding of goede raad moeten ontberen; ja zelfs van deskundigenzijde allerlei beschuldigingen moeten incasseren. Ook zij kreeg te maken met tactloosheid en minachting, al dan niet in deskundige trucage bewoordingen verpakt."[73]

("Reading this article was the first time in my life that I realised what my mother went through during my suicidal adolescence. After all, in addition to her concern for my well-being and my regular rejection of her, my hateful, prickly and accusatory remarks, she also lacked the support of any help, guidance or good advice; indeed, even from the side of the experts, she has had to endure all kinds of accusations. She, too, had to deal with tactlessness and contempt, whether or not couched in expert trickery.")

This personal change by Bolderhey is reminiscent of how inside Pandora the idea came up to start advocating for the relations too. Lineke Marseille, who worked closely with Linda Horn on setting up Labyrint, remembers how they started to notice a new dynamic in the clients' movement:

"... volgens mij ontwikkelde er zich gewoon een soort idee, niet alleen door de mensen die ons belden [bij Pandora], *maar juist dus ook door de mensen met wie we samenwerkten, van: er zijn omstanders. Er is familie. En ik heb heel scherp een herinnering aan een periode waarin* [iemand in de cliëntenbeweging] *weer instortte. En hoe mensen om haar heen,* [...] *vrienden vooral,* [...] *die ook ervaring hadden in het wegloophuis* [voor

("... as I see it, some kind of idea developed, not just from the people who telephoned us [at Pandora], but also from the people we collaborated with, like: there are bystanders. There is family. And I have a distinct memory of a period when [someone in the clients' movement] had a breakdown. And how people around her, [...] friends mostly, [...] who had experience from working in the runaway home [for people who had

---

[73] Patricia Bolderhey, 'Behandelde, familie, behandelaar (5)', *Maandblad Geestelijke Volksgezondheid* 35 (1980) 2, 152-154, 152.

mensen die waren weggelopen uit een psychiatrisch ziekenhuis] *enzo, die dus heel erg sociaal-maatschappelijk gefocust waren op die geestelijke gezondheidszorg en de mensen met psychiatrische problematiek oftewel afwijkend gedrag, dat die heel erg daaromheen gingen staan. En zeiden: wij maken een ondersteuningsrooster, en wij zorgen dat ze nooit alleen is. En dat ook daaruit zo langzamerhand dat beeld ontstond van familieleden, waardoor er zoiets ontstond als aandacht voor* [hen]. [...] *Hoe organisch dat groeide.*"[74]

run away from a psychiatric hospital] and the like, who were very socially focused on that mental health care and the people with psychiatric problems or different behaviour, that those people gathered around her. And said: we will draw up a support schedule, and we will make sure that she is never alone. And that from there, slowly, that picture of the family members was formed, and attention to them rose. [...] How organically that grew.")

With a clear view of the diverging interests of people with mental health issues and their family members, it was clear from the start that the new initiative Labyrint would be established apart from its mother organisation, Pandora. But that did not change the fact that Labyrint was a direct heir to the mainstream clients' movement of the 1970s and the anti-psychiatry ideas that shaped it. The development of this family organisation was a continuation of the social explanatory model of the 1970s that the undifferentiated clients' movement was rooted in.[75]

In contrast, Ypsilon was the fruit of a new and completely different development in psychiatry: the return of the biomedical explanatory model, that started gaining renewed traction from the mid-1980s onwards. It was not that this outlook on mental health problems had disappeared entirely, but it had been extremely unpopular in progressive circles. Psychiatrist Piet Stolk, for example, had taken a stand against the social model with his book *Een soort vuur* (Some Kind of Fire) in 1975, but his ideas were received so negatively by the staff of the Sint Joris psychiatric hospital that he led, that he felt forced to step down four years later.[76] In 1978, criminologist Wouter Buikhuisen proposed a biosocial approach to criminological research, only to see his ideas framed in a prolonged campaign in national newspapers and opinion weeklies as 'brain research on criminals' equated with 'Nazi practices'. His inaugural lecture was disrupted, important partners severed all ties with him, and his institute received bomb threats.[77]

---

[74] Interview Linda Horn & Lineke Marseille, 28 May 2021.

[75] Interview Linda Horn & Lineke Marseille, 28 May 2021.

[76] Oosterhuis & Gijswijt-Hofstra, *Verward van geest*, 926.

[77] Eelco Boss, *Buikhuisen in KRI-minologisch perspectief. Het onderzoek van prof. dr. W. Buikhuisen*

But the most powerful example lies in the events following the psychiatrist Herman van Praag's inaugural lecture at the University of Utrecht in 1978, in which he dissected the scientific foundations of anti-psychiatry and concluded that there were none. Posters with slogans attacking Van Praag were hung all over the cities' university districts, biomedical psychiatry conferences at his university were disrupted, and he and his family even received death threats. An invitation to take a position in the United States in 1981 may have come as a relief to Van Praag and his family. He would not return until 1993, when the biomedical model was again dominant.[78]

Simultaneously, however, a new generation of psychiatrists was exploring new approaches, in particular in the research and treatment of schizophrenia. In 1982, psychiatrist Don Linszen started the Adolescentenkliniek (Adolescents' Clinic) in Amsterdam for young people with a first psychosis, where involving the family became standard. Although in its first years the clinic largely departed from anti-psychiatry thinking, it radically replaced the hostile approach towards families with a collaborative one.[79] Meanwhile, psychiatrist Rigo van Meer was working on a similar approach towards the family, but his research departed from the position that schizophrenia was an illness of the brain instead of something caused by bad parenting. He promoted the reintroduction of the term 'schizophrenia', which had been banned by anti-psychiatry, and got a lot of resistance as a result.[80]

Both Van Meer and Linszen started working in the mid-1980s with the concept of 'expressed emotion', EE for short.[81] EE refers to the attitude of relations towards a loved one with a severe mental health issue. Since the late 1950s, international studies had shown that if close family members reacted to someone with for example schizophrenia or anorexia nervosa in an emotional, over-involved, critical or hostile manner, the risk of relapse rose significantly. When instead the family environment managed to keep the level of their 'expressed emotion' low, that boosted the chances of recovery.[82]

---

door de ogen van een reclasseringstijdschrift (Master's thesis Universiteit Utrecht 2012); Hellema, *Nederland en de jaren zeventig,* 58.

[78] Hunsche, *De strijdbare patiënt,* 59; Oosterhuis & Gijswijt-Hofstra, *Verward van geest*, 764; Tjerk de Reus, *God, religie en ons brein. In gesprek met psychiater Herman van Praag* (Kampen 2011) 82-96; 'Herman van Praag', https://en.wikipedia.org/wiki/Herman_van_praag?oldid=1067816665 accessed 28 December 2023.

[79] Flip Schrameijer, *De adolescentenkliniek. Onderzoekers en behandelaars over schizofrenie* (Amsterdam, Antwerpen 2005) 32-71.

[80] Oosterhuis & Gijswijt-Hofstra, *Verward van geest*, 923, 926; Rigo van Meer, 'Steunende gezinsbegeleiding bij schizofrenie', *Maandblad Geestelijke Volksgezondheid* 41 (1986) 9, 867-877; Rigo van Meer, *Leven met schizofrenie. Een handleiding voor familie, vrienden en andere betrokkenen* (Amsterdam 1987); Rigo van Meer, *Schizofrenie van nabij. Belasting van familieleden van schizofreniepatiënten en effecten van steunende gezinsbegeleiding* (Delft 1991); ' "Ypsilon stapte niet in valkuil van ideologie" ', *Ypsilon Nieuws* (1996) 65, 3.

[81] Van Meer, 'Steunende gezinsbegeleiding'; Schrameijer, *De adolescentenkliniek,* Chapter 3, 4.

[82] Elizabeth Kuipers & Estelle Moore, 'Expressed Emotion and Staff-Client Relationships: Implications for Community Care of the Severely Mentally Ill', *International Journal of Mental Health* 24 (1995) 3, 13-26.

However, in the face of severe mental health issues, it is not easy for close relations to suppress their concerns and their pain. In 1981, American social workers Carol Anderson and Gerard Hogarty came up with a solution: psycho-education, educating close relations on the mental illness of their loved one and its consequences, and training them in dealing with the situation in a de-escalating way. Anderson and Hogarty were not interested in an answer to the question what caused mental health problems; in their search for a practical approach, it was clear to them that mother-blaming and family-blaming had nothing to offer. That was a radical change compared to shutting out relations from anything to do with diagnosis or treatment, keeping them uninformed, blaming them and encouraging patients to break away from them. Instead, in this approach, relations were recognised as primary caregivers and regarded as allies, not enemies.[83] By the late 1970s, this approach was starting to catch on internationally. That both the psychoanalytically, anti-psychiatry oriented Linszen and the biomedically oriented Van Meer adopted it in the mid-1980s, shows how competing explanatory models existed side by side at this time, creating space for relations to come out and organise.[84]

A literary reflection: Hersenschimmen (1984)

In their efforts to educate the nation about dementia, the Alzheimerstichting got help from an unexpected ally: literature. In 1976, writer Inez van Dullemen had reached quite a large audience with her book *Vroeger is dood* (Bygones), in which she described the progression of her parents' dementia from her position as a daughter as an utterly bewildering, embarrassing and infuriating experience.[85] When in August 1984, right in the middle of the preparations for the Alzheimerstichting, the novel *Hersenschimmen* (Out of Mind) by J. Bernlef came out, this book did the opposite: it took the reader inside dementia, showing the experience from the perspective of the person suffering from it.[86] What's more, it firmly established the idea that dementia was a very serious illness of the brain and an enormous burden on the patient's relations – exactly the message the Alzheimerstichting wanted to get across.[87] The novel would become an important tool in the foundation's efforts to destigmatise the disorder and turn it into something that could be talked about.

---

[83] Anne Harrington, 'Mother Love and Mental Illness: An Emotional History', *Osiris* 31 (2016) 1, 94-115, 113; John Neill, 'Whatever Became of the Schizophrenogenic Mother?', *American Journal of Psychotherapy* 44 (1990) 4, 499-505; Mary V. Seeman, 'The Changing Role of the Mother of the Mentally Ill: From Schizophrenogenic Mother to Multigenerational Caregiver', *Psychiatry – Interpersonal and Biological Processes* 72 (2009) 3, 284-294.

[84] Schene & Van Wijnbergen, *Familieleden van mensen met een psychotische stoornis,* 84.

[85] Inez van Dullemen, *Vroeger is dood* (Amsterdam 1976).

[86] J. Bernlef, *Hersenschimmen* (fiftieth edition; Amsterdam 2010 [1984]).

[87] Koos Neuvel, *Alzheimer. Biografie van een ziekte* (Amsterdam [2014]) 134-135.

Bernlef was already an acclaimed literary writer, but had never been very widely read. That was about to change. By the end of the year, newspaper *de Volkskrant* put *Hersenschimmen* at number one in their list of best novels of 1984. Over 1985, parallel to the foundation taking off, sales of the book rose to seventy thousand, the next year to a hundred thousand. Continuing as a steady seller, in 2010 it reached its fiftieth edition, and the author was looking back at a million copies sold, translation into sixteen languages, three theatre adaptions and a movie.[88] It is still recommended to close bystanders of people with dementia: even prominent Dutch dementia specialists Philip Scheltens and Huub Buijssen name *Hersenschimmen* as the book that opened their eyes to the experience of dementia.[89]

In *Hersenschimmen,* the reader is there, inside the head of Maarten Klein, when he starts to get confused about what day of the week it is, why his children are not at home, and why his friend does not bring his dog around anymore. Through the reactions of his wife Vera, we learn that Maarten is retired, that their children are grown-ups and live on their own, and that the friend's dog was killed in an accident some time ago. We accompany Maarten while his state of mind steadily deteriorates. He struggles increasingly with his understanding of his familiar surroundings, the objects and the people in it, and slowly loses track of the times he lives in. By the end of the book, when Maarten is placed in a nursing home, his observations and language become haphazard and his past and present become fluid:

"Heel in de verte klinkt geweervuur... schoten... mooie boel is dat, nog oorlog ook... komt er dan nooit een eind aan?... van binnen bezet... mijn bevrijders hebben mij bezet, dat is het... steeds meer gecensureerd... er komt zowat niets meer door."[90]

("There is gunfire in the distance... Shots... fine kettle of fish, and war too... will it never end?... occupied inside... my liberators have occupied me, that's it... more and more censored... almost nothing comes through anymore.")

Although the words dementia or Alzheimer's are nowhere to be found in the book, the novel was instrumental in making the breakthrough that the initiators of the Alzheimerstichting wished with regard to educating the Dutch people about the illness.

---

[88] Neuvel, *Alzheimer*, 130; Erica van Boven, *Bestsellers in Nederland 1900-2015* (Antwerpen, Apeldoorn 2015) 149; J. Bernlef, 'Herinneringen van een vergeetachtige', in: *Hersenschimmen* (fiftieth edition; Amsterdam 2010 [1984]) 5-9, 9; 'Hersenschimmen jubileert', *Medisch Contact* 7 April 2010, https://www.medischcontact.nl/actueel/laatste-nieuws/artikel/hersenschimmen-jubileert accessed 9 December 2023.

[89] Ischa Meijer, 'J. Bernlef', in: Ischa Meijer, *De interviewer en de schrijvers. 50 literaire interviewers van 1966 tot 1993* (Amsterdam 2003) 277-282, 281-282; Neuvel, *Alzheimer,* 133-134.

[90] Bernlef, *Hersenschimmen,* 176.

It opened an unknown world to the public: that of elderly people who were gradually losing their grip on their lives as a consequence of dementia.[91]

Although the Alzheimerstichting had nothing to do with the book – Bernlef had read up on dementia in scientific literature, and then used his imagination[92] – it aligned with the image that the Alzheimerstichting wanted to portray: that mental deterioration in an elderly person is not just a natural process, it is an illness and a particularly horrific one.[93] The reader may, however, identify more with Maarten's wife Vera, feeling what it is like for her to hear him ask a widowed friend about how her husband is doing every time he sees her. Or find the stove smoking alarmingly after Maarten has smashed in a window to let the dog in and then turned up the heat. Or being taken for his mother, one particularly challenging morning:

“ *‘Is papa al naar kantoor?’*
‘Maarten, ik ben het, Vera!’
‘Je moet niet zo tegen me schreeuwen.’
Ze verbergt haar gezicht in haar handen.
Waarom is ze nu opeens zo opgewonden?
Waarom huilt ze zo hartverscheurend?
‘Je moet niet huilen. Ik wil niet dat je huilt.’
‘Vera,’ snikt ze, ‘ik ben Vera!’
‘Natuurlijk ben je Vera,’ zeg ik. ‘Dacht je dan dat ik dat niet wist?’ ”[94]

(“ ‘Has Daddy gone to the office yet?’
‘Maarten, it's me, Vera!’
‘You shouldn't yell at me like that.’
She hides her face in her hands. Why is she so excited all of a sudden? Why is she crying so heartbreakingly?
‘You shouldn't cry. I don't want you to cry.’
‘Vera,’ she sobs, ‘I'm Vera!’
‘Of course you're Vera,’ I say. ‘Did you think I didn't know that?’ ”)

Bernlef's book reached an audience that was much larger than he had expected, which may have had something to do with the concurrent publicity offensive by the new Alzheimerstichting. What's more, it was perceived by many readers as a true story. Time and time again, the author was asked how he could have portrayed the experience of dementia so truthfully: had he perhaps suffered from it for a while and come back from it? The writer's objection that if that was the case, he would not have been able to remember, did not help him to convince readers that the novel was a product of his imagination. Moreover, doctors and nurses insisted that the way Bernlef pictured dementia was completely truthful.[95] Here, literature is ascribed the power to imagine the unimaginable,

---

[91] Neuvel, *Alzheimer,* 130-131.
[92] Meijer, ‘J. Bernlef’, 281.
[93] Lakeman, *Toevlucht en thuisbasis,* 86.
[94] Bernlef, *Hersenschimmen,* 92.
[95] Bernlef, ‘Herinneringen van een vergeetachtige’, 8-9.

shaping society's idea of what goes on in the heads of patients who are unable to speak about their experiences themselves. The fact that the relations of these patients recognised their own experiences in the story may have contributed to its success significantly.

The experiences that triggered the family organisations of the early 1980s

It was a wide range of triggers that made relations organise in the LSOVD, the ADB, Labyrint, and Ypsilon – a mix of old and new. Many relations had a hard time finding support where they would usually seek it in a time of need: the taboo associated with mental health issues might have been broken, but ignorance and stigma were still powerful around 1980. Especially in conservative circles, this could result in people with mental health issues and their relations feeling isolated from their communities. When relations approached the mental health care domain, they often found that the professionals focused exclusively on the patient and family members remained unseen. That was no longer just related to mother-blaming and family-blaming attitudes, it was also a consequence of new laws and regulations being implemented. The right to privacy, and in particular the way this was interpreted by mental health care workers, shut out relations completely. The more difficult it became to legally arrange involuntary commitment in a psychiatric hospital for a person in crisis, the more frightening it could become for relations in fear of their loved one ending up uncared for, addicted, homeless or worse. And even if someone was admitted, the relief might be brief, as the circumstances in psychiatric hospitals could still be worrisome.

Ignorance, stigma and blame

Despite all the attention to psychiatry that had been raised by the countermovement since the 1960s, mental health issues were still hard for lay people to understand, just as relations had difficulty knowing what to do when they were confronted with such issues for the first time, or where to find help. The result was that family members could remain in the dark for a long time.[96] For a man who told his story to a journalist from women's weekly *Libelle* in 1987, for instance, this obscurity had led to haunting doubts even years after he had divorced his wife, whose unexplained, increasingly violent outbursts had become unbearable to him:

---

[96] Henk Kuipers, 'Drugsverslaving, voor het hele gezin: Een hel zonder grenzen', *Nieuwsblad van het Noorden* 28 June 1980; Horn, 'Een vergeten groep', 878-880; ' "Ook familie van lijders aan schizofrenie krijgt stempel" ', *Provinciale Zeeuwse Courant* 10 September 1986; Rotterdam City Archive, Archive Psychiatrische Inrichting Maasoord later Deltaziekenhuis, access no. 230-04, inv. no. 250, letter from Ruud Monster to Ypsilon discussion group leaders, undated [late 1986], examples of press releases.

"Ik hield nog veel van haar, maar ik kon op die manier niet met haar leven. Ik besloot van haar te scheiden. Jantien is nu al enige maanden onder psychiatrische behandeling in een kliniek. Haar familie heeft sindsdien alle contact met mij verbroken. Ze wilden me niet vertellen hoe ze daar uiteindelijk terecht was gekomen. Wat haar is overkomen, is mijn schuld. Ik weet dat het onzin is, het zat er al jaren in, maar ik trek het me toch aan. [...] *Het ergste vind ik eigenlijk dat ik niet weet wat ze heeft, waarom ze zo is geworden en waaraan ons huwelijk kapot is gegaan."*[97]

("I still loved her very much, but I couldn't live with her that way. I decided to divorce her. Jantien has been under psychiatric treatment in a clinic for several months now. Her family has cut off all contact with me since. They wouldn't tell me how she ended up there. What happened to her is my fault. I know it's nonsense, I had seen it coming for years, but it still upsets me. [...] The worst thing for me is that I don't know what is the matter with her, why she has become this way and what has destroyed our marriage.")

Not being able to interpret the signs was also a problem for relations of people with a drug addiction. Many parents did not know what drugs and drug paraphernalia looked or smelled like, nor how to tell that someone has used them or might be struggling with addiction.[98] LSOVD mother Hennie Bachman told a journalist in 1987:

"Ikzelf wist het bijvoorbeeld pas na vier jaar, toen mijn zoon het me vertelde. Maar je ziet de puinhoop almaar groter worden en je weet niet hoe het komt en je weet niet wat je eraan moet doen. Daarbij komt dat je vanuit je omgeving commentaar krijgt. En als je met de huisarts, dominee of pastoor gaat praten krijg je goedbedoelde adviezen, die nergens op slaan. Want zij hebben geen ervaring met drugverslaafden."[99]

("Me, I didn't know until four years had passed, when my son told me. But you see the mess getting bigger and bigger and you don't know why and you don't know what to do about it. In addition, you will receive comments from those around you. And if you talk to the doctor, vicar or pastor, you get well-intentioned advice that makes no sense. Because they have no experience with drug addicts.")

---

[97] Tonie Broekhuysen, 'Bert (36): "De uitbarstingen kwamen steeds vaker voor, op die manier kon ik niet met haar leven" ', *Libelle* 19 June 1987.

[98] J.E. de Leeuw den Bouter, 'OVD en hulpverlening, een onderzoek', *Info* (1990) special, 20-31, 24.

[99] Untitled interview with Hennie Bachman, *Info* (1987) 23, 4-6, 5.

Once family members got in touch with mental health or addiction care, that did not necessarily mean that it was explained to them what was happening.[100] Psychiatrist Rigo van Meer saw this happen with relations of young people going through psychosis: people who had never heard of schizophrenia, insecure and confused, wondering whether their child was on drugs.[101] Van Meer's analysis was that professional caregivers did not succeed well in explaining what was going on.[102] But it could also be the case that they didn't want to. Pieter Los, a psychiatrist from an earlier generation, recalled in 1987 that before anti-psychiatry, psychiatrists did not tell the family what the symptoms were called (let alone the diagnosis), for fear that they would look them up and find that these were symptoms of schizophrenia, a severe mental illness for which there was no cure, and think therefore, it was better 'to keep the patient out of the diagnosis'.[103] When anti-psychiatry arose and schizophrenia became interpreted as a healthy reaction to an unhealthy situation, the term remained taboo, albeit for different reasons.[104]

As a result, families could remain in the dark for years and years. When in 1992, Ypsilon mother Guusje Silver appeared in the newspaper, telling her story about her son who took his life when he could no longer cope with his psychoses, she was baffled by the number of letters she received from family members telling her that only after reading this article did they understand what had been the matter with their deceased loved one.[105] These family members did not want to be protected from the truth. They wanted to be taken seriously and informed.

The stigma and lack of knowledge in the population not only meant that problems were not recognised, it also meant that relations were not acknowledged in their difficult position.[106] For parents of young people with a drug addiction, this experience was all-encompassing.[107] Nobody seemed to want to know about them, in sharp contrast to the public and media interest in sensational stories about people who were addicted to drugs.[108]

Not being seen was an experience that was not exclusive to families who were dealing with drug addiction. The telephone operators at Pandora found that once they started digging deeper than the – often practical – questions relations called their hotline about, the floodgates opened and a lot of grief and misery came out.[109] Never before had someone

---

[100] Horn, 'Een vergeten groep'.

[101] Jan Westerlaken, 'Schizofrenie ramp voor het gezin', *Leidsch Dagblad* 9 March 1991.

[102] Kees de Leeuw, 'Een nuttig boek over schizofrenie', *Algemeen Dagblad* 27 June 1987.

[103] P.L. Los, 'Met schizofrenie terug naar af?', *Nederlands Dagblad* 16 July 1987.

[104] Oosterhuis & Gijswijt-Hofstra, *Verward van geest*, 926.

[105] Guusje Silver, 'De dood van mijn zoon', *Nieuwsbrief Ypsilon* (1992) 38, 26-31.

[106] Horn, 'Een vergeten groep', 881.

[107] Ton Cramer, 'Oprichting Landelijke Stichting Ouders van Drugverslaafden', *FZA Kwartaalberichten* 6 (1980) 2, 35-36, 36.

[108] Van Amerongen, 'Ouders van drugsverslaafden', 115; interview Alphons Katan, 4 December 2018.

[109] Museum of the Mind, Haarlem, Pandora Library, inv. no. 1036, Linda Horn, 'Van lotgenoot tot bondgenoot', 3.

asked these family members the question how *they* were doing. The people to whom they usually turned for support – the extended family, the family doctor, their pastor – often failed in situations like these. Psychiatrists Aart Schene and Bob van Wijngaarden consider individualism the main trigger of the family movement, in that families in the 1980s had increasingly become isolated and left to their own devices in coping with mental health problems.[110] But the fact that this was also a problem in tightly-knit Christian communities points to deeper roots of this problem. The ADB volunteers, for example, noted that the church officials they approached were convinced that 'these things did not happen in their communities'. Especially those from the smaller branches of the orthodox Reformed Church said they were never confronted with psychiatric problems. The number of telephone calls from members of these churches to the ADB, however, was remarkably high.[111]

Relations were also confronted with stigma directly. During a radio show in 1987, a caller mentioned how outsiders told her to her face that she was to blame for the fact that her husband was in a psychiatric hospital, that she must have wanted him locked away.[112] An Ypsilon mother told a journalist a particularly poignant story:

> *"De buurt heeft David nu geaccepteerd. Maar ik heb 't meegemaakt dat hij werd opgepikt door de spoorwegpolitie. Hij kwam me gewoon van de trein afhalen. Ik heb die politieman gezegd dat mijn zoon schizofreen was. Hij zei: dat is mijn pakkie an niet. Toen zei ik: 'Ik weet niet of u zelf kinderen hebt, maar ik hoop dat u dit nooit zal meemaken'. Weet je wat hij zei? 'Dat zal mij nooit gebeuren, want daar heb je zelf óók schuld aan'. Ik vloog die man bijna aan."*[113]

> ("The neighbourhood has accepted David now. But I have experienced him being picked up by the railway police. He just came to collect me from the train. I told the policeman that my son was schizophrenic. He said: that's not my problem. Then I said, 'I don't know if you have children of your own, but I hope you never get to experience this.' Do you know what he said? 'That will never happen to me, because you are also to blame for something like that yourself'. I almost lashed out at that man.")

Stigma could take on a specific shape for Christian family members, particularly those in the Reformed Churches. They were often haunted by questions of faith: why does my loved one have to suffer so much, why do I, what does God expect from me, why do I feel like

---

[110] Schene & Van Wijnbergen, *Familieleden van mensen met een psychotische stoornis*, 84.

[111] UA-GKN-F, inv. no. 1492-1469, 'Verslag van het werkgroepenberaad op 26 november 1987 te Leusden van de werkgroep familieleden', 2.

[112] 'Familie psychiatrische patiënten klaagt haar nood', *Ypsilon Nieuwsbrief* (1988) 2, 22-23.

[113] Marja Klein Obbink, 'De diagnose: schizofreen', *De Stem* 11 November 1989.

He has left me? But as their situation was not something that could be talked about in their church community, they were left to their own devices in dealing with these questions.[114] As a consequence, these believers could feel disconnected from their fellows, as Christien le Clerq explained:

"In een kerkdienst kun je je zo verschrikkelijk alleen en verdrietig voelen, terwijl de kerkelijke gemeente uit volle borst een lied vol geloofsvertrouwen zingt. Want juist dat geloofsvertrouwen mis je in je moeilijke situatie. Je voelt je dan buiten de gemeenschap staan en dat doet extra pijn. [...] *Doordat je zo moeilijk met anderen kunt praten en zoveel onbegrip ontmoet (ook in kerkelijke kring) kom je alleen te staan.* [...] *Zo voel je je in je moeilijkste periodes van God en mensen verlaten. Of moet het zijn van mensen en God verlaten?"*[115]	("During a church service, you can feel so terribly alone and sad, while the church congregation lustily sings a song of faith. Because it is precisely that faith that you lack in your difficult situation. You feel as if you are standing outside the community and that hurts even more. [...] Because it's so difficult to talk to others and you encounter such a lack of understanding (also in church circles) you end up alone. [...] This is how, in your most difficult times, you feel forsaken by God and people. Or should it be forsaken by people and God?")

On the one hand, Christian family members suffered from the public stigma that followed from the ignorance and prejudice of fellow members of the congregation. When a member became physically ill, they and their family could count on compassion, visits and prayers, but when the problem was in the mind, there was often only silence.[116] In the best case, the silence came from not knowing about mental health issues or how to approach the subject. In the worst case, patients and their relations found themselves facing the conviction that what was wrong with them was a sign of a lack of faith, or even of the devil – in orthodox religious communities such religious explanations could be very much alive.[117] Social worker Reina van Mourik remembers how sometimes

---

[114] Hans Binneveld, *Filantropie, repressie en medische zorg. Geschiedenis van de inrichtingspsychiatrie* (Deventer 1985) 164-169; Aleid Schilder, *Hulpeloos maar schuldig. Het verband tussen een gereformeerde paradox en depressie* (Kampen 1987).

[115] Archive Smith, *Nu moet ik er naar toe* (special issue of *'n Bijzondere Krant)* (1990) 3, 2, 'Van God en mens verlaten'.

[116] UA-GKN-F, inv. no. 1492-1479, 'Verslag ontmoetingsdagen 1985 in Noord-Holland voor familieleden en vrienden van (ex)psychisch zieke mensen', 15-16.

[117] UA-GKN-F, inv. no. 1492-1490, *Eigendruk* (January 1986) 4, 3, D.C.B., 'Mede-leven, mede-lijden of.... Beschuldigende vingers?'; Schilder, *Hulpeloos maar schuldig*; interview Reina van Mourik, 12 May 2021.

at Veldwijk psychiatric hospital, where she worked from 1979 onwards, a recovering patient who had been visited by a group of Reformed Church elders relapsed, having been scolded for not having prayed enough.[118]

On the other hand, it was self-stigma that got relations into trouble. A Christian, angry with God for letting a loved one and the rest of the family suffer so much, was prone to feelings of guilt and self-reproach, questioning the strength of their own faith and being torn between all these conflicting feelings. These family members needed a place where they could talk about these issues with people who were going through the same thing *and* understood the value their faith had to them.[119]

Feelings of guilt, however, were not exclusive to religious family members. In 1986, a woman wrote in Labyrint's newsletter *Eigendruk* about the tangle of feelings she experienced towards her manic-depressive mother:

"Het 'opgeluchte', maar ook uit je evenwicht brengende gevoel als je je moeder weg moet brengen voor een opname in een kliniek. Het schuldgevoel meer aandacht aan haar te moeten geven, omdat ze het zo moeilijk heeft. Horen hoe graag ze dood zou willen, maar niet weet hoe! Dat zijn dingen die je niet gemakkelijk vergeet of even naast je neerlegt."[120]

("The 'relieved', but also unsettling feeling when you have to take your mother to be hospitalised. The guilt of having to pay more attention to her, because she is having such a hard time. Hearing how much she would like to die, but doesn't know how! These are things that you don't easily forget or put aside.")

Unseen and rebuffed by mental health care professionals

But relations not only encountered rejection in lay environments, they could feel it with professionals too: the most frequent complaint of family members in the movement was that mental health care professionals were unwilling or unable to deal with them in a constructive way. Even social workers, who in many institutions were the primary contacts for relations, often seemed unavailable or aloof.[121] For example, information-

---

[118] Interview Reina van Mourik, 12 May 2021, addendum in e-mail 16 November 2021.

[119] Archive Smith, *Nu moet ik er naar toe* (special issue of *'n Bijzondere Krant)* (1990) 3, 2, 'Van God en mens verlaten'.

[120] UA-GKN-F, inv. no. 1492-1490, *Eigendruk* (January 1986) 4, 2, 'Overleven'.

[121] Horn, 'Een vergeten groep'; Q.A. Jansen, 'Openingswoord', in: *Verslag tweede themadag LSOVD 8 oktober 1983* (Bilthoven 1983) 2-4, 4; Jet Bruinsma, 'Ouders schizofrenen steunen elkaar in Ypsilon', *de Volkskrant* 17 July 1986.

seeking questions from relations unfamiliar with the workings of a psychiatric hospital were often perceived as criticism and accordingly received the response: “*Mijnheer, mevrouw, als u denkt dat wij het niet goed doen, dan neemt u hem maar weer mee naar huis*” (“Sir, Madam, if you think that we are doing it wrong, you can take him back home with you”). The message was, the family organisations concluded, one of reproach: you were unable to cope, now you have lost your right to be involved in the situation.[122] A ‘daughter-of’ found that it didn’t matter which approach she tried:

“Als je niets vraagt ben je ongeïnteresseerd, als je teveel vraagt dan ben je een kenau, als je iets rustig vertelt wordt geconstateerd dat je merkwaardig koel blijft onder de omstandigheden en als je geëmotioneerd raakt, dan weten ze geen raad meer met je. En dan denk ik nu maar even niet hoe er omgegaan wordt met mijn moeder, daar.”[123]

(“If you don’t ask anything you are uninterested, if you ask too much you are a harpy, if you tell something calmly it is observed that you remain remarkably cool under the circumstances and if you get emotional, they don’t know what to do with you anymore. And let’s not get into how my mother is treated there.”)

One of the issues those in the family movement experienced in this regard was a blind spot when it came to the ways families were burdened when dealing with mental health issues and giving care at home. When the first conferences on the relations’ issues were organised in the second half of the 1980s, many professionals attended. But they seemed to assess the load of care that families carried quite differently to those families themselves, according to this report in Ypsilon’s newsletter:

“In de zaal zaten zeer veel hulpverleners, enkele mensen van de Cliëntenbond en van Labyrinth [sic] *en een groep Ypsilon-vrouwen. Tijdens haar spreekbeurt maakte Ria* [van der Heijden, voorzitter van Ypsilon] *zeer duidelijk, dat langdurige thuiszorg een veel te zware taak en*

(“There were a lot of mental health care workers in the room, some people from the Cliëntenbond and of Labyrinth [sic] and a group of Ypsilon women. During her presentation, Ria [van der Heijden, Ypsilon’s chairwoman] made it very clear that long-term home care is far too

---

[122] Museum of the Mind, Haarlem, Pandora Library, inv. no. 1036, Linda Horn, ‘Van lotgenoot tot bondgenoot’, appendix, *Eigendruk* 2 [late 1984 or early 1985], 1.

[123] Museum of the Mind, Haarlem, Pandora Library, inv. no. 1036, Linda Horn, ‘Van lotgenoot tot bondgenoot’, appendix, Linda Horn, ‘Verslag van de reacties op de radiouitzending over Labyrint’.

daarom een onmogelijke belasting is voor de meeste ouders, met name voor de velen die boven de zestig zijn. Inge van Ooyen [sic; voorzitter van Labyrint] *sprak geëmotioneerd over de onmogelijke taak om met een psychiatrische patiënt samen te leven. Een van de weinige reacties vanuit de hulpverlening hierop was: 'De draagkracht van een gezin is inderdaad dikwijls te klein. MAAR HETZELFDE GELDT VOOR EEN TEAM IN BESCHERMDE WOONVORMEN.' Dan sta je als ouders met een weekdienst van 7 x 24 uur wel even met je oren te klapperen!"*[124]

heavy a task and therefore an impossible burden for most parents, especially for the many who are over sixty. Inge van Ooyen [sic; Labyrint's chairwoman] spoke emotionally about the impossible task of living with a psychiatric patient. One of the few reactions from the professionals was: 'The coping capacity of a family is indeed often too small. BUT THE SAME GOES FOR A TEAM IN SHELTERED LIVING ARRANGEMENTS.' As parents with a weekly shift of 7 x 24 hours, that will ring in your ears for a while.")

Mother-blaming and family-blaming – revisited

Ypsilon founder Ria van der Heijden had personally experienced mother-blaming in her contacts with the doctors who diagnosed her son in the 1970s. It had weighed heavily on her, and on other mothers like her. In fact, she was convinced that mother-blaming and family-blaming theories, and the practices that resulted from them, were the reason why it was not until the mid-1980s that relations found the courage to speak out against a psychiatry that disparaged them:

"Het is altijd fout wat je als opvoeder gedaan hebt: of je was veel te dominant of te weinig. Maar dat kan natuurlijk niet. Het is inhumaan om de ouders te belasten met de schuld dat hun kind schizofreen is. [...] *Maar die hardnekkige visie heeft er wel toe geleid dat het lang heeft geduurd voor deze ouders zich durfden te manifesteren.*[125]

("It is always wrong what you have done as an educator: either you were far too dominant or not enough. But that's not possible of course. It is inhumane to burden the parents with the blame that their child is schizophrenic. [...] But as a result of that persistent view, it has taken a long time before these parents dared to show themselves.")

---

[124] 'Open oor voor Ypsilon op Utrechtse studiedag', *Nieuwsbrief Ypsilon* (1987) 9/10, 3-4, 3.

[125] Jet Bruinsma, 'Ouders schizofrenen steunen elkaar in Ypsilon', *de Volkskrant* 17 July 1986.

Mother-blaming and family-blaming ideas had not remained limited to the fields of autism and anorexia nervosa: over the course of the 1970s, on the wings of anti-psychiatry, these theories became influential throughout Dutch mental health care.[126] Historian Gemma Blok has discerned two phases in Dutch anti-psychiatry: the first, from 1965 to 1975, focused on empowering patients and helping them uncover the psychosocial background of their problems by promoting their self-expression; and the second, more radical phase, from 1975 to 1985, that was focused on dismantling the psychiatric institutions system, but in which a hostile attitude towards the family also became a prominent characteristic.[127]

Only in the autism field, as we saw, did an independent Dutch research tradition function as a counter-weight to these ideas. But in the mainstream of mental health care, theories similar to the ones we discussed regarding anorexia nervosa, became part of modern, progressive psychiatry in this period. Particularly when a person was diagnosed with psychosis or schizophrenia – the latter term was rejected for belonging to the biomedical realm, but still used in a lot of the scientific communication[128] – their parents, partners or entire families were increasingly accused of having caused the patient's misery. In addition, in the 1980s, the family-blaming perspective was on the rise in addiction care.

It was the American psychiatrist and psychoanalyst Harry Stack Sullivan who, in the 1920s, had started to develop the idea that schizophrenia was caused by traumatic experiences in early childhood, resulting from the personality and behaviour of the mother. That was a very innovative stance, as at that point psychiatry had for decades been looking for brain structures, hereditary factors, and other biological origins of schizophrenia. Inspired by Sigmund Freud, early psychoanalysts like Sullivan started to look for causes and remedies in suppressed inner conflicts brought on by their patients' upbringing, by their parents. It was not that they set out to find someone to blame – what they wanted was to find an alternative cure for what they saw as the severest form of mental illness. Before anti-psychotic medication (that would be introduced in the 1950s), ways to calm down frantic psychotic behaviour were limited, and treatment options – like insulin coma therapy, electroconvulsive therapy and lobotomy – were violent, traumatising and often crippling. To psychoanalysts, talking therapy held the

---

[126] Gemma Blok, *Baas in eigen brein. 'Antipsychiatrie' in Nederland 1965-1985* (Amsterdam 2004) 187.

[127] Blok, *Baas in eigen brein,* 14-16, 157-161, 188.

[128] I am aware that using the term 'schizophrenia' is problematic, but in order to follow the scientific discourse of the time, there is no other option. For a discussion of the validity of the term, see 'Bestaat schizofrenie wel of niet', https://www.psychosenet.nl/psychose/schizofrenie/bestaat-schizofrenie/, accessed 3 December 2023. On the efforts of the Dutch patients' association Anoiksis to have the term replaced by 'perception disorder' in the DSM-5, see Bill George, 'What's in a name? Client participation, diagnosis and the DSM-5', *Journal of Mental Health* 19 (2010) 6, 479-482.

promise of a humane cure. Freud warned his followers that his theories and methods were unsuitable for the treatment of schizophrenia, as he felt that psychosis stood in the way of developing a viable therapeutic relationship. Nevertheless, psychoanalysts like Sullivan, Frieda Fromm-Reichmann and John Rosen took his ideas into the realm of schizophrenia.[129]

Through the 1930s, several studies appeared suggesting that the family relationships were the problem, and more specifically, the personality of the mother and sometimes the father.[130] In 1948, Fromm-Reichmann was the one to coin the term 'schizophrenogenic mother'. "The schizophrenic is painfully distrustful and resentful of other people," she wrote, "due to the severe early warp and rejection he encountered in important people of his infancy and childhood, as a rule, mainly in a schizophrenogenic mother."[131] The basic premise was that the mother of someone with a schizophrenia diagnosis was dominant and rejecting, overprotective and anxious – the paradoxes were a hallmark of psychoanalysis.[132]

In 1949, the Austrian-American psychiatrist Trude Tietze published an article that provides an interesting example of how the reasoning worked out. Based on interviews with twenty-five mothers of men who were diagnosed with schizophrenia, Tietze concluded that these women were all tense, anxious, trying to hide their anxiety, emotionally empty, lacking in warmth. Science journalist Edward Dolnick remarks that this

> *"… does not seem an outlandish attitude for mothers whose children were victims of an overwhelming and mysterious disease. […] Another observer might have seen that maternal shock and despair as predictable. These were, after all, parents whose once-healthy children were in the chronic ward of a mental hospital where they would likely live out their lives, victims of a disease that had descended without warning."*[133]

But Tietze considered the characteristics she had found in the mothers to be the cause of their childrens' illness. They had never been able to bond with their children the way they were supposed to. And the 'subtly dominating mother' in particular was a risk:

---

[129] Harrington, 'Mother Love', 104-105; Carol Eadie Hartwell, 'The Schizophrenogenic Mother Concept in American Psychiatry', *Psychiatry* 59 (1996) 3, 274-297, 289.

[130] Edward Dolnick, *Madness on the Couch: Blaming the Victim in the Heyday of Psychoanalysis* (New York 1998) 94.

[131] Cited in Dolnick, *Madness on the Couch,* 94.

[132] Neill, 'Whatever Became', 503; Harrington, 'Mother Love', 106-107.

[133] Dolnick, *Madness on the Couch,* 96.

"Her methods of control are subtle and therefore do not provoke open rebellion as undisguised domination may. The children exposed to this form of subtle domination under the disguise of maternal love and sacrifice are deprived of any outlet of their aggressive impulses."[134]

The concept of the schizophrenogenic mother quickly gained popularity. It was not that no-one was critical: in 1952, for example, the Hungarian-American paediatrician and psychoanalyst Margaret Mahler explicitly countered it when she wrote: "We see schizophrenic children whose mothers appear not to lack warmth, genuine love, or acceptance of the individual child, nor do they appear to be exceptionally possessive, infantilizing and restrictive."[135] But the promotors of the schizophrenogenic mother theory were so influential at the time that they used Mahler's work to *support* it.[136]

The next step was to consider that schizophrenia might be caused by pathological dynamics in families, particularly in their communication patterns. Inspiration for this train of thought was found in systems theory: the family was perceived as a system, and when this system malfunctioned, all members of it suffered. A crucial concept here was the double bind theory, developed by a multidisciplinary group of scientists at the Palo Alto Mental Research Institute in California in the 1950s. A double bind is a conflicting message, like a mother telling a child: "For once will you offer out of your own initiative to help clear the table?" According to the theory, there are three ways to respond to a double bind: with suspicion, dismissal or withdrawal – corresponding to the three main forms of schizophrenia: paranoia, hebephrenia and catatonia. No longer was the mother the sole culprit, it was the whole family's way of communicating that created severe mental health issues in the child.[137]

In systems theory and double bind theory, the mother was again seen as the dominant factor, and the father as weak and spineless. In addition, brothers, sisters and partners were included in the toxic environment of the 'identified patient': the person in the family who expresses its internal conflicts by developing mental health problems – the canary in the coalmine.[138] Children who grew up in an environment like that, unable to face their world or change it, escaped by changing their perception, the American psychiatrist Theodore Lidz wrote: "[The person suffering from schizophrenia] can abandon causal logic, change the meaning of events, retreat to the period of childhood when reality gave way before the

---

[134] Cited in Dolnick, *Madness on the Couch,* 97.

[135] Cited in Hartwell, 'The Schizophrenogenic Mother Concept', 282.

[136] Hartwell, 'The Schizophrenogenic Mother Concept', 282.

[137] Hartwell, 'The Schizophrenogenic Mother Concept', 283-286; Harrington, 'Mother Love', 107; Blok, *Baas in eigen brein,* 48-50; Dolnick, *Madness on the Couch,* 117-123.

[138] Blok, *Baas in eigen brein,* 48-50.

fantasy of his wish, and regain a type of omnipotence and self-sufficiency. In short, he can become schizophrenic.”[139]

While studies disproving the theories kept appearing, no-one was interested.[140] On the contrary, the schizophrenogenic family evolved further with the growing influence of anti-psychiatry, led by figureheads such as the South-African psychiatrist David Cooper and, in particular, his British colleague R.D. Laing. For Laing, schizophrenia was not an illness, but a strategy for living in an unliveable situation (for the person undergoing it), and a political conspiracy against them (on the part of the mother, the family, the doctors and society). It was not the ‘schizophrenic’ individual who was mad, it was the family they grew up in, and the society for whose purpose his family brainwashed them. Laing called psychosis *metanoia*, a process that a person needed to work through to fix the damage done by their upbringing, a journey that offered the chance of a breakthrough in their life. Although the anti-psychiatrists saw society as the cause of people getting stuck mentally, that criticism still largely boiled down to the micro-society of the family that destroyed its children.[141] That all the patients whose psychosis Laing allowed to ‘bloom’ recovered while in his care, was proof to him that he was right: after all, they left his facility in fine shape, and only relapsed after having returned to their families, which meant that these families had again done their destructive work.[142]

From the mid-1970s onwards, studies debunking the schizophrenogenic mother and the schizophrenogenic family increased in number.[143] A Dutch example of how anti-psychiatry was challenged on this point, was psychiatrist Piet Stolk’s book *Een soort vuur*.[144] Stressing how mothers and fathers suffered from its mother-blaming and family-blaming theories, he pointed out the chicken-and-egg dilemma they contained:

“Zelfs als we zo ver zouden gaan aan te nemen dat er bij schizofrenie altijd gestoorde gezinsrelaties zijn, dan rijst toch de vraag of deze ook altijd de oorzaak zijn van de psychose, dan wel soms ook

(“Even if we were to go so far as to assume that in schizophrenia there are always disturbed family relationships, the question arises whether these are always the cause of the psychosis, or

---

139 Dolnick, *Madness on the Couch,* 124-125.

140 Neill, ‘Whatever Became’, 501; Dolnick, *Madness on the Couch,* 155-157.

141 Blok, *Baas in eigen brein*, 26; Gemma Blok, ‘ “Tall, Spanking People”: The Idealisation of Adolescents in a Dutch Therapeutic Community’, in: Marijke Gijswijt-Hofstra & Hilary Marland, *Cultures of Child Health in Britain and the Netherlands in the Twentieth Century* (Amsterdam 2003) 265-285, 270.

142 Dolnick, *Madness on the Couch,* 132-136; Hartwell, ‘The Schizophrenogenic Mother Concept’, 288; Blok, *Baas in eigen brein,* 10.

143 Neill, ‘Whatever Became’, 501; Hartwell, ‘The Schizophrenogenic Mother Concept’, 289.

144 Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 926.

het gevolg van bepaalde karaktertrekken van het kind die als voorboden van de psychose te beschouwen zijn. [...] *Zijn de eigenschappen, die bij de ouders van schizofrenen worden gevonden, niet gemakkelijk te begrijpen als hun reactie op de stoornis bij het kind?"*[145]

whether they are sometimes also the result of certain character traits of the child that can be regarded as harbingers of the psychosis. [...] Are not the traits found in the parents of schizophrenics easy to understand as their reaction to the disorder in the child?")

But like the critical international literature, Stolk's views did not gain traction.[146] Leading theorists like Lidz responded by claiming that their critics did not have their own decades-long experience with actual patients, by declaring working with statistics suspect, and by suggesting that the genetic theories pursued by biomedically oriented researchers were to be avoided, as Nazi eugenics had taught mankind not so long ago.[147] The work of the American psychotherapist Jay Haley and the Italian psychiatrist Mara Selvini-Palazzoli, to name a few, kept providing mental health care professionals with new insights and new methods based on family-blaming principles.[148]

One of the first Dutch institutions that started to 'involve' relations in treatment based on anti-psychiatry ideas was the Amstelland therapeutic community at the Meerenberg psychiatric hospital in Bloemendaal ('Santpoort'). The official purpose of the family afternoons organised here by professionals from 1973 onwards was to inform parents of patients and to improve their contact with their children. But in practice, the therapists used the opportunity to confront the parents with their children's feelings – and their own, for that matter.[149] 'Mother-of' Sera Anstadt remembered those afternoons well:

"Hoewel, volgens hun opvatting, de maatschappij en de ouders hun kinderen ziek hadden gemaakt, wilden ze nu gesprekken met diezelfde ouders organiseren, samen met de patiënten. Op de afgesproken bijeenkomst kwamen de meeste ouders. Velen van hen zagen er angstig, hulpeloos en verlegen uit. Ze wisten weinig over

("Although, in their view, society and the parents had made their children sick, they now wanted to organise conversations with those same parents, together with the patients. Most of the parents came to the agreed meeting. Many of them looked frightened, helpless and shy. They knew little about

---

145 P.J. Stolk, *Een soort vuur. Verkenningen in de klinische psychiatrie* (Amsterdam 1975) 54.

146 Blok, *Baas in eigen brein,* 178.

147 Dolnick, *Madness on the Couch,* 162.

148 O. Pirson et al., 'Schizofrenie en de familie', supplement to *Neuron* 17 (2012) 6, 4.

149 Blok, ' "Tall, Spanking People" ', 277-280.

de ziekte van hun kinderen, die in [Amstelland] *inmiddels de taal van de hulpverleners hadden overgenomen. Het was ze duidelijk gemaakt hoe ze zich tegenover hun ouders moesten gedragen. Er werd zonder enige terughoudendheid de ene beschuldiging na de andere door de microfoon geuit. Sommige kinderen wilden zelfs helemaal niet aanwezig zijn op deze 'ergerlijke' familiemiddag. De ouders kregen weinig kans iets te zeggen. Er gingen maar weinig kinderen bij hen zitten. Ik had de indruk dat sommigen wel wilden maar zich groot hielden tegenover hun medepatiënten. Ik heb drie van deze zinloze bijeenkomsten meegemaakt. Vaak verlieten de ouders met tranen in hun ogen het groepsgebeuren."*[150]

the illness of their children, who had in the meantime adopted the language of the mental health care workers in [Amstelland]. It had been made clear to them how they should behave towards their parents. Without holding back, one accusation after another was made through the microphone. Some children even didn't want to be present at all on this 'annoying' family afternoon. The parents were given little opportunity to say anything. Few children sat with them. I had the impression that some wanted to, but bore up in front of their fellow patients. I have sat through three of these pointless gatherings. Often the parents left the group event with tears in their eyes.")

The most widely used practical application of blaming theories in the 1970s and 80s, however, was in family therapy. In the early 1980s, psychologist Gerda Methorst interviewed Dutch partners of psychiatric patients about the family therapy sessions they attended. A middle-aged man told her about a conversation he had with his wife's doctor in the presence of both his wife and his daughter, while being watched by the doctor's team through a one-way mirror:

"We werden in een kamer geleid, waar mijn vrouw al naar toe was gebracht, nou een kamer, meer een zaal eigenlijk, met camera's en microfoons en van die politiespiegels maar dan over de hele wand... we waren volstrekt onvoorbereid, mijn eerste reactie was weglopen, maar dat doe je niet, het gaat tenslotte om je vrouw... toen moesten we praten... ik wou wat

("We were led into a room, where my wife had already been taken into, well a room, more of a hall actually, with cameras and microphones and those police mirrors, but then all over the wall... We were completely unprepared, my first reaction was to run away, but you don't, after all, it's about your wife... Then we had to talk... I wanted to ask

---

[150] Sera Anstadt, *Al mijn vrienden zijn gek. De dagen van een schizofrene jongen* ('s-Gravenhage 1983) 56-57.

vragen... over de procedure of hoe het ging maar dat mocht niet, zíj stelden de vragen, wíj moesten antwoorden, het enige wat ik te horen kreeg was dat dit nu eenmaal zo hoorde en dat het de behandeling van mijn vrouw alleen maar ten goede zou komen (...) nee, ook later, iedere poging van mij om informatie te krijgen werd afgesneden... dat maakt bitter, je voelt je met de rug tegen de muur staan..."[151]	something... about the procedure or how it went, but that was not allowed, they asked the questions, we had to answer, the only thing I was told was that this was just the way it was supposed to be and that it would only benefit my wife's treatment (...) no, even later, every attempt I made to get information was cut off... That makes you bitter, you feel like your back is against the wall.")

The course of events was intimidating to relations, perhaps not even so much because the whole family was labelled as sick, as because nothing was explained to them and no guidance was offered for improving the family relationship. As a consequence, the relations in Methorst's research had very negative views on family therapy.[152] Most of them did not know, at least initially, that the professionals' attitude towards the family had to do with their ideas on the origins of mental health issues and who was to blame for them. Once she found out, a 'mother-of' confronted her son's psychiatrist in a letter:

"*... Ik vind deze zienswijze een verziekte vorm van psychiatrie. Ik denk soms, dat u totaal niet beseft wat u mensen aandoet. In de eerste plaats de patiënt, die voortdurend en in een soort stress zijn verleden om en om blijft keren. Maar ook de ouders, van wie niets meer overblijft en die de vreugde en de fijne tijd met hun kinderen, die er ook wel degelijk zijn geweest, zien ondergespit en bedolven met een soort psychiatrische gier, die alles bezwaddert.*"[153]	("I think this view is a screwed-up form of psychiatry. I sometimes think that you don't realise what you are doing to people. In the first place, to the patient, who constantly and under a kind of stress keeps turning his past around and around. But also to the parents, of whom nothing remains and who see the joy and the good times with their children, that have most certainly been there too, dug under and buried with a kind of psychiatric shit, that smears everything.")

---

[151] G.J. Methorst, *Mannen en vrouwen van psychiatrisch patiënten, Een onderzoek naar verschillen in ervaringen, huwelijksbeleving en psychisch welbevinden* (PhD thesis Landbouwhogeschool Wageningen 1985) 193.

[152] Methorst, *Mannen en vrouwen van psychiatrisch patiënten,* 263-266.

[153] Van Vlodrop & Thewissen-van Velzen, *Onze schizofreniepatiënten,* 25.

Hartwell situates the scientific end of theories on the schizophrenogenic family at a 1977 conference declaring the double bind null and void.[154] Interestingly, 1977 was also the year when the therapeutic community Conolly at Brinkgreven hospital in Deventer, which had been a textbook example of a facility driven by anti-psychiatry and mother-blaming principles, changed course to a more conservative way of working, replacing its staff in the process. One of the reasons was that their therapies were rejected as cold and inhuman, especially for the relations.[155] In hindsight, a nurse said:

> *“Partners van patiënten, of moeders, die werden soms echt onaardig behandeld. Daar werd gewoon de schuld gelegd. Ze hadden de opvoeding niet goed gedaan, qua verwachtingspatroon naar het kind toe. Elke zin, elke oogopslag, elk verbaal of non-verbaal contact van ouder naar kind kreeg een betekenis in zo’n setting. En dat kwam op die mensen bedreigend over. Ik vond dât weer onmenselijk.”*[156]

> (“Partners of patients, or mothers, they were sometimes treated really unkindly. The blame was simply placed on them. They hadn’t done a good job of raising their child, in terms of expectations. Every sentence, every glance, every verbal or non-verbal contact from parent to child took on a meaning in such a setting. And that came across as threatening to those people. I thought *that* was inhumane.”)

But as Hartwell also points out, that did not mean that these ideas evaporated immediately, as generations had grown up and made their careers with them.[157] As a consequence, in the Netherlands, like elsewhere, mother and family-blaming would linger at least another ten years. Even in 1987, an article in Ypsilon’s newsletter painted family therapy as a method that was still common in institutions, albeit obsolete and on its way out.[158] In addiction care, however, it was gaining popularity. In July 1987, newspaper *De Stem* wrote about a recent research report from the Criminologisch Instituut (Criminological Institute) in Groningen that had discovered a new type of hard drug user: the ‘decent young man’.[159] He got into trouble because his parents had failed while he was growing up – because his father had lost his job, his parents had divorced, or some other emotional shock had overwhelmed the child and the parents

---

[154] Hartwell, ‘The Schizophrenogenic Mother Concept’, 288.

[155] Blok, *Baas in eigen brein,* 94-99.

[156] Blok, *Baas in eigen brein,* 99.

[157] Hartwell, ‘The Schizophrenogenic Mother Concept’, 288.

[158] ‘Gezinstherapie, helpt het echt?’ *Nieuwsbrief Ypsilon* (1987) 12, 20-23.

[159] It is unclear from the article, but this must be Koert Swierstra, Otto Janssen & Jan Hendrik Jansen, *Heroïnegebruikers in Nederland. Deel II De reproductie van het heroïnegebruik onder nieuwe lichtingen* (Groningen 1986).

had not given him adequate support.[160] LSOVD chairwoman Lenie Booy-van Andel was livid after reading the article and wrote a letter to the editor:

"Al die verhalen van: 'zielige jeugd', 'gebroken gezinnen', 'geen (of te weinig) liefde gekregen' e.d. zijn juist die verhalen, waarmee vele onderzoekers zich laten beduvelen. Uiteraard is een verslaafde er altijd op uit, om een excuus te vinden voor zijn verslaving, en de schuld ligt altijd bij een ander, nooit bij hem! En wie zijn dan het beste als de 'schuldigen' aan te wijzen? Precies, Pa en Ma hebben het altijd verkeerd gedaan. En de onderzoekers sukkelen braaf mee, en als ze de gezinnen, waaruit hun 'onderzoekings-objecten' voortkomen onderzoeken, krijgen ze nog vaak gelijk ook! Ja natuurlijk, want voordat een verslaafde bij een hulpverleningsinstituut als b.v. een CAD aanklopt, heeft zij/hij door het onophoudelijk manipuleren van zijn ouders, het wekken van medelijden, het tegen elkaar uitspelen van zijn ouders, de onophoudelijke leugens, het bedrog, de jammerklachten en de beloften van beterschap (zo van: geloof me nou nog een keer, en dan...) beide ouders zozeer tegen elkaar opgezet, dat het voorheen gemiddeld gelukkige huwelijk, nu, als de onderzoeker arriveert, inderdaad volkomen is stuk gelopen."[161]

("All those stories of: 'miserable childhood', 'broken families', 'not (or too little) loved' etc. are precisely the stories with which many researchers let themselves be fooled. Of course, an addict is always out to find an excuse for his addiction, and the blame always lies with someone else, never with him! And who is best to blame? Exactly, Mum and Dad have always done it wrong. And the researchers obediently come along, and when they investigate the families from which their 'research objects' originate, they often turn out to be right! Yes of course, because before an addict knocks on the door of a care institute such as a CAD, she/he has, through incessantly manipulating his parents, arousing pity, playing off his parents against each other, the incessant lies, the deceit, the lamentations and the promises of improvement (like: believe me just one more time, and then...) pitted both parents against each other so much, that the previously averagely happy marriage, now, when the researcher arrives, has indeed completely broken down.")

What resonates in Booy-van Andel's reply is the protest discourse that the LSOVD would develop in response to the way many of their constituents had been blamed by

---

[160] Jan van de Ven, 'Het nieuwe type heroïnegebruiker is een nette jongen', *De Stem* 21 July 1987.
[161] L.G. Booy-van Andel, 'Geachte redactie', *Info* (1987) 23, 11-13, 12.

professionals for their child's heroin addiction.[162] Initially, addiction care workers only had the methods they used with alcoholics, aimed at abstinence. This model was hard enough for alcohol users, but it proved even more difficult for problematic hard drug users. Drug addiction care professionals were left without effective tools to face the continuing rise in heroin use. What *had* been developed since the Second World War, however, were theories on where addiction originated, and they went along familiar lines: a person's alcoholism was the result of a childhood with a failing mother.[163] This psychoanalytic approach to addiction was developed further when a decade later, increasing numbers of young people became addicted to hard drugs.[164] In 1992, psychiatrist Martien Kooyman summarised the literature of the 1970s and 80s as follows:

"There is an over-protective, indulgent and permissive mother with the addict as her favorite child. Fathers of male addicts are reported to be detached, uninvolved, weak or absent. Father-son relationships are described as being quite negative with harsh and inconsequent discipline. In contrast to males, female addicts seem to be in overt competition with their mothers. They see the mothers as overprotective and authoritarian, while their fathers are reported to be indulgent of them, sexually aggressive and often alcoholic. The probability of incest is much greater than normal with estimates as high as 90% in female heroin addicts."[165]

As a result, addiction care professionals kept the family at bay.[166] To the puzzlement of those in their care who cared about their relationship with their family, like a Surinamese woman who was treated in a therapeutic community:

"De hulpverleners vonden, dat ik me te afhankelijk opstelde tegenover mijn familie. Ik moest voor mezelf opkomen. Het was beter, dat ik met de familie kapte. Ik begreep ze niet. Familiebanden zijn belangrijk bij ons."[167]

("The care workers thought that I was too dependent on my family. I had to stand up for myself. It was better that I cut my ties with the family. I didn't understand them. Family ties are important to us.")

---

[162] Henny Korver, 'Door drugsprobleem geteisterde ouders verenigen zich, hun waarschuwing: "Verslaafd kind moet de deur uit" ', *De Telegraaf* 20 September 1980; Marjo van der Meulen, 'Ouders kunnen drugsverslaafde kind niet helpen', *Het Parool* 14 October 1980; Q.A. Jansen, 'Openingsspeech', *Info* (1984) 9, 3-5, 3.

[163] Blok, *Ziek of zwak*, 129-131.

[164] Martien Kooyman, *The Therapeutic Community for Addicts: Intimacy, Parent Involvement, and Treatment Outcome* (PhD thesis Erasmus University Rotterdam 1992) 78; Blok, *Ziek of zwak*, 171-174.

[165] Kooyman, *The Therapeutic Community*, 78.

[166] Van Amerongen, 'Ouders van drugsverslaafden', 115.

[167] Quoted in Blok, *Ziek of zwak*, 209.

Others responded more pragmatically. If the professionals who decided whether you could get some methadone or not, or whether you could take a break in a clinic for a while from the hard life that came with heroin addiction, wanted to hear about your terrible childhood and nasty parents, that was what you gave them.[168]

In the United States, where the first therapeutic communities developed in the 1960s, initially all contact with relations was denied. Soon, however, professionals realised that upon discharge, people would probably return to their families, and thus it made sense to involve the relations in therapy. In the Netherlands, therapeutic communities specialising in addiction care, like the Emiliehoeve in The Hague, set up family groups in the mid-1970s, involving relations by way of group therapy. As we saw earlier in this chapter, these groups were not necessarily supportive to parents, but they were fertile ground for their mutual support groups.[169]

Developed, as they were, over the course of many decades, mother-blaming and family-blaming took a long time to lose their tight grip on mental health care. In the United States, historian Anne Harrington has argued, parents, especially mothers, of adult children with a schizophrenia diagnosis were responsible for putting an end to them in the late 1970s. She sees deinstitutionalisation as the major trigger for their politicised collective experience identity: the radical closing of psychiatric hospitals, inspired by anti-psychiatry, that took place there in the 1960s and 70s.

These parents had experienced the ways the promised community care fell short in many places, and many former patients were unable to make it on their own. The lucky ones had relations who did their best to care for them and find additional professional help. Having been confronted with mother-blaming and family-blaming for as long as they could remember, at some point, relations found out that there were other ways to look at severe mental health issues – that instead of problems caused by cold or smothering parents, there were also psychiatrists who spoke of illnesses caused by brain malfunctions. That gave them the courage to organise, resulting in hundreds of local and regional 'Parents of Adult Schizophrenics' groups. In 1979, a hundred of those groups together founded the National Alliance for the Mentally Ill (NAMI). NAMI became very influential, collaborating with the government on the changes they envisioned, running a charity to fund biomedical scientific research, and undertaking public-relations activities to spread their view on schizophrenia. As a result, Harrington argues, over the 1980s the paradigm in American psychiatry started shifting decisively towards a renewed dominance of the biomedical explanatory model.[170]

---

[168] Blok, *Ziek of zwak*, 213-214.

[169] Kooyman, *The Therapeutic Community,* 80; Van Amerongen, 'Ouders van drugsverslaafden', 115-124.

[170] Harrington, 'Mother Love', 111-114.

Ypsilon, the largest and strongest family organisation in Dutch mental health care, has historically been regarded in the same light: as a decisive factor in tipping the balance in Dutch psychiatry from the social model to the biomedical model in the 1980s and 90s.[171] And indeed, the parallels are striking: mother-blaming and family-blaming had rendered relations of people with schizophrenia marginalised; and when they got in touch with biomedically oriented psychiatrists, they found the vocabulary and the allies they needed to revolt.

The narrow focus on the activism of the relations of people with schizophrenia, their rejection of mother-blaming and family-blaming, and the simultaneous turn in the dominant explanatory model in mental health care, however, obscures the different trajectory of mother-blaming and family-blaming with regard to other diagnoses (see Chapter 2). Notably, that it was never adopted by early Dutch autism experts and was successfully opposed by them and the NVA in the 1970s.[172] That it continued for anorexia nervosa, where it was not until the late 1980s that the first specialised care facility was set up in the Netherlands where a more family friendly approach was introduced.[173] Or that it would continue to put blame on relations of people with other severe mental health issues. Not only in addiction care – in 'new', upcoming diagnoses like ADHD it would also show its face.[174]

NAMI may in hindsight seem like a formidable force able to bring about a paradigm change by itself, but can we attribute a similar influence to the Dutch family movement and Ypsilon in particular? Certainly not to the whole spectrum of family organisations, for as we have seen and will continue to see, the Dutch family movement came in various colours, and its organisations were very divided on the question of which explanatory model deserved their adherence. As the most vocal organisation of the bunch, and moreover, with a strongly biomedical orientation, Ypsilon was definitely a factor to be reckoned with, but we should not lose sight of the fact that it focused only on schizophrenia, and its influence is hard to tell apart from that of the psychiatrists it worked with.

Concerns over standards of care in a new way

Despite the efforts in psychiatric hospitals to improve patients' circumstances, a technical survey, commissioned by the government, confirmed in 1977 that at least half of the nation's patients in long-term care were still hospitalised in buildings that did not meet

---

[171] Blok, *Baas in eigen brein,* 187-190; Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 928-929.

[172] Edo Nieweg, 'De mythe van de koele moeder herzien. Over vooruitgang en vooroordeel in de psychiatrie', *Maandblad Geestelijke Volksgezondheid* 57 (2002) 9, 845-860.

[173] René Sieders, '20 jaar', *ANtenne* (October 1998) 107, 4-7, 5.

[174] Linda M. Blum, 'Mother-blame in the Prozac Nation: Raising Kids with Invisible Disabilities', *Gender & Society* 21 (2007) 2, 206-226.

modern standards. These buildings were old, dilapidated, without privacy, unfit for working according to modern therapeutic insights; in addition, long-term wards were understaffed, the nurses there overburdened, the turnover in personnel was high, and there was no budget for even the slightest little treat.[175] Seeing a psychiatric hospital from the inside for the first time in the 1980s could still come as a shock to patients and family members alike.

The government had drawn up a national plan for large-scale renovations, demolition of institutions that were beyond repair and the development of brand-new hospital buildings. But the process had come to a halt when in 1982, the Moratorium was declared – the ban on renovations and new developments that Pandora director and Cliëntenbond chairman Hans van der Wilk and his influential professional allies convinced parliament to declare, in anticipation of a radical reform of psychiatry. In the years that followed, policies aiming to reduce the capacity of psychiatric hospitals and promote more small-scale and (family) care in the community were indeed set up, developments that went hand in hand with strategies to shorten and prevent hospitalisation.[176] Combined with a lack of personnel and other resources, however, this could lead to poignant situations. The Health Inspectorate's annual report from 1987 painted an alarming picture of severe neglect of patients in long-term care, in some cases even resulting in injury or death.[177]

For the mainstream of the clients' movement, focusing on improving circumstances in institutions was contrary to their agenda of putting an end to psychiatry altogether. As a consequence, the interests of the patients who were inside suffered. The patient councils in psychiatric hospitals and assisted living facilities, many of which had been set up with the help of the Cliëntenbond over the 1970s, increasingly took up advocacy inside the institutions in the 1980s. Charting their own course, they built collaborative relationships with hospital boards to address issues in patients' daily lives that needed to be fixed in the short term, like the lack of privacy, the poor quality of meals or problematic interpersonal treatment of patients by the staff.[178] Those were issues that had been an important trigger for family members to organise, especially those in Ypsilon.[179]

In addition to continuing worries over the standard of care in institutions, family organisations were dealing with the shortcomings of the outpatient mental health care system. During the late 1970s and early 1980s, this was re-organised from the original patchwork of organisations into one: the RIAGGS (Regionale Instellingen voor Ambulante Geestelijke Gezondheidszorg, Regional Institutions for Ambulatory Mental Health Care). The idea behind the mass merger was that having one point of contact should

---

[175] Oosterhuis & Gijswijt-Hofstra, *Verward van geest*, 818-820.

[176] Schene & Van Wijnbergen, *Familieleden van mensen met een psychotische stoornis,* 83-84; Hunsche, *De strijdbare patiënt,* 108, 115-116.

[177] Ward op den Brouw, ' "In de steden zie je steeds meer psychoten" ', *NRC Handelsblad* 24 June 1988.

[178] Hunsche, *De strijdbare patiënt,* 190-194; Oosterhuis & Gijswijt-Hofstra, *Verward van geest*, 1082.

[179] Van Vlodrop & Thewissen-van Velzen, *Onze schizofreniepatiënten,* 57.

make mental health care more easily accessible. And it did, judging from the rapidly rising numbers of people who turned to RIAGGs for help. But that was more than the new organisation could handle, and soon the clinics were reproached for giving priority to milder cases and leaving people with more severe mental health issues to their own devices. Those active in the family movement experienced the RIAGGs as bureaucratic, impersonal and uncommunicative. They reported that waiting lists were long, that the staff were always changing, and that the professionals were often careless in attending their appointments. And, indeed, that it was especially difficult to find help in cases of the severest mental health problems.[180]

Parents who came together in the LSOVD were facing an addiction care sector that did not meet their hopes and expectations in other ways. Some rehabilitation centres, like the therapeutic communities, were among the most modern, but they were very difficult to get into: a person who wanted to be treated for an addiction had to prove they were very motivated and to come and stay out of their own volition, resulting in many failing to be admitted or running away as soon as their motivation dwindled.[181] But there was also a lack of facilities, and for some groups treatment options simply did not exist.[182] For minor girls with a heroin addiction, for example, there were no rehabilitation facilities at all in the early 1980s, making author Yvonne Keuls turn her novel *Het verrotte leven van Floortje Bloem* (1982) into a pamphlet pleading for a specialised hospital for this group.[183]

In outpatient care, the situation varied. The CADs, the local clinics for alcohol and drugs, had managed to stay out of the merger of ambulatory care organisations into the RIAGGs, arguing successfully that their specific attention to addiction would get lost in such a large organisation.[184] But in the experience of LSOVD parents, that did not necessarily help them and their mutual support groups: some CADs worked well with them, some less so.[185]

Dealing with legal changes

As we have seen, the clients' movement had paved the way for the family organisations by advocating for the interests of those who suffered from mental health issues and becoming a major voice in the public debate on psychiatry. Initially, family members like Corrie van Eijk-Osterholt and the MOB parents who founded the Cliëntenbond had been undisputed allies in the fight for patients' rights. But when, step by step, the strengthening of patients'

---

[180] Oosterhuis & Gijswijt-Hofstra, *Verward van geest*, 1007; Van Vlodrop & Thewissen-van Velzen, *Onze schizofreniepatiënten*, 30-31.

[181] Blok, *Ziek of zwak,* 187-194.

[182] 'Vervolg Verslag van de Eerste Regionale Oudercontactdag van de Landelijke Stichting "Ouders van Drugverslaafden" ', *Info* (1984) 11, 3-10, 3-4.

[183] Yvonne Keuls, *Het verrotte leven van Floortje Bloem* (Baarn 1982) preface.

[184] Oosterhuis & Gijswijt-Hofstra, *Verward van geest*, 1003.

[185] 'Ouderdag in De Bilt', *Info* (1986) 18, 4-5, 4.

(legal) position became a reality, this had consequences for the position of the relations. On the one hand, this was applauded by family activists, especially those in the Cliëntenbond and Labyrint. In the Cliëntenbond, for example, by the end of the 1970s, 'parents-of' were no longer seen as clients and were increasingly pushed out as members.[186] Chairman Arie Groot, one of the original MOB parents, agreed wholeheartedly and personally invited Hans van der Wilk to succeed him in 1979.[187]

But the emancipation of people with severe mental health problems, and especially the legal changes that were happening, came with a flipside. In 1983, articles were added to the Dutch Constitution guaranteeing every citizen's privacy and integrity of the body.[188] As a consequence, mental health professionals – not only those who, inspired by anti-psychiatry, had been reluctant to get relations involved anyway – felt forced to stop informing family members altogether, unless their patient gave them explicit permission.[189] From their loyalty with and focus on the patient, but also out of uncertainty about the exact interpretation of the law, many implemented the rules in the strictest way possible. A common complication that resulted from that attitude was that relations were unprepared for the consequences of major changes in a hospitalised loved one's situation, for example when they were transferred to another ward, or sent on leave or discharged altogether, and then suddenly turned up at home unannounced.[190] In outpatient care the situation was no different: 'mother-of' Sera Anstadt had to watch her psychotic son grow worse and worse while almost all of her attempts to reach out to the professionals were brushed off by them.[191]

In addition, in anticipation of the *Wet BOPZ Wet (Bijzondere Opnemingen in Psychiatrische Ziekenhuizen,* Law on Special Admissions to Psychiatric Hospitals), the standard in Dutch mental health care by the late 1970s became that involuntary commitment was only an option in case of acute danger.[192] From that, it followed that a person in crisis should come and ask for help themselves. This could be very hard on a family when a loved one rejected all help, even though in the eyes of their relations, they were in a dangerously bad state – a difference of opinion that is not unusual when severe mental health problems are in play. For example, even if someone in a psychotic state

---

[186] This would become official in 1982, but it remained a point of discussion in the Cliëntenbond. NL-HaNA-CB, inv. no. 27, minutes of the general assemblies of 12 November and 11 December 1982; interview Titia Feldmann, 20 February 2020.

[187] Hunsche, *De strijdbare patiënt,* 51.

[188] Oosterhuis & Gijswijt-Hofstra, *Verward van geest*, 860.

[189] Personal archive Jan Heijmans, unpublished interview Jan Heijmans with Linda Horn, June 2013; interview Reina van Mourik, 12 May 2021.

[190] Horn, 'Een vergeten groep', 882-887; Van Vlodrop & Thewissen-van Velzen, *Onze schizofreniepatiënten,* 56; interview Annelies Faber, Els Borgesius & Paul Baart, 13 January 2022.

[191] Anstadt, *Al mijn vrienden zijn gek,* 17-22, 46-47, 99.

[192] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 860.

was literally starving, creating risky situations at home or living on the streets, mental health care workers would often refuse to step in. They claimed the law no longer allowed them to, because the behaviour of the person was considered their autonomous choice and no grounds for intervention. Psychiatrists worried that they would be prosecuted if they signed off on committing someone against their will and that this would not stand up in court. As a consequence, they often waited until after some incident had happened before signing the papers.[193] The result was that family members dealing with a person in crisis 24/7 had no other choice but to hold on, at the risk of losing their own sanity, until the situation improved, or escalated to the point that involuntary commitment became an option.[194] Ypsilon in particular rose up against this consequence of the new patients' rights.[195] Along similar lines, the LSOVD demanded legal pathways to involuntary rehabilitation, especially in the case of minors with a drug addiction.[196]

In response to the policy document *Geestelijke Volksgezondheid* (Mental Health) of 1984 (that was soon nicknamed the *Nieuwe Nota,* the New Memorandum), the alarm was raised by other critics too. Following up on the public debate on psychiatry that had resulted in the Moratorium, in this policy document the national government announced a deinstitutionalisation and substitution policy for the Netherlands. Critics pointed out how in other countries such policies had amounted to the closing down of entire psychiatric institutions, without the promised substitute of community care in place, resulting in large numbers of former patients ending up uncared for and often even wandering the streets. The Mental Health Care Inspectorate and other experts issued warnings about the growing numbers of former patients housed in private hostels (exploited for their money rather than being taken care of), and growing numbers of people with mental health issues ending up homeless or in the prison system.[197] Although Dutch deinstitutionalisation would be slower and more modest than abroad – the capacity of Dutch institutions would not be reduced to about a third until early in the twenty-first century[198] – Mental Health Care Inspector Jitze Verhoeff pointed out that in the face of a growing population and increasing numbers of people in need of mental health care, the implications of that reduction would be great.[199]

---

[193] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 857-866; P.J. Stolk, 'Behandeling BOPZ. Zelfverwaarlozing is ook een gevaar', *Nieuwsbrief Ypsilon* (1992) 38, 16-18.

[194] Van Vlodrop & Thewissen-van Velzen, *Onze schizofreniepatiënten*, 75-77.

[195] Van Vlodrop & Thewissen-van Velzen, *Onze schizofreniepatiënten*, 75-77.

[196] Cees Koring, ' "Drugsverslaafde moet onder curatele" ', *De Telegraaf* 8 November 1980; R. van Amerongen, 'Inleiding van drs. R. van Amerongen op de Provinciale Dag op 16 april 1988 te Amersfoort', *Info* (1989) 29, 6-11, 8-9.

[197] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 1194; G. Blok & T.C. Bolt, 'Geschiedenis van de zorg voor mensen met EPA; wederzijdse aanpassing als ideaal', in: Ad Kaasenbrood & Lex Wunderink (eds.), *Ernstige psychiatrische aandoeningen* (Houten 2021) 19-34, 28.

[198] Blok & Bolt, 'Geschiedenis van de zorg voor mensen met EPA', 25.

[199] Ward op den Brouw, ' "In de steden zie je steeds meer psychoten" ', *NRC Handelsblad* 24 June 1988.

In their annual report of 1987, the Mental Health Care Inspectorate indeed reported growing numbers of 'psychotics' in the streets.[200] A year later, psychiatrist Piet Stolk wrote:

> *"Wat voor hen overblijft is een hol in het park, waarin ze vergeefs beschutting zoeken voor hun hallucinaties. Nooit de troetelkinderen van de gemeenschap, worden ze thans uit ideologische en ethische motieven naar de goot verwezen. Voor hen heeft ons land het niveau van een ontwikkelingsland bereikt."*[201]

> ("What is left for them is a hollow in the park, where they seek shelter from their hallucinations in vain. Never the sweethearts of the community, they are now, for ideological and ethical reasons, consigned to the gutter. For them, our country has reached the level of a developing country.")

Perhaps the harshest reality was for those who suffered both from drug addiction *and* severe psychiatric problems – who had 'double trouble', or a 'double diagnosis', as it would later be called. This is not a marginal group: estimates from the beginning of this century indicate that 60-80% of Dutch people who receive addiction care had a psychiatric problem at some point in their lives, while 20-50% of psychiatric patients would also sooner or later deal with an addiction.[202] From the 1970s onwards, the number of patients with multiple, complex problems had increased, with the majority of cases a combination of an addiction and another severe mental health issue.[203] As addiction care had increasingly developed into a separate branch of mental health care, addiction treatment centres only offered their services to those without psychiatric problems, and mental health care institutions only accepted patients without an addiction. For a long time, this catch-22 situation remained unresolved, leaving those who suffered from it and their families in great despair. The first initiatives in which psychiatry and addiction care started to collaborate in order to help this group would not be taken until the 1990s, and the specialised forms of treatment needed in order to help people with a double diagnosis would take until the twenty-first century to develop.[204] In the family movement this situation was reflected as well: it was not until the late 1990s that

---

[200] Ward op den Brouw, ' "In de steden zie je steeds meer psychoten" ', *NRC Handelsblad* 24 June 1988.

[201] Quoted in Van Vlodrop & Thewissen-van Velzen, *Onze schizofreniepatiënten,* 90.

[202] Anneke van Wamel, Christien Muusse & Sonja van Rooijen, *Geïntegreerde behandeling van dubbele diagnose cliënten. Handreiking* (Utrecht 2012) 7.

[203] Blok, *Ziek of Zwak*, 205-206.

[204] Blok & Bolt, 'Geschiedenis van de zorg voor mensen met EPA', 25-26; Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 921.

the mainstream family organisations and the LSOVD would start to collaborate.[205] The stigma associated with addiction, that present-day researchers find to be even stronger than the stigma associated with other mental health problems,[206] may very well have something to do with that.

Conclusion

One by one, in quick succession and largely even simultaneously, a variety of family organisations entered the Dutch mental health care arena in the early 1980s: within five years, first the LSOVD, then In Perspektief, then Ypsilon and then Labyrint were established. What was unprecedented was the way they put the position of relations of people with severe mental health issues on the mental health care agenda. This started with *herkenning* and *erkenning*: recognising your own difficult fate in the experiences of others, discovering that you were not alone, and getting the recognition that you were justifiably claiming the right to be seen, to be heard and to be reckoned with. Such assertiveness in relations of people with severe mental health issues was new.

That assertiveness had grown from the individualism that resulted from the liberation and democratisation ideals of the 1970s. Relations were able to benefit from the space that was created by a clients' movement that recognised what it meant to be a close bystander, and a psychiatric field where the dominant social explanation model was yielding place to a renewed interest in a biomedical model, and concomitantly starting to let go of its mother-blaming and family-blaming theories. Instead of being excluded from having a say in care arrangements that increasingly relied on them, the relations were now able to demand their place at the table.

Brought together or supported by professionals in mental health care, the clients' movement or Christian social work – many of whom had first-hand experience as a relation – the family organisations had the awareness, the expertise and the tools at their disposal that had been developed by previous liberatory movements. There was a lot of work to be done now in order to educate the public and the professionals about the burden of care borne by relations, to address old and new shortcomings of the mental health care system, and to figure out how to respond to legal changes that supported people with severe mental health issues, but could complicate matters for their families.

---

[205] Van Amerongen, 'Ouders van drugsverslaafden', 124; 'Samenvatting van het jaarverslag 1997 van de LSOVD', *Info* (1998) 68, 24-29, 24; Annelies Faber, 'De familievertrouwenspersoon', *Relatief* (2004) 2, 3-6, 6.

[206] Leonieke van Boekel et al., 'Comparing stigmatising attitudes towards people with substance disorders between the general public, GPs, mental health and addiction specialists and clients', *International Journal of Social Psychiatry* 61 (2015) 6, 539-549, 539.

§

By the second half of the 1980s, all family organisations had found their feet and were ready to present themselves in the arena. That did not mean, however, that the players in that arena were ready to welcome them. In a letter to the editor of the leading professional magazine *Maandblad Geestelijke Volksgezondheid* (MGV, Mental Health Monthly), Jan van den Berg, an activist in the clients' movement, gave them a piece of his mind:

> *"Samenvattend kan men stellen dat er een driehoeksverhouding is ontstaan waar twee partijen,* GGZ*ers en ernaaststaanden, elkaar gevonden hebben tegenover de derde. Waar het in dit geval om reeds verloren mensen gaat is het des te gruwelijker vast te moeten stellen dat in zulke situaties die derde partij wiskundig verliest. De twee partijen die elkaar vonden, hebben grote psychologische overeenkomsten: een barre egocentrie die ziende-blind maakt voor de gevolgen van de zelfgenoegzame onverbeterlijkheden, en een weergaloze handigheid in het schoonpraten en verdringen van eigen tekortkomingen. Het behoeft geen betoog dat dit de blik op de realiteit verduistert en leidt tot onbeschrijflijke ellende, zielepijn en beschadiging."*[207]

> ("Summarising, one can say that a triangular relationship has arisen where two parties, mental health professionals and bystanders, have found each other against the third. In this case, where we are talking about people who are lost already, it is all the more horrifying to have to conclude that in such situations the third party loses mathematically. The two parties that found each other have great psychological similarities: a harsh egocentrism that makes them blind to the consequences of their self-congratulatory incorrigibility, and an unparalleled skilfulness in justifying and repressing their own shortcomings. Needless to say, this obscures the view of reality and leads to indescribable misery, anguish and damage.")

During their build-up years, the family organisations would face the challenges they met in the mental health arena, but also in dealing with each other. Through these interactions, the family movement would solidify and step by step conquer its seat at the table.

---

[207] Jan van den Berg, 'Familieleden en de psychiatrie', *Maandblad Geestelijke Volksgezondheid* 42 (1987) 1, 60-63, 62-63.

Chapter 4

The build-up years of the family organisations: The arena in the 1980s and 90s

In 1986, journalist Arend Jan Heerma van Voss noticed a new trend: an awakening concern for the burden of care that relations of people with mental health issues had to bear, and a new tendency among these relations to organise. In his position as editor-in-chief of the leading journal the *Maandblad Geestelijke Volksgezondheid* (MGV, Mental Health Monthly), Heerma van Voss decided to make this development the main theme of the September issue.[1] Two feature articles introduced family organisations: one mentioned Ypsilon, the other Labyrint.

In the first article, psychiatrist Rigo van Meer presented his research on the effects of supportive counselling for families with a member who suffered from schizophrenia, offering scientific evidence for the benefits of working with relations instead of denouncing them. It was quite a bold move in a field that was still largely guided by anti-psychiatry, family-blaming ideology and a new-found, exclusive solidarity with patients. Van Meer reintroduced the term schizophrenia without even putting it in quotation marks, and presented the relations as allies instead of bad influences who should be kept at bay. Ypsilon was only referred to briefly in the text, but the article's prominent placement in the magazine was celebrated in the association as a big success.[2]

In the article that followed, Pandora staff member and Labyrint founder Linda Horn presented her own survey of the burden on families. Based on an analysis of the telephone calls to the Pandora hotline by family members and friends of people with mental health issues, she analysed in detail the problems these relations encountered in dealing with mental health care. Concluding the article with a list of ways mental health care failed the family members, she announced Labyrint's inception in a lengthy footnote.[3] Horn's bold move was demanding attention for the ways the shortcomings in mental health care and policy left relations to suffer. Even more so because, as a Pandora

---

[1] A.J. H. v. V. [A.J. Heerma van Voss], untitled foreword to *Maandblad Geestelijke Volksgezondheid* (1986) 9, 865-866.

[2] Rigo van Meer, 'Steunende gezinsbegeleiding bij schizofrenie', *Maandblad Geestelijke Volksgezondheid* 41 (1986) 9, 867-877; interview Bas van Raaij, 21 June 2018.

[3] Linda Horn, 'Een vergeten groep: familieleden van psychiatrische patienten', *Maandblad Geestelijke Volksgezondheid* 41 (1986) 9, 878-889.

employee, she did so from a position at the heart of the clients' movement, which was growing ever more suspicious of family members.

The MGV family movement theme issue of 1986 introduced the new organisations right in the centre of the mental health care arena – the authoritative journal was widely read in the field, from mental health care professionals to policy makers, and from journalists following the sector to activists in the clients' movement. In this chapter, we will take a final tour around this arena, this time to see how the family organisations of the 1980s were received, how they were shaped by their interactions with the players they encountered, and how in turn, they came to shape those interactions themselves.

One of the organisations' first stops was the media – channels that reached professionals as well as channels targeting the general public – in order to get their message out and to find supporters. Stigma, professional attitudes and a lack of basic understanding of mental health issues among the population complicated this task. The literary reflection in this chapter is illustrative of these challenges. Like the Landelijke Stichting Ouders van Drugsverslaafden (LSOVD, National Foundation Parents of Drug Addicts), the novel *De moeder van David S., geb. 3 juli 1959* (The Mother of David S., Born 3 July 1959, 1980) by Yvonne Keuls put relations on the map as a party in need and a party of interest. The message that the writer wanted to communicate to and about parents who were dealing with the consequences of heroin addiction in their adolescent child was that each was responsible for their own choices in life: the child for their drug use and the consequences thereof, the parents for how they allowed those consequences to affect the rest of the family. It was no coincidence that this message was central in the LSOVD mutual support groups, too. However, for readers and the media, the nuances of this idea would turn out difficult to grasp.

The government, in particular the Ministry of Welfare, Health and Culture, welcomed the family organisations with open arms. In the deinstitutionalisation policy that they were preparing, the importance of family caregivers was evident. The organisations were eager to have a say in the policymaking process, as they foresaw serious consequences for clients and relations if wards for chronic patients closed while the development of the promised community care lagged behind, as had happened in other deinstitutionalising Western countries. Relations worried that mental health care organisations would fail to provide adequate care and thus that the burden on the family would increase to unacceptable levels. Gaining access to the highest ranks of policymaking was one of the family organisations' first accomplishments.

Mental health care professionals were tougher nuts to crack. It would take great perseverance to change their view on the family. But the more the organisations were able to educate family members and help them develop their assertiveness, the more their efforts were supported from below: by relations who would no longer put up with being ostracised and demanded a say in the mental health care of their loved one.

The family organisations had to carve out their place alongside one another and alongside the clients' movement, which already had a place in the arena. Mutual frictions would make the organisations collide, but also sharpen their arguments and strengthen their identities. Nudged by a government that wanted to see them grow into the role of the 'third party' negotiating with care providers and insurers in the mental health care system of the future, towards the turn of the century, they would start to develop into a more collaborative, combined clients' and family movement where organisations could work together while respecting their differences.

The media and the public

The potential of the family organisations was huge and they all knew it. Based on scientific literature, the Ministry of Welfare, Health and Culture estimated in 1984 that a quarter of the population had some form of mental health trouble, 14% was diagnosed by a family doctor as mentally ill, and 1.7% ended up in mental health care.[4] In a population of about 14.5 million,[5] that added up to at least about two hundred fifty thousand people who were diagnosed with a serious mental illness, and several times as many relations who might be interested in joining a family organisation. Even for a diagnosis-oriented initiative like Ypsilon or the LSOVD, the statistics were promising. The estimated number of people with a heroin addiction, for example, reached thirty thousand in 1983, indicating that an organisation focused on parents alone had a potential membership of tens of thousands.[6] For the young organisations, that was an exciting, but also daunting, prospect.

Facing the potential

The first priority of the family organisations was of course to get their message out to relations who could benefit from the mutual support that they wanted to offer, and whom they needed to grow their organisations. The LSOVD was able to take off quickly by inviting existing Anonieme Families (Anonymous Families) groups to join it. From the start, however, they found that it was hard to build up the organisation's strength because of the burdensome and volatile home situation of most (potential) members.[7] For

---

[4] *Geestelijke volksgezondheid. Nota* (Tweede Kamer, vergaderjaar 1983-1984, 18463, nrs. 1-2) 15.

[5] 'Bevolkingsteller', https://www.cbs.nl/nl-nl/visualisaties/dashboard-bevolking/bevolkingsteller accessed 23 February 2024.

[6] Gemma Blok, *Ziek of zwak. Geschiedenis van de verslavingszorg in Nederland* (Amsterdam 2011) 181.

[7] Q.A. Jansen, 'De driehoek verslaafde-ouder-hulpverlener', *FZA Kwartaalberichten* 6 (1981) 4, 8-10, 9; Bob van Amerongen, 'Ouders van drugsverslaafden: van schuld naar verantwoordelijkheid. Een terugblik op tien jaar', *Maandblad Geestelijke Volksgezondheid* (1989) 2, 115-124.

the other organisations too, imagining how many relations could come knocking on their doors could be quite intimidating, given their modest manpower and the vulnerability of their volunteers.[8]

For In Perspektief and Labyrint, this was even a reason to limit their publicity campaigns, despite the networks and media connections they had at their disposal through their foremothers, the Algemeen Diakonaal Bureau van de Gereformeerde Kerken (ADB, General Diaconal Bureau of the Reformed Churches) and Pandora. They made the conscious choice to start small and close to home – in the province of Utrecht and the city of Amsterdam, respectively – with the intention of growing slowly from there, taking care to set up new groups in other areas only if there was enough to build on there and the national organisation was able to support them.[9]

Ypsilon's strategy was the complete opposite. In the build-up towards its first national meeting in 1986, founder Ria van der Heijden featured prominently in the press with her personal story and her sharp analysis of what was wrong in Dutch mental health care.[10] The number of people who registered for the meeting was so high that the committee had to organise a second one a few months later to accommodate everyone. Ria's son and co-founder Bas van Raaij remembers how, at the first conference, they put participants together based on their post codes, and at the end of the day concluded that almost the entire map of the Netherlands was now covered with Ypsilon mutual support groups.[11] In the aftermath, the Eindhoven contact person was so successful in generating media attention for his first local Ypsilon meeting, that one hundred sixty people turned up. Many of them went home feeling disappointed after having been told that there was nothing much yet that he could offer them.[12] To the Ypsilon founders, action was key, even if that meant taking the risk that things would not always be perfect.[13]

Dealing with ignorance and stigma

In their contacts with the general public, the new organisations soon confirmed their assessment that, despite the taboo-breaking work of the clients' movement in the

---

[8] M. Colijn, 'Landelijke Dag op 6 april. De OVD in al zijn facetten', *Info* (1991) 6, 16-19, 18-19; interview Margriet Mannak, 21 September 2021; interview Linda Horn & Lineke Marseille, 28 May 2021.

[9] Het Utrechts Archief, Utrecht, Archive Deputaten Gemeenteopbouw van de Gereformeerde Kerken in Nederland (aanvulling) (1859) 1962-1999, access no. 1492, 'Familie en vrienden van psychisch zieke mensen' [hereafter UA-GKN-F], inv. no. 1492-1487, Linda Horn, 'Notulen van 14-9-1983 Praatgroepen Familieleden'; personal archive Linda Horn [hereafter Archive Horn], *Jaarverslag 1989* (Utrecht 1990) 18 and *Jaarverslag 1990* (Utrecht 1991) 10-15.

[10] UA-GKN-F, inv. no. 1492-1488, Ria van der Heijden, 'Impressie', untitled Ypsilon newsletter [Summer 1987].

[11] Interview Bas van Raaij, 21 June 2018.

[12] UA-GKN-F, inv. no. 1492-1488, Marleen Hoornstra-Laufer, 'Verslag bijeenkomst contact- en gespreksgroepleiders'.

[13] UA-GKN-F, inv. no. 1492-1488, 'Redactioneel', untitled Ypsilon newsletter [April 1986].

previous decade, few people in the 1980s were well informed about mental health issues. Early interviews with Ypsilon spokespersons in the newspapers show how they had to explain over and over again that schizophrenia had nothing to do with a split mind.[14] In Perspektief volunteers who gave lectures to church communities found that many people confused mental illness with mental handicap, and used stigmatising terms like 'crazy' or 'psychopath' for anyone who displayed unusual behaviour.[15] Volunteer and 'wife-of' Margriet Mannak remembers:

> *"Het was heel vaak dat mensen bij psychiatrisch zieken denken aan zwakbegaafd. Dat werd heel vaak door elkaar gehaald.* [...] *Mongolen, zoals ze dat dan zeiden. Of dat iemand die psychiatrisch ziek is meteen helemaal niks meer wist. Dat soort misverstanden moest je dan ophelderen.* [...] *Dus dat de mensen er gewoon uitzien.* [...] *En dat ze gewoon kunnen praten, en gewoon meestal heel intelligent zijn."*[16]

> ("It was very common for people to think of psychiatrically ill people as simple-minded. The two were confused very often. [...] Mongols, as they used to say. Or that someone who is mentally ill suddenly didn't know anything anymore. That was the sort of misunderstanding you had to clear up. [...] That these people look normal. [...] And that they can talk normally, and are usually very intelligent.")

Mannak was also confronted with stigma by association: when she told her personal story as a 'wife-of', some listeners drew conclusions about her mental state, too: "*Ik heb zelfs wel een keer zoiets gevoeld van: nou ja, er zal met haar ook wel wat aan de hand zijn*" ("Sometimes I even felt something like: well, there must be something wrong with her too").[17]

The consequences of ignorance and stigma could be far-reaching. Social worker and In Perspektief volunteer Reina van Mourik noticed for example that in some orthodox communities, people who had recovered and had been discharged from a psychiatric hospital were never received back by their families. Those were the communities she would reach out to actively through their church elders. A conversation with a preacher she approached in the orthodox community of Urk taught her a lot about how little outsiders knew about mental health issues and how they feared them:

---

[14] E.g. 'Schizofrenie geen zeldzame "gekte" ', *Het Vrije Volk* 15 May 1986; Bram Pols, 'Lijdensweg schizofreen geldt evenzeer voor de naaste familie', *Trouw* 9 June 1986; Romain van Damme, 'Het is een soort afscheidsproces', *De Stem* 18 December 1987.

[15] UA-GKN-F, inv. no. 1492-1484,*'n Bijzondere Krant* 1984 ([3]), [3], 'Te gek om los te lopen'.

[16] Interview Margriet Mannak, 21 September 2021.

[17] Interview Margriet Mannak, 21 September 2021.

> *"… hij had zoiets van: afschermen hè, de lieve Heer zal het allemaal wel genezen. Ik zeg: ja, dat is misschien wel zo, maar Hij heeft ons nog wel nodig om die pillen uit te reiken* […]. *En dan zie je dat mensen ook opgelucht zijn. Dat was toen natuurlijk, en nu nog, zoveel onkunde en angst."*[18]

> ("… he was like: better block that, the dear Lord will make it all heal. I say: yes, that may be true, but He still needs us to hand out those pills […]. And then you also see a sense of relief in people. So much ignorance and fear, then as well as now.")

Words that matter

Part of the family organisations' educational efforts was not only teaching people about mental health issues, but also how to speak appropriately about such matters. As direct offspring of the clients' movement of the 1970s, Labyrint rejected terms like 'mental illness', 'patient' and 'schizophrenia', and instead spoke of 'people with serious mental health problems'.[19] The byline they chose, *organisatie voor familieleden en vrienden van 'psychiatrische patiënten'* (organisation for family members and friends of 'psychiatric patients'), reveals how challenging this was to combine with sending a clear message to the public.[20] When others used illness terms in the media, Labyrint and Pandora often seized that as an opportunity to educate. In response to how Ypsilon's Ria van der Heijden was quoted in a *Volkskrant* article in 1986, for example, Lineke Marseille wrote a letter to the editor on behalf of Pandora, the Cliëntenbond and the Landelijke Patiëntenraden (LPR, National Patient Councils) expressing how offensive these statements were to them:

> *"Verder zijn wij van mening dat het zinloos is om de problemen van mensen die 'schizofreen' worden genoemd als een ziekte te betitelen want dat levert niets meer op dan een woord voor iets onbenoembaars. Bovendien is het zinloos omdat je psychische moeilijkheden (die volstrekt persoonlijk zijn, en ontstaan door*

> ("Furthermore, we believe that it is pointless to label the problems of people who are called 'schizophrenic' as a disease, because that results in nothing more than a word for something indescribable. Moreover, it is pointless because you cannot adequately treat psychological difficulties (which are

---

[18] Interview Reina van Mourik, 12 May 2021.

[19] UA-GKN-F, inv. no. 1492-1487, letter from Egbert van der Poel to the board of the Algemeen Diakonaal Bureau, 31 October 1984.

[20] Museum of the Mind, Haarlem, Pandora Library, inv. no. 1036, Linda Horn, 'Van lotgenoot tot bondgenoot. Over de positie en de zorgen van direct betrokkenen van z.g. psychiatrische patiënten' (June 1985) appendices, *Eigendruk* ([1984]) [1], [1].

> *niet meer te achterhalen ontwikkelingen en gebeurtenissen) niet op een medische manier adekwaat kunt behandelen: het is pijn aan je ziel, niet aan je lijf.*"[21]

> completely personal, and arise from developments and events that can no longer be traced) in a medical way: it is pain in your soul, not in your body.")

The founders of Ypsilon did not use their illness terminology unwittingly – they were perfectly aware of the taboo on using biomedical terms that had become the norm since the 1970s. In fact, initially, they had called their organisation Vereniging Ouders van Chronisch Psychotici (VOCP, Association Parents of the Chronically Psychotic) to avoid the term schizophrenia. When Ria van der Heijden met psychiatrist Rigo van Meer, she advised him to change the title of the information brochure he had just published – that was bluntly entitled *Schizofrenie* (Schizophrenia) – as other psychiatrists had explained to her that the label damaged people and scared away parents. But in Van Meer's opinion, it helped both patients and parents to understand what was happening to them. Ypsilon quickly adopted Van Meer's position. Together they were very influential in reintroducing the word schizophrenia in the Netherlands over the 1980s and 90s.[22]

There was more about Ypsilon's vocabulary that defined its identity, though. Ypsilon representatives spoke of 'our patients', 'our people' or 'our children', even when referring to adults with a schizophrenia diagnosis. They spoke of how only schizophrenia constituted 'real psychiatry', and how their constituents were the only ones dealing with serious mental illness in the family. As a consequence, they tended to dismiss the experiences of relations belonging to Labyrint and In Perspektief, where everybody was welcome regardless of diagnosis or label, but where most members also had loved ones suffering from the severest of mental health problems.[23] That was frustrating, Reina van Mourik of In Perspektief remembers:

> *"Ypsilon* [...] *was eigenlijk alleen voor familieleden van psychiatrisch patiënten met schizofrenie. En schizofrenie, het leek haast alsof dat de enige psychiatrische ziekte was. Af en toe kwam er een manisch-*

> ("Ypsilon [...] was really only for family members of psychiatric patients with schizophrenia. And schizophrenia almost seemed to be the only psychiatric illness. Every now and then a manic-

---

[21] Lineke Marseille, untitled letter to the editor of *de Volkskrant* on behalf of Pandora, 17 July 1986, printed in Pandora's *Knipselkrant: informatie over psychiatrie* (1986).

[22] Rigo van Meer, 'Woorden vóór daden', *Ypsilon Nieuws Introductienummer* (October 1993) 39; Nico de Boer, ' "Riaggs moeten stoppen met ouwehoerdingetjes" ', *De Gazet* 22 (1995) 6, 6-8, 6.

[23] Interview Bas van Raaij, 21 June 2018; interview Annelies Faber, Els Borgesius & Paul Baart, 13 January 2022.

depressief iemand tussendoor, maar dan vroegen ze zich eigenlijk af of dat wel ziek was. Zo van: het ene moment konden ze wel gewoon doen, het andere moment deden ze gek. Nou, dat was heel erg lastig. [...] *En wij hebben* [bij In Perspektief] *vanaf het begin gezegd, ook vanuit de familieleden die we aan tafel hadden, waarvan de meesten ook inderdaad familieleden waren van mensen met schizofrenie,* [...] *wij hebben gelijk gezegd: wij gaan voor iedereen."*[24]

depressive person would come in, but then they would wonder if that person was really ill. Like: one moment they could behave normally, the next moment they were acting crazy. Well, that was very, very difficult. [...] And we [at In Perspektief] have said from the beginning, also coming from the family members we had at the table, most of whom were indeed family members of people with schizophrenia, [...] we said from the start: we will be there for everyone.")

Behind the contrasting vocabularies was a fundamentally different outlook that, despite the organisations' common cause of advocating in the interests of relations, resulted in each of them taking a very different perspective and very different strategy. For Labyrint, shaped by the critical reading, thinking and debating that was customary in the countermovement, advocacy in the interests of family would always be respectful of the autonomy of clients:

"Dat betekent dat veranderingen in de psychiatrische hulpverlening, gericht op reductie van bedden in de massale inrichtingen, ten gunste van alternatieven, in beginsel worden verwelkomd. Inrichtingen hebben ruimschoots de tijd gehad om hun nut te bewijzen en erg overtuigend is dat doorgaans bepaald niet gelukt. Waarom dan zo wars zijn van alternatieven die voor cliënt én familie wellicht beter uitpakken? Meer oog hebben voor cliëntbelangen betekent verder dat men uitermate zorgvuldig is met het gebruik van controversiële en minder controversiële ziektebeelden, omdat dat de beeldvorming en de stigmatisering minder

("This means that changes in psychiatric care, aimed at reducing beds in mass hospitals, in favour of alternatives, are welcomed in principle. Institutions have had plenty of time to prove their usefulness, and they have generally not managed to do so in a very convincing way. So why be so averse to alternatives that might work out better for both client and family? Paying more attention to the interests of clients also means that one is extremely careful with the use of controversial and less controversial diagnoses, because this has a less negative impact on the representation

---

[24] Interview Reina van Mourik, 12 May 2021.

negatief beïnvloedt. Men kan zeker niet zonder meer achter het zogenaamde 'bestwil-principe' staan, waardoor bijvoorbeeld de familie kan bepalen of iemand opgenomen moet worden omdat dat beter voor hem of haar zou zijn en waarvoor Ypsilon juist pleit."[25]	and stigmatisation. We certainly cannot simply support the so-called 'for-your-own-good principle', which allows the family to decide, for example, whether someone should be committed because it would be better for him or her and for which Ypsilon is advocating.")

Ypsilon, however, put the safety of patients first, rather than their autonomy. The parents united in this association had adolescent or adult children whose chronic psychoses got in the way of their ability to take care of themselves or make rational decisions about their needs – or at least that was how the Ypsilon members experienced it. They reasoned from the perspective of advocacy in the interest of patients who, in their eyes, were not able to manage their own lives:

"Een ernstig gestoorde en psychotische patiënt is [...] *niet in staat om te beslissen wat in zijn eigen belang is. En daarmee rijzen er verschillende vragen, zoals: wat is in het belang van de patiënt? Wie beslist in zijn plaats? Volgens de aanhangers van de tegenbeweging is het belang van de patiënt meestal nog steeds: geen gedwongen medicatie en terug naar de vrijheid. Maar veel psychiaters en ook de familie van schizofrene patiënten denken daar anders over: je bent niet vrij, als je gevangen zit in je psychotische angsten; je bent niet vrij als de samenleving je overal wegjaagt, omdat je ziek en vies bent of* [men] *bang van je is, omdat je misschien gevaarlijk bent, je uitbuit, omdat je gek bent."*[26]	("A severely disturbed and psychotic patient is unable to decide what is in his own best interest. And with that, several questions arise, such as: what is in the interest of the patient? Who decides on his behalf? According to the supporters of the countermovement, the interest of the patient is usually still: no forced medication and back to freedom. But many psychiatrists and the families of schizophrenic patients have a different view on that matter: you are not free if you are trapped in your psychotic fears; you are not free if society chases you away everywhere because you are ill and dirty or [people are] afraid of you, because you may be dangerous; [people may] exploit you, because you are crazy.")

---

[25] Linda Horn, 'Tussen twee grenzen van het eigenbelang', *Welzijnsmaandblad* 40 (1986) 9, 11-16, 15.

[26] Jan van Vlodrop & Mary Thewissen-van Velzen, *Onze schizofreniepatiënten, wat er met hen gebeurt. Noodkreet zwartboek eisenpakket* ([Rotterdam] [1989]) 34.

These contrasts resulted in a choice for relations of people with schizophrenia: both Ypsilon and Labyrint were an option for them. Some people joined both organisations, as they felt they were both valuable in their own right, while others tried them both and then chose which one they felt most comfortable in.[27] As Annelies Faber, a Labyrint 'mother-of' and 'sister-of', explained:

> *"Qua doelgroep hoorde ik eigenlijk bij Ypsilon* [...]. *Mijn broer was schizofreen, autistisch, en mijn zoon is dat ook. Maar waar ik enorm de pest altijd over had, was dat ze het* [bij Ypsilon] *hadden over 'onze mensen', en 'onze mensen' betekende eigenlijk dat die mensen zelf niet konden nadenken. Want de ouders en de naasten wisten altijd beter wat er met die patiënt aan de hand was dan de patiënt zelf, die ook niks gevraagd werd.* [...] *Ik dacht, het is allemaal goed en wel, maar laten we vaststellen dat af en toe ook familie deel van het probleem is en van lieverlee moeten ze ook deel van de oplossing worden.* [...] *Dus wij waren veel meer eager op de rechten van patiënten waar het ging om hun eigen lotsbestemming.* [...] *Wij waren ook voor 'onze mensen', maar er zat een hele gevoelswaarde bij waardoor duidelijk werd dat wij uit die traditie van Pandora kwamen en van cliëntenrechten en van Corrie van Eijk-Osterholt met haar* [boek] Laten ze het maar voelen..."[28]

> ("In terms of target group, I actually belonged to Ypsilon [...]. My brother was schizophrenic, autistic, and so is my son. But what I always hated was that [Ypsilon members] were talking about 'our people', and 'our people' actually meant that those people couldn't think for themselves. Because the parents and the relations always knew better what was the matter with that patient than the patient himself, who was not asked anything either. [...] I thought that was all well and good, but let us note that sometimes family is part of the problem and, bit by bit, they must also become part of the solution. [...] So we were much more focused on patients' rights when their own destiny was at stake. [...] We were also for 'our people', but there was a strong emotional value that made it clear that we originated from that tradition of Pandora and of clients' rights and of Corrie van Eijk-Osterholt with her [book] *Laten ze het maar voelen...*"

The LSOVD, meanwhile, was dealing with a terminology and ideology struggle of its own. Arguing that people with a drug addiction should be considered patients suffering

---

[27] Interview Annelies Faber, Els Borgesius & Paul Baart, 13 January 2022.

[28] Interview Annelies Faber, Els Borgesius & Paul Baart, 13 January 2022.

from the illness that was addiction,[29] they tried to educate the general public on the way addiction care professionals and authorities looked at drug users. To the LSOVD parents, this view was an important tool to use against the popular idea that addiction was a bad habit resulting from poor personal choices or a poor upbringing – an attitude that was stigmatising for both users and their relations. In the second half of the 1980s, when the number of people who were addicted to heroin was peaking, any romantic notions that had been associated with drug use in progressive circles in the previous decade was gone. Instead, heroin became widely associated with degradation, prostitution, public nuisance, crime and AIDS, resulting in a further decline in empathy and tolerance for drug users and their families.[30]

The increasing public order problems associated with drug use generated a lot of public interest in everything related to it. In theory, that created opportunities for the LSOVD to present its destigmatising point of view. But it was not that simple. The foundation found that it was hard to find parents who were willing and able to talk openly about their situation. Many found it difficult to handle their emotions faced with an interviewer, and it could be that their child forbade them to talk to the press, but the main issue was mustering the courage to come out with their stories in public at all.[31] The few who did, often did so anonymously or under a pseudonym, and even that was risky, because people who knew them could identify them from their story anyway.[32] One family whose story was featured in a newspaper even had to move away because of the backlash they suffered in their neighbourhood.[33] That made the need for destigmatisation of people with a drug addiction and their families crystal clear, but at the same time many felt the stigma was too strong to challenge personally.

In addition, the media were not necessarily interested in the message that the LSOVD wanted to spread: that people with a heroin addiction should be treated as patients, that their parents were not to blame for their child's addiction nor able to do something about it, and that the best thing parents could do was to come to terms with how everybody was responsible for their own life choices – their child as well as they themselves.[34] Often, the LSOVD found,

---

[29] E.g. Q.A. Jansen, 'De driehoek verslaafde-ouder-hulpverlener', *FZA Kwartaalberichten* 6 (1981) 4, 8-10; 'Ouders voelen zich vaak het kind van de rekening', *Leeuwarder Courant* 25 September 1981.

[30] Blok, *Ziek of zwak,* 216, 219; Marcel de Kort, *Tussen patiënt en delinquent. Geschiedenis van het Nederlandse drugsbeleid* (Hilversum 1995) 234-238; Arjan Nuijten, *Regulating Paradise: The Local Origins of Harm Reduction in the Netherlands* (PhD thesis University of Amsterdam 2024) 6, Chapter 3.

[31] Henny Korver, 'Door drugsprobleem geteisterde ouders verenigen zich, hun waarschuwing: "Verslaafd kind moet de deur uit" ', *De Telegraaf* 20 September 1980.

[32] Jan Woelre, *Mijn zoon is verslaafd. Een lijdensweg door de hulpverlening* ('s-Gravenhage 1985); Margo Colijn, *De droom van Mary. Ouders over hun drugverslaafde kind* (Zutphen 1996). In contrast, Maria Meynen, author of *Cirkel van verslaving. Brieven aan mijn zoon die stierf aan een overdosis* (Amsterdam 1985) published her books under a pseudonym, but she and her family appeared openly in the national press, e.g. Wim Koesen, 'De martelgang van het gezin Schram', *De Telegraaf* 12 November 1979.

[33] 'Vrije heroine: zwaard van Damocles voor ons', *Het Parool* 30 January 1984.

[34] Marjo van der Meulen, 'Ouders kunnen drugsverslaafde kind niet helpen', *Het Parool* 14 October 1980; Charles Langeveld, 'We zijn moe, maar wel strijdlustig', *FZA Kwartaalberichten* 6 (1981) 4, 11-12.

journalists were looking for sensation, for stories that sold well, but that presented drug users and the families they came from in ways that only stigmatised them further.[35] This was something other family organisations could relate to. Ypsilon's Bas van Raaij called it outrageous what the press would ask sometimes:

> *"Het liefst willen ze iemand die op dat moment op het dak staat met zijn psychiater. 'Kunnen we morgen iemand filmen die psychotisch is?', vragen ze dan. Ze realiseren zich niet hoe kwetsbaar deze mensen zijn en ze hebben vaak geen enkel inzicht in de ziekte, het gaat hen om de 'shot'."*[36]

> ("Ideally, they want someone who, at that moment, is standing on the roof with his psychiatrist. 'Can we film someone who is psychotic tomorrow?', they ask. They don't realise how vulnerable these people are and they often don't have a clue about the illness, it's all about the 'shot'.")

The LSOVD's first chairman Rinus Jansen often solved the problem by talking to journalists himself, and his brother-in-arms Douwe Bartstra had even published his personal story in newspaper *Het Parool* – although neither of them appeared in the press under their (real) name. After the two left the LSOVD in the mid-1980s, however, the foundation struggled to stay afloat and its media presence suffered. When Bep Griffioen took the lead in 1989, she first concentrated on rebuilding its relationship with addiction care and the government.[37] In 1991, the LSOVD decided to face its problem with the media head on. The organisation set up a committee to that end and engaged 'father-of' Alphons Katan, an experienced public policy professional, as an advisor. Becoming its chairman in 1993, he was able to secure project funding for PR training for the LSOVD's staff member and volunteers.[38]

With new skills and increased confidence, in 1996, the LSOVD widened its target group by changing the name of the foundation from Ouders van Drugsverslaafden

---

[35] 'Verslag van de Provinciale Dag Zeeland van de Landelijke Stichting "Ouders van Drugverslaafden", gehouden op 1 juni 1985 te Goes, Hotel Terminus', *Info* (1985) 14, 5-6; interview Alphons Katan, 4 December 2018.

[36] Adrianne Dercksen & Sonja van 't Hof, *Erkenning gevraagd. Organisaties van patiënten, cliënten en hun familie in de geestelijke volksgezondheid* (Utrecht 1996) 60; Petra Hunsche, *De strijdbare patiënt. Van gekkenbeweging tot cliëntenbewustzijn. Portretten 1970-2000* (Amsterdam 2008) 235-236.

[37] Q.A. Jansen, 'Openingswoord', in: *Verslag tweede themadag LSOVD 8 oktober 1983* (Bilthoven 1983) 2-4, 2; Van Amerongen, 'Ouders van drugsverslaafden', 117-118; personal archive Ria van den Abeele [hereafter Archive Van den Abeele], Rogier de Jong, 'De moeder van de LSOVD', unpublished interview with Bep Griffioen.

[38] Alphons Katan, 'De LSOVD in beweging', *Info* (1994) 50 6-7, 6; Archive Van den Abeele, Rogier de Jong, 'Mensen, wij moeten onszelf rechtop houden', unpublished interview with Alphons Katan.

(Parents of Drug Addicts) to Ouders van Druggebruikers (Parents of Drug Users), to make clear that every parent with worries about their child's drug use was welcome to join them.[39] However, the media remained non-receptive to their point of view. In response, the foundation turned more inwards again, focusing on mutual support and building up great expertise in that area.[40]

A literary reflection: De moeder van David S. (1980)

The LSOVD was not alone in its difficulties communicating a nuanced message about the relations of people with a drug addiction. Even the famous writer Yvonne Keuls experienced her limited ability to shape interpretations of her novel *De moeder van David S., geb. 3 juli 1959* (The Mother of David S., Born 3 July 1959) and the media and the public's preference for sensationalism when it came to discussing drugs, drug users and their families.[41] Published in 1980, when the heroin problem was increasingly frightening that public, the book became a bestseller almost overnight.[42]

Part of the reason for its success was that the story was true to life: it was based on the stories of actual parents of children with a heroin addiction. Between 1975 and 1978, Keuls had interviewed one hundred forty parents of addicted children as research for her book. Some of these parents were involved in early local mutual support groups. In fact, Keuls, together with two medical directors of psychiatric hospitals in the The Hague region, had supported the parents in setting up the LSOVD. Together, they presented themselves to State Secretary Els Veder-Smit of Health and Environmental Hygiene on 28 March 1980: the parents with a manifesto announcing their organisation and its demands, Keuls with the first copy of *De moeder van David S.*[43] Soon after, however, the ties between the writer and the parents withered. The parents were so emotionally burdened by their home situations that Keuls found it impossible to collaborate with them on improvements to addiction care and drug policies. She continued her mission on her own, touring the country with her book.[44]

Yvonne Keuls had become a household name with her best-selling novel *Jan Rap en z'n maat* (Anybody and His Brother, 1977).[45] The fictional story was 'based on truth', she claimed: she had derived the characters and storylines from her experiences with the young people that sought refuge in a shelter she had run in The Hague for a while.

---

[39] 'Van het bestuur', *Info* (1996) 59, 3-4.

[40] Interview Alphons Katan, 4 December 2018.

[41] Yvonne Keuls, *De moeder van David S., geb. 3 juli 1959* (Baarn 1980).

[42] Erica van Boven, *Bestsellers in Nederland 1900-2015* (Antwerpen, Apeldoorn 2015) 145-146.

[43] 'Ouders komen in actie tegen "falend drugbeleid" overheid', *Nederlands Dagblad* 29 March 1980.

[44] Personal telephone conversation with Yvonne Keuls, 1 November 2019.

[45] Yvonne Keuls, *Jan Rap en z'n maat* (Baarn 1977).

Painting the troubled lives of these abused and neglected teenagers in a novel was her way of exposing the neglect and injustices they suffered.[46]

After writing *Jan Rap en z'n maat,* in which drug problems played only a small part, Keuls was looking for a way to do something for the victims of drug addiction. Originally, like many Dutch people, she too had felt that the parents were to blame for a child's heroin addiction. But an activist nun who organised support for young people with a heroin problem made the writer aware of what the parents endured, and made her realise that they were victims too. From her amalgamation of their real-life experiences, Keuls created the story. Most of the characters were fictional – only Len, 'the mother of David S.', was largely modelled on a woman whose actual name was Len,[47] and who was one of the founding 'parents-of' of the LSOVD.[48] By making the character Len a married, stay-at-home mother of four children in a well-to-do family, Keuls intended to counter popular assumptions about the cause of drug addiction: that it was the result of broken homes, working mothers or a lower-class background.[49]

Through the eyes of Len, the reader follows David's path as he starts experimenting with drugs at the age of fifteen, and within a few months develops a strong heroin addiction. His parents, completely ignorant on the subject of drugs, do not recognise his addiction in the beginning, but soon enough the family is confronted with the consequences. Len sees David withdrawing, while continuing to lean on them when he is in a bad state, manipulating them and stealing from her and her husband Simon, their other children and Len's mother to support his habit. Criminals come to the house seeking payment for David's debts, while the neighbourhood accuses the parents of having failed to bring up their child properly, and shuts the family out.

Initially, Len and Simon try to discipline David, care for him and spoil him to get him away from drugs, but all that results in are conflicts that make their other children suffer and bring their marriage to the brink of collapse. Len responds by focusing entirely on David and showering him with maternal care. An alternative psychiatrist, Kees, confronts her with the consequences of her approach:

" 'Jíj helpt hem verder aan de drugs.'	(" '*You* are getting him deeper into drugs.'
'Ik...??'	'Me...??'
'Ja, jíj, door de hele dag met hem bezig	'Yes, *you*, by busying yourself with him all

---

[46] Yvonne Keuls, *Madame K. Van Indisch kind tot Haagse dame* (Amsterdam 2001) 192-209.

[47] Keuls, *De moeder van David S.,* 5; Keuls, *Madame K.,* 224; Michiel Berkel, ' "Ik moet godverdomme mijn boodschap kwijt" ', *Haagse Post* 69 (1982) 25, 74-78, 77; Yvonne Keuls & Tony van Verre, *De arrogantie van de macht* (Baarn 1986) 7; Eva Roskam, *Lezen over Yvonne Keuls* (Den Haag 1987).

[48] Marjo van der Meulen, 'Ouders kunnen drugsverslaafde kind niet helpen', *Het Parool* 14 October 1980.

[49] Yvonne Keuls, 'Signaleren en informeren', *Bulkboek* 11 (1982) 126, 32-37, 33-34.

te zijn, door bij hem een schuldgevoel te kweken, door hem doorlopend te laten zien dat jullie kapot gaan met je gezin. Door je gezeur en je hysterie. Jíj helpt hem verder aan de drugs, want je begrijpt helemaal niets van hem. Jíj hebt hulp nodig en die moet je gaan zoeken, maar niet bij mij, want ik help David.'

Ik was razend op Kees. Hoe durfde hij dit te zeggen? Alles had ik voor David over, ik was zelfs bereid kapot te gaan aan hem. Mijn gezeur, mijn hysterie... Ik was razend op Kees en ik ging naar [mijn vriendin] *Gerrie om mijn hart te luchten. 'Ach, dat is dat geklets van die alternatieven,' zei Gerrie, 'die proberen altijd de schuld op de ouders te gooien.'* ”[50]

day, by cultivating a sense of guilt in him, by constantly showing him that you and your family are breaking down. Because of your whining and your hysteria. *You* get him deeper into drugs, because you don't understand anything about him. *You* need help and you have to go find it, but not from me, because I am helping David.'

I was furious with Kees. How dare he say that? I would do anything for David, I was even willing to end up destroyed for him. My whining, my hysteria... I was furious with Kees and I went to [my friend] Gerrie to vent. 'Ah, that's that rubbish of those alternatives,' said Gerrie, 'they always try to cast the blame on the parents.' ”)

Over the course of the book, however, Len learns to separate herself from her son and recognise that they are each individuals making their own choices. In a mutual support group, she learns to draw boundaries between his responsibilities and her own. Towards the end of the book, she finds a way towards a new mother-and-son relationship, and explains it to David like this:

“*Zolang je je ziek voelt wil ik je helpen, op míjn manier, ík stel mijn grenzen vast.* [...] *Als jij afkickt, David, heb ik daar geen verwachtingen meer bij. Ik houd er rekening mee, dat je na een week weer naar een dealer loopt. Maar die week is dan toch niet voor niets geweest. Je bent hier, niet in je kamer, maar in de logeerkamer van ons huis. Je bent niet mijn* [met de brievenbus] *klepperende kind dat een beroep op mijn moedergevoel doet, je bent mijn afkickende*

“As long as you feel sick, I want to help you, in *my* own way, *I* am the one setting my boundaries. [...] If you try to get clean, David, I don't have expectations about that anymore. I keep in mind that a week later you will probably run to a dealer again. But that week then has not been in vain. You are here, not in your room, but in the guestroom of our house. You are not my [mailbox] clattering child appealing to my maternal

---

[50] Keuls, *De moeder van David S.*, 97.

> *zoon die verzorging nodig heeft. Maar in deze week kunnen we misschien toch een basis voor een andere relatie met elkaar leggen.*”[51]

> feelings, you are my detoxing son who needs care. But during this week, we may be able to lay a foundation for a different relationship with each other.”

Written in a very accessible style, with plain words and lots of dialogue and drama, the book spoke to Dutch parents as well as their teenage children, especially in the way it educated them about drug use and addiction. Critics who focused on its literary merits found the qualities of *De moeder van David S.* questionable, but those who stressed its educational value recommended it.[52] Talk show *Rondom tien* devoted a much-talked-about studio discussion to the subject in 1982, featuring Keuls as well as several LSOVD parents, and repeated it two years later when the telefilm of the book premiered.[53] Later, theatre companies toured the Netherlands and Belgium with a stage version.[54]

With her book and its spin-offs, Keuls educated the nation to see heroin addiction as a mental illness.[55] She criticised the stigma and isolation of the parents, and showed them how to pick up their lives again so as to develop a new relationship with their child. Perhaps the strongest message she intended to send was that parents were not to blame for their child’s addiction, but both parties had their own individual responsibility: the drug user for the consequences of their choice to use heroin, the parents for saving the rest of the family’s sanity by distancing themselves from the life choices of the addicted child.[56]

But to a readership that had little knowledge of the workings of the drug problem in the first place, this message was too advanced – to them, the book was a warning against the dangers of heroin in the first place.[57] Its message was even difficult to understand for those in the know, as was shown in a confrontation between Keuls and Reverend Hans Visser in the first *Rondom tien* panel discussion. Visser, who ran a well-known shelter

---

[51] Keuls, *De moeder van David S.,* 254.

[52] Van Boven, *Bestsellers*, 145-146; Irene Geerts, *The image of a generation: (Gender) images of heroin addicts and their parents in the Netherlands, 1980-1985* (Master’s thesis VU University Amsterdam 2017) 50-57, 62-67.

[53] Archive Netherlands Institute for Sound & Vision, Hilversum, Sound & Vision Television Archive [hereafter NISV-SVTA], *Rondom tien,* ‘Mijn kind is drugsverslaafd’, 30 September 1982; *Rondom tien,* ‘Ouders van drugsverslaafde kinderen’, 14 March 1985; *De moeder van David S.* (1982), telefilm directed by Ruud Keers, 30 September 1982.

[54] Jacques J. d’Ancona, ‘Marijke Merckens spottend: “Hollywood moet nog bellen” ’, *Nieuwsblad van het Noorden* 9 May 1987.

[55] Helga Ruebsamen, ‘De waarheid transparant verpakt’, *Het Vaderland* 26 April 1980; Michiel Berkel, ‘ “Ik moet godverdomme mijn boodschap kwijt” ’, *Haagse Post* 69 (1982) 25, 74-78, 75.

[56] Geerts, *The image of a generation,* 45.

[57] Geerts, *The image of a generation,* 51-52, 54-56.

for people with a heroin addiction in his church in Rotterdam, told Keuls that he felt that the picture that she painted of those people was too black, too hopeless. The writer replied by saying that, on the contrary, her book was hopeful, because it was not about the son, it was about the mother:

> *"Ik heb een boek geschreven en dat heet de moeder van David S. En ik heb niet een boek geschreven: David S., de zoon van mevrouw..., hè. Het gaat om die moeder. En dus eindigt mijn boek zeer positief en hoopvol. Want de moeder heeft zich gered, met haar gezin."*[58]

> "I have written a book and it's called the mother of David S. And I didn't write a book: David S., the son of Mrs...., did I. It's about that mother. And so my book ends on a very positive and hopeful note. For the mother saved herself, with her family."

With that, one of the most famous writers in the Netherlands underlined the common cause of the budding family movement in mental health care: that 'relations-of' deserved support in their own right, and a life of their own. But like them, she found that the public and the media did not take up that message easily.

The Ministry and the government

"Mevrouw, wij zitten al tien jaar op u te wachten!"[59] ("Madam, we have been waiting for you for ten years!") For many years, Ria van der Heijden repeated these words by Deputy Chief Inspector of Mental Health Henny Verhagen during the first visit of an Ypsilon delegation to the Ministry of Welfare, Health and Culture in 1985. Whether the inspector wanted to underscore the dire need for family organisations in general, or the likes of Ypsilon in particular, the fact is that the government welcomed all family initiatives in mental health care that saw the light in the early 1980s.[60] Aware of all the drastic changes in laws and policy that were underway – the finalisation of the law on involuntary commitment and other laws and regulations securing patients' rights, the implementation of deinstitutionalisation, and its substitute, community care – and which would directly affect the relations, the organisations were eager to be heard.

---

[58] NISV-SVTA, *Rondom tien,* 'Mijn kind is drugsverslaafd', 30 September 1982, at 49:27.

[59] Ria van der Heijden, ' "Mevrouw, we zitten al tien jaar op u te wachten" ', *Ypsilon Nieuws Introductienummer* (1993) 14-15.

[60] UA-GKN-F, inv. no. 1492-1490, R.M. den Hartog-van Ter Tholen, 'Toespraak ter gelegenheid van de opening van het kantoor van de Stichting Labyrint op vrijdag 28 november 1986', 2-3.

A warm welcome

One of the ways the government expressed its appreciation for the new initiatives was by being relatively quick with providing them with some financial support. In contrast to the clients' organisations that started ten years earlier, applying for and securing government subsidies now seemed a natural thing to do. Although some family organisations complained that it took a long time before money that was granted actually appeared in their bank accounts,[61] and the LSOVD already experienced cutbacks within a few years,[62] the subsidy process seems to have been quite easy. Labyrint's Linda Horn remembers:

> *"En als je dan duidelijk kon maken dat het echt een nood was bij mensen, en dat je voor tienduizend gulden per jaar daar best iets aardigs aan kon doen, en dat je dat natuurlijk, dat je dat graag voor twee of drie jaar wilde hebben, en dat je dan zou evalueren en weer verder kijken, in mijn herinnering was het dan niet zo heel moeilijk om dat los te krijgen. Het ging dus ook niet echt om hele hoge bedragen."*[63]

> ("And if you could make it clear to them that there was really a need in people, and that for ten thousand guilders a year you could do something about that, and of course, you would like to have that for two or three years, and that you would then evaluate and look further, as I remember, it wasn't that hard to get that from them. It wasn't about very large amounts.")

That it wasn't about large amounts of money was true for all of the organisations. For the most part, the work was done voluntarily – even professionals like Christien le Clerq of the ADB and Pandora's Linda Horn and Lineke Marseille often put in more hours than they were paid for, and would continue or come back as volunteers after retiring or changing jobs.[64] The national offices of the LSOVD and Ypsilon were housed in the living rooms of chairpersons Rinus Jansen and Ria van der Heijden, respectively, for years.[65]

---

[61] UA-GKN-F, inv. no. 1492-1490, R.M. den Hartog-van Ter Tholen, 'Toespraak ter gelegenheid van de opening van het kantoor van de Stichting Labyrint op vrijdag 28 november 1986', 3; Jan van Atten, 'Hoe is Ypsilon ontstaan?', *Nieuwsbrief Ypsilon* (1987) 9/10, 21.

[62] 'Verslag van de Provinciale Dag Zeeland van de Landelijke Stichting "Ouders van Drugverslaafden", gehouden op 1 juni 1985 te Goes, Hotel Terminus', *Info* (1985) 14, 5.

[63] Interview Linda Horn & Lineke Marseille, 28 May 2021.

[64] Christien le Clerq & Daisy Smith, 'Over In Perspektief', in: Christien le Clerq, Daisy Smith & Olda van den Burg-Wigboldus (eds.), *Verdriet zoekt onderdak. Over pastoraat aan familieleden van (ex-)psychisch zieke mensen* (Zoetermeer 1994) 59-66.

[65] Letter from D.S.J. Bartstra, secretary of the LSOVD, to the foundation's membership, 12 November 1985 printed in *Info* (1985) 15, 2-3; Ria van der Heijden, 'Bestuursmededelingen', *Nieuwsbrief Ypsilon* (1987) 9/10, 2.

The mutual support groups were set up and run by local volunteers in meeting rooms that were made available free of charge by churches, RIAGGs (Regionale Instellingen voor Ambulante Geestelijke Gezondheidszorg, Regional Institutions for Ambulatory Mental Health Care) and CADs (Consultatiebureaus voor Alcohol en Drugs (Clinics for Alcohol and Drugs).[66]

As an activity of the Reformed Churches, In Perspektief was not eligible for government funding, but the church authorities generously supported Le Clerq's initiative. Their most important funding came directly from the churches, while ADB employee Rick Geukema, after Le Clerq's retirement, seems to have spent most of his time on In Perspektief despite his other duties. Labyrint, offspring of Pandora, also had the advantage that staff members of the mother organisation were employable in the new initiative. That is how Linda Horn and Lineke Marseille already had a solid relationship with the Ministry and knew their way around government subsidies. This was particularly important to them because they felt it was unethical to charge relations for joining the organisation or taking part in its activities.[67]

But it was not just money-wise that Labyrint, Ypsilon and the LSOVD were welcomed warmly in government circles. At even the highest levels of the Ministry, there was an interest in building a relationship with them.[68] From the government perspective, the family organisations came at exactly the right time because they could be helpful in implementing the new policy for the mental health care sector that had been presented in the mental health policy document *Geestelijke Volksgezondheid* (Mental Health) of 1984, known as the *Nieuwe Nota* (New Memorandum).[69] With expenditure in the sector increasing as a result of the rising number of people seeking mental health care, while the country was going through an economic crisis, the memorandum focused on more cohesive and less expensive forms of mental health care. The main instruments for achieving that goal were deinstitutionalisation and substitution: the reduction of 'beds' in psychiatric hospitals while simultaneously expanding the number of places in facilities in the community, such as sheltered living arrangements, where people with severe, chronic mental health problems could live more independently, in small units, with

---

[66] Bob van Amerongen, 'Verslag van de oudergroependag', FZA *Kwartaalberichten* 6 (1981) 4, 7-8; 'Hoe verder met de kontaktgroepen van Ypsilon', untitled Ypsilon newsletter [April 1986], [2-3]; 'Berichten uit de regio', *Informatiebulletin* [Labyrint] (1989) 8, 2; UA-GKN-F, inv. no. 1492-1485, Rick Geukema, 'Enkele konklusies en afspraken vanuit het financieel beraad In Perspektief zaterdag 25 november 1989'.

[67] Interview Linda Horn & Lineke Marseille, 28 May 2021.

[68] Q.A. Jansen, 'De driehoek verslaafde-ouder-hulpverlener', FZA *Kwartaalberichten* 6 (1981) 4, 8-10, 8-10; 'Verslag van de eerste regionale oudercontactdag van de landelijke stichting "Ouders van drugsverslaafden" ', *Info* (1984) 10, 3-10, 5; UA-GKN-F, inv. no. 1492-1490, R.M. den Hartog-van Ter Tholen, 'Toespraak ter gelegenheid van de opening van het kantoor van de Stichting Labyrint op vrijdag 28 november 1986'.

[69] *Geestelijke volksgezondheid. Nota* (Tweede Kamer, vergaderjaar 1983-1984, 18463, nrs. 1-2).

outpatient support. It was certainly an austerity measure, but the policy was also strongly inspired by the anti-psychiatry ideas of the previous decade – in particular the ideal of reintegrating patients into communities in an effort to do something about stigma.[70]

That policy made heavy demands on family members as caregivers, as R.M. den Hartog-van Ter Tholen of the Ministry said in her speech at the opening of the Labyrint office in 1986. The policy makers figured that the family organisations could be an asset to the new policy, by supporting relations in coping with their situation, as well as by educating society so that communities would become more tolerant of new neighbours coming from psychiatric hospitals.[71] The family organisations were useful to the Ministry in a more direct way, too: investing in good relationships allowed government staff not only to acquire important information, but also to show parliament that they were on the right track, doing what they could to facilitate the new policy. But it was a two-way street: both sides benefited from the mutual flow of information.[72]

Concerns over new policies

To the organisations, their government contacts were crucial, for as we have seen, they had serious concerns about the new policies. Concerns about the continuing cutbacks that worsened the circumstances in psychiatric hospitals. Concerns about the lack of continuity in care once a patient was discharged from an institution. Concerns about patients ending up wandering the streets, in a poor mental state, self-medicating with drugs and alcohol, eating out of garbage cans. Even before any of these changes saw the light, many relations had found that the burden of care exceeded their coping capacity. The prospect of more care duties instead of more support coming their way was more than many of them could bear.

Although they shared these worries, Ypsilon and Labyrint (and, in Labyrint's wake, In Perspektief) were in complete opposition regarding what should be done about them. Ypsilon wanted nothing less than to stop deinstitutionalisation and to have the criteria for involuntary commitment to a psychiatric hospital broadened again.[73] In the eyes of Labyrint, homeless people with severe mental health problems were autonomous sufferers who were in their right mind if they rejected the psychiatric institution:

---

[70] Harry Oosterhuis & Marijke Gijswijt-Hofstra, *Verward van geest en ander ongerief. Psychiatrie en geestelijke gezondheidszorg in Nederland (1870-2005) Band II* (Houten 2008) 1048-1060.

[71] UA-GKN-F, inv. no. 1492-1490, R.M. den Hartog-van Ter Tholen, 'Toespraak ter gelegenheid van de opening van het kantoor van de Stichting Labyrint op vrijdag 28 november 1986', 2-3.

[72] Interview Linda Horn & Lineke Marseille, 28 May 2021.

[73] Van Vlodrop & Thewissen-van Velzen, *Onze schizofreniepatiënten,* 60-94; Lies Bosscher, 'Ypsilon in een bananendoos. Fragmenten uit de afscheidsspeech van voorzitter Lies Bosscher op de Landelijke Dag', *Ypsilon Nieuws* (2001) 95, 11-12, 11.

> *"Zwerven zou op zich niet zo'n ramp zijn als het mooi weer bleef in dit land, maar wanneer het flink vriest en je vermoedt dat je man of je dochter wellicht ergens in een doos of op een tijdens het vorstverlet verlaten bouwplaats, probeert te bivakkeren, dan wordt het je bang te moede. Hoe begrijpelijk het ook is dat familieleden het als hun belang beschouwen dat zo iemand 'voor eigen bestwil' wordt opgenomen, omdat hij of zij dan tenminste de winter overleeft, het is tegelijkertijd een vorm van inmenging in het leven van de cliënt die nu juist allerlei controverses oproept en waarmee je mijns inziens bijzonder voorzichtig te werk moet gaan. Ter toelichting: als u wel eens de moeite hebt genomen om u te verdiepen in datgene dat* [sic] *deze 'zwervers' met hun psychiatrisch verleden (en heden), bezighoudt, dan zult u gemerkt hebben dat zij – hoe ellendig dat vaak ook is – liever zwerven dan terugkeren naar inrichtingen waaraan ze veel verschrikkelijke herinneringen hebben en die hen – laten we dat niet uit het oog verliezen – ook helemaal niets kunnen bieden dan een asiel waar het eten op tijd komt en waar men voorzien wordt van medicamenten die hoogstens wat dempen en die meestal allerlei bijverschijnselen hebben."*[74]

> ("Wandering in itself would not be such a disaster if the weather remained nice in this country, but when it freezes heavily and you suspect that your husband or daughter may be trying to camp somewhere in a box or on a construction site that has been abandoned during the frost, you become frightened. However understandable it is that family members consider it in their interest that such a person is committed 'for their own good', because then he or she will at least survive the winter, it is at the same time a form of interference in the life of the client that raises all kinds of controversies and regarding which, in my opinion, you have to be particularly careful. To explain: if you have ever taken the trouble to delve into what concerns these 'wanderers' with their psychiatric past (and present), you will have noticed that they – however miserable that often may be – would rather wander than return to institutions of which they have many terrible memories and which – let us not lose sight of this – can offer them nothing at all but an asylum where food is served on time, and where one is provided with medication that attenuates at most a little and that usually has all kinds of side effects.")

In favour of deinstitutionalisation – a hard-earned goal of the clients' movement after all – Labyrint insisted on developing solid alternative forms of care to support both clients living independently and their relations who might or might not be willing or able to step up to a role as informal caregivers. The organisation did not want people with severe mental health issues to be confined to institutions: it underlined demands

---

[74] Horn, 'Tussen twee grenzen', 14.

for better care in the community, as well as for communities to become more accepting of such people living in their midst.[75]

Addiction care policies were meanwhile developed in a separate section of the Ministry, in close connection with drug policy at large – these channels were as separate from mainstream mental health care policy as the LSOVD was from the family movement. As health problems in the population had risen with the rise of drug use in the 1970s, the government had initially only facilitated addiction care and advised from the sidelines. With the revision of the *Opiumwet* (Opium Law) in 1976, however, drug policy converged with the view of mental health care professionals, who generally regarded people with an addiction as patients instead of as criminals. After a few years, once heroin became a public health and order problem that neither the law nor addiction care had the answer to, there was a lengthy standstill between traditional – abstinence focused – addiction care on one side, and alternative care workers, who were convinced that harm reduction was a more realistic way to battle the heroin problem, on the other.[76]

By the early 1980s, the problem was spinning out of control and causing a lot of suffering in users and a lot of nuisance in cities where hard drug scenes had developed. As historian Arjan Nuijten has shown, local care professionals, organisations and authorities took the lead in experimenting with policies aimed at decreasing the negative effects of drug use, drug trade and drug-related crime in inner cities. When the AIDS epidemic hit in the mid-1980s and it became apparent that the virus also spread through sharing syringes for injecting drugs, the urgency of these harm reduction policies, as they came to be called, became even more pressing, not only for the health of users, but also for the health of the general population.[77]

For many of the parents in the LSOVD, the choice for a harm reduction policy must have been a hard one. Many of their children were living in seedy squats or on the streets, prostituting themselves or resorting to criminal behaviour to meet the needs of their heroin addiction, while in the parents' eyes, addiction care and law enforcement largely stood by and enabled drug dealers to push their deadly merchandise. Over the years, the parents came to see that forcing their children into rehabilitation was no use, but well into the 1990s, they continued to insist on a drug policy that focused on identifying and addressing the cause of drug addiction: in the substances themselves, they meant, instead of in the parents or the family.[78]

---

[75] Horn, 'Tussen twee grenzen', 16.

[76] De Kort, *Tussen patiënt en delinquent,* 228-250; Blok, *Ziek of zwak,* 181-217; Nuijten, *Regulating Paradise,* Chapter 2.

[77] De Kort, *Tussen patiënt en delinquent,* 259-268; Blok, *Ziek of zwak,* 217-228; Nuijten, *Regulating Paradise*, Chapter 3.

[78] NISV-SVTA, *Gedane zaken*, 9 February 1986, at 16:10-28:20; Van Amerongen, 'Ouders van

Through their newly acquired contacts, the organisations were getting their opinions across at the highest levels of government – a huge step forward for relations who until recently had not been heard at all. But the ponderous course of mental health care and addiction care policies was not easy to influence, especially for young organisations that were just getting started and still new to the scientific and professional arguments behind those policies. This is illustrated by the 1983 speech in which a key official of the Ministry of Welfare, Health and Culture, Eddy Engelsman, announced that the LSOVD had been granted their first subsidy. Before disclosing the good news, he lectured his audience saying that the idea that addiction was an illness was outdated. It had been important in the efforts to destigmatise drug users and their relations, but as a care approach it had not yielded results: it had obscured the social causes of addiction and resulted in users adopting a passive attitude. That did not mean that Engelsman wanted to blame the parents. But that the substance in itself was to blame instead, was also too limited a view. Addiction was much too complicated for one-sided explanations. It should be met with a pragmatic approach, focusing on easy access to help and on minimising the burden to society, while the individual, their environment and society at large should accept their responsibilities – "*... de gezinstherapie blijkt belangrijke nieuwe mogelijkheden te hebben,*" ("... family therapy turns out to offer important new possibilities"), he concluded.[79]

The resistance did not intimidate the early LSOVD parents. In the volatile atmosphere of the drug debate in the 1980s and 90s, their opinions were often completely contrary to those of the government and the addiction care sector, but chairmen and board members like Rinus Jansen and Douwe Bartstra in the early 1980s (see Chapter 3) and Alphons Katan in the 1990s were not afraid to take a controversial stand.[80] Even if that made their relationship with the addiction care professionals suffer, they nevertheless managed to maintain a close relationship with the Ministry. In other periods, when the organisation was struggling, its leaders tended to focus more on developing the LSOVD's mutual support and toned down its political views.[81] In the other family organisations, the situation was more linear: once they had a well-developed mutual support system and a stable internal organisation, they started expanding their work towards political advocacy.[82]

---

drugsverslaafden', 118; archive Van den Abeele, Rogier de Jong, 'Mensen, wij moeten onszelf rechtop houden', unpublished interview with Alphons Katan.

[79] E. Engelsman, 'Het drugbeleid, de hulpverlening en de ouders van drugverslaafden', in: *Verslag tweede themadag LSOVD 8 oktober 1983* (Bilthoven 1983) 21-29.

[80] NISV-SVTA, *Gedane zaken*, 9 February 1986, at 16:10-28:20; Van Amerongen, 'Ouders van drugsverslaafden', 118; archive Van den Abeele, Rogier de Jong, 'Mensen, wij moeten onszelf rechtop houden', unpublished interview with Alphons Katan.

[81] Jansen, 'Openingswoord', 2; Van Amerongen, 'Ouders van drugsverslaafden', 117-118; archive Van den Abeele, Rogier de Jong, 'De moeder van de LSOVD', unpublished interview with Bep Griffioen.

[82] Interview Bas van Raaij, 21 June 2018; interview Margriet Mannak, 21 September 2021; interview Annelies Faber, Els Borgesius & Paul Baart, 13 January 2022; interview Bert Stavenuiter, 27 January 2022; interview Cisca Goedhart, 18 November 2022.

The next mental health care policy

The point of departure of the *Nieuwe Nota,* the government policy document of 1984, had been the improvement of the position of clients along lines that had been put forward over the previous decade by their organisations. Despite the implications that the new deinstitutionalisation policy – a key part of it – could be expected to have for informal caregivers, no attention was paid to the relations. When in 1993, the follow-up document *Onder anderen* (Amongst Others) appeared, the picture was completely different. This time, the role of and burden on relations were explicitly acknowledged and appreciated. And so were their organisations – Ypsilon was even mentioned by name.[83]

With the number of people calling for psychiatric help rising faster than ever, mental health care was a responsibility the government wanted to share.[84] Following the 1987 recommendations of a government advisory committee that became known as the Commissie Dekker (Dekker Committee), it intended to rely on market players and market mechanisms to make the arrangements in a system for which the government made the rules. In the future, all health care arrangements were to be negotiated between three main market players: the health care providers, the insurers and the care consumers. In mental health care, the last would comprise both clients and relations.[85]

Harry Oosterhuis and Marijke Gijswijt-Hofstra have argued that, despite how neoliberal this policy of government retreat may have seemed, the ideals of the clients' movement of the 1970s and 80s actually shaped the laws and policies that were implemented.[86] In the 1980s, the government had already begun to change the orientation of the health care system from supply-led to demand-led, and to involve patients' and clients' organisations in health care decision-making by stimulating the creation of national and regional platforms to represent patients and clients at the negotiating table. From 1990 onwards, clients' and family organisations were also invited to take part in hundreds of health innovation projects that were set up in mental health care, in particular for the benefit of patients in long-term care.[87]

Within ten years, relations and their organisations had managed to go from being completely overlooked in the negotiations over mental health care policy to securing their position, together with the clients' movement, in the latest government policy and at the tables where decisions about the future would be made. There, they were not just

---

[83] *Onder anderen. Geestelijke gezondheid en geestelijke gezondheidszorg in maatschappelijk perspectief* (['s-Gravenhage] 1993), 8, 18, 19, 31.

[84] *Onder anderen,* 16-17, 20.

[85] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 1080-1083.

[86] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 1056-1062.

[87] Jeannette van Tulder & René Borkus, *Veranderend perspektief. 10 jaar patiënteninvloed in de gezondheidszorg* (Haarlem 2001) 41-42; interview Bas van Raaij, 21 June 2018.

acknowledged as a party of interest, but as equal to the mental health care providers and insurers. It was a huge step forward.

The Bakkenist report

Compared to the other parties at those tables, however, the clients' and family organisations had only short legs when taking that huge step. As almost exclusively volunteer organisations with tiny, insecure budgets, they were like David facing Goliath compared to the mental health care sector and the government. Their participation demanded such an enormous amount of work that it even jeopardised their own initiatives and activities.[88] To help level the playing field, parliament passed a motion in 1993 to make structural subsidies available for the clients' and family organisations, so that they could at least come to rely on their budgets, just as the care providers and the insurers could. The motion's implementation was stalled for years, however, when the other two parties advised against it. The mental health care providers did not find it necessary for the clients' and family organisations to receive structural funding, while the care insurers felt that they should be the ones to represent the voice of the client.[89]

Figuring out how to finance the clients' and family organisations in the future went hand-in-hand with critical scrutiny by the government of those that already received subsidies. On the one hand, the Ministry wanted to make sure that its money was well spent, while on the other, it wanted to push harder towards collaboration between organisations so that they would gain strength in the face of the mighty organisations of care providers and insurers. Regarding the family movement in mental health care, the Ministry's eye fell on Ypsilon, Labyrint and In Perspektief. In addition to Ypsilon and Labyrint, which had received government funding since the mid-1980s, In Perspektief had in 1990 become a foundation independent of the ADB, and thus also managed to secure a small subsidy. Since their break-up in 1984, Rick Geukema of the ADB had successfully worked towards a reconciliation with Labyrint, and over the years, the relationship between the two organisations had indeed improved. When In Perspektief became a foundation in 1990, its first employee Daisy Kajim went to work in the Labyrint office. Although the first year was not easy for anyone, the work floor was where true collaboration would be built, especially through the efforts of Kajim's successor Peter Houweling.[90]

In 1993, consultancy firm Bakkenist was commissioned by the Ministry to evaluate Ypsilon, Labyrint and In Perspektief. The consultants' report, delivered in 1994, concluded that government support for all three organisations was justified, as they

---

[88] Van Tulder & Borkus, *Veranderend perspektief,* 29-24.

[89] Van Tulder & Borkus, *Veranderend perspektief,* 40.

[90] Le Clerq & Smith, *Over In Perspektief,* 59-66; interview Linda Horn & Lineke Marseille, 28 May 2021.

catered to different needs in the population. The only concrete change the consultants suggested was one towards which the parties concerned had already been working for years: Labyrint and In Perspektief should integrate their office organisations, while being allowed to hold on to their own identities.[91]

The report gives detailed insight into how the organisations were doing at the time. It portrays Ypsilon as a thriving association with fifty regional mutual support groups, six part-time staff members supported by hundreds of active volunteers and lots of advocacy activities, individual as well as collective. In Perspektief was the smallest organisation, with one part-time employee and fifteen regional groups whose volunteers, with the support of Reformed-Church *sociale activeringswerkers* (social activation workers), organised mutual support and educational lectures for church communities. Labyrint was pictured as a struggling foundation with seventeen regional groups, largely dependent on the work of the three employees (roughly equalling Ypsilon's six in terms of hours) and volunteers in the central office. In recent years, the report described, Labyrint had needed to focus a lot of its attention on organisational matters because the continued efforts to merge with In Perspektief were still proving complicated and, in that turmoil, Annelies Faber had to find her way as the new coordinator succeeding founder Linda Horn. As a consequence, vital tasks in support of regional groups and volunteers, as well as advocacy, had suffered.[92]

Ypsilon was presented in a much more positive light. It was not only larger, it was also organised better, had strong political networks in government as well as in mental health care, and had more results to show. It would be reasonable for the Ministry, the consultants felt, to ask Ypsilon not to isolate itself from the other family organisations, but any pressure to collaborate more formally would not only be ineffective, they wrote, it would also be unjust.[93] The evaluation reflected a bias in favour of Ypsilon that was inspired by the 1990s climate in psychiatry. The consultants' perspective reveals that anti-psychiatry had gone out of fashion, while the appropriateness of the biomedical perspective now went literally without saying. Labyrint was rooted in anti-psychiatry, the consultants wrote, "*een beweging die inmiddels aan scherpte verliest*" ("a movement that is losing its edge"),[94] marking it as a thing of the past and implicitly praising Ypsilon for its modern outlook.

As a consequence, the report described Labyrint not on its own merits, but in terms of what it was *not,* compared to Ypsilon. It stressed, for example, that Labyrint did not primarily address mental health care professionals, without making explicit that

---

[91] J. Elias & W. van Santen, *Drie familie-organisaties GGZ. Rapport uitgebracht aan: De Staatssecretaris van het ministerie van Welzijn, Volksgezondheid en Cultuur* (Diemen etc. 1994) 3-4.

[92] Elias & Van Santen, *Drie familie-organisaties GGZ.*

[93] Elias & Van Santen, *Drie familie-organisaties GGZ,* 3.

[94] Elias & Van Santen, *Drie familie-organisaties GGZ,* 12.

this was a consequence of its choice to unconditionally respect client autonomy. The consultants also bought into the idea that the problems of the Labyrint constituency were a passing matter, whereas those of the Ypsilonners were not: *"Er is minder continuïteit in de betrokkenheid van familieleden dan bij Ypsilon, ook omdat men vaak niet met een chronische situatie heeft te maken ('op zeker moment ga je weer tennissen')."*[95] ("There is less continuity in the involvement of family members than in Ypsilon, also because often people are not dealing with a chronic situation ('at some point you go play tennis again').") That last remark would be repeated tauntingly in Ypsilon circles as proof of how it was the only organisation representing people suffering from 'real psychiatry'. In their eyes, Labyrint and In Perspektief diluted the message that Ypsilon wanted to get across.[96]

The merger of Labyrint and In Perspektief would become final in 1997. Although the office staff on both sides had already worked together in harmony for years, the boards of the organisations continued to be at odds with each other over the Christian identity issue, aggravated by how hard it was for In Perspektief as the 'newcomer' to fit in with the larger Labyrint.[97] To clear the way for a merger, social worker Reina van Mourik, who had been actively involved in In Perspektief since its beginnings, stepped down as chairwoman and two mediators helped both sides reconcile their differences. In Margriet Mannak, another long-time volunteer, they found the person who would finally make it happen. The prolonged discussion about what the new organisation should be called attests to this difficult process. Only when Van Mourik suggested that combining the two existing names gave new meaning to both – 'from the labyrinth towards a new perspective' – both sides agreed; the name Labyrint~In Perspektief continued to show the separate identities of the two merging partners.[98]

The mental health care field

The family organisations stepped quite literally into the mental health care arena at that conference in June 1986 where representatives of all the major players – but predominantly professionals with an anti-psychiatry orientation – were assembled. Ria van der Heijden, Bas van Raaij and Hennie Bruens were prepared to confront them with everything that weighed on the shoulders of Ypsilon relations. When Van der Heijden

---

[95] Elias & Van Santen, *Drie familie-organisaties* GGZ, 12.

[96] Interview Bas van Raaij, 21 June 2018.

[97] Interview Reina van Mourik, 12 May 2021; interview Margriet Mannak, 21 September 2021; interview Annelies Faber, Els Borgesius & Paul Baart, 12 January 2022.

[98] 'De nieuwe stichting Labyrint~In Perspektief', *Relatief* 1 (1997) 1, 21; interview Reina van Mourik, 12 May 2021; interview Margriet Mannak, 21 September 2021; interview Annelies Faber, Els Borgesius & Paul Baart, 12 January 2022; interview Cisca Goedhart, 18 November 2022.

stood up at the audience microphone, she had a piece of paper in her hand with the ten most pressing issues that she wanted to bring forward. One after the other, she hurled them into the hall: it is inhumane to burden parents with the idea that they made their child schizophrenic! It is inhumane that parents are kept at bay by mental health care workers! It is inhumane that... Initially, people started to boo her in response, but the uproar died down. And afterwards, Van Raaij recalls, leading figures in the sector flocked towards his mother. As she was gathering business cards, he realised: "We are in business!"[99]

Approaching the professionals

To Ypsilon, building close relationships with psychiatrists, nurses and other mental health care professionals was key. Not only were they the ones whom the parents' association held largely responsible for everything that was wrong with psychiatry, but they were also the primary actors who could make a difference in the lives of their loved ones. Van der Heijden, with her energetic, outgoing and straightforward personality, won many of them over, developing close personal relationships in the sector that helped her organisation along.[100] In addition, as we have seen in Chapter 3, Ypsilon worked closely with biomedically oriented researchers in the field, psychiatrist Rigo van Meer in particular.

At the LSOVD and In Perspektief, collaborating closely with professionals went without saying, too. From the start, In Perspektief had been connected with Veldwijk psychiatric hospital in Ermelo, in particular through social worker Reina van Mourik.[101] In addition, it profited from the relationship of the ADB with the social activation workers in Reformed-Church social work centres all over the country.[102]And the LSOVD collaborated with the CADs, the clinics for alcohol and drugs, largely through the efforts of Bob van Amerongen, who as a 'father-of' and a prevention professional working at the umbrella organisation of the CADs, always took the position of the liaison between the two.[103]

Labyrint felt more comfortable operating at a healthy distance from the professionals – in their view, that created more space for criticism.[104] As supporters of deinstitutionalisation, it focused on building a professional relationship with the RIAGGs, the national network of regional organisations where all outpatient care was concentrated

---

[99] Interview Bas van Raaij, 21 June 2018.

[100] Interview Bas van Raaij, 21 June 2018; interview Paul van Trigt, 30 November 2021.

[101] Interview Reina van Mourik, 12 May 2021.

[102] Le Clerq & Smith, 'Over In Perspektief', 59-60.

[103] Van Amerongen, 'Ouders van drugsverslaafden'.

[104] Jet Bruinsma, 'Labyrint helpt familieleden van psychiatrische patiënt', *de Volkskrant* 19 March 1987.

since 1980. In addition, Labyrint worked with another kind of professional: lawyers. Legal experts were important in evaluating the consequences for relations of the new laws that were being developed in the context of patients' rights: only when a client was in a state of extreme distress and incapacity would the involvement of family members in decision-making be allowed.[105] Knowing that it would be a long and hard process to strengthen the relations' legal position in response, Labyrint set out to develop guidelines for mental health care professionals. Showing professionals how to include relatives in their work without compromising patients' rights, such guidelines would also educate relations on how to prepare for their dealings with mental health care.[106]

Working with the relations of their patients was of course not a completely new idea to mental health care professionals. Just like doctors and nurses in general hospitals and practices were in touch with relations of people who were physically sick, this was quite natural, as Joost Vijselaar has shown in detail for the period between 1890 and 1950.[107] Up to the 1970s, social workers working side by side with psychiatrists were responsible for actively reaching out to the family. Like In Perspektief's Reina van Mourik, they educated the relations and supported them in their difficult situation.[108] The relationship, however, was strictly hierarchical: the authority of the professionals was unquestioned, and a lay person had no say in the matter. As we have seen in the case of Mies Osterholt, this could have serious consequences when those professionals were not as benevolent as patients and relations might expect.[109]

Since then, inspired by anti-psychiatry, social workers' attention to the family had been replaced in many institutions with an exclusive focus on and loyalty to the patient, and as a result, social workers there had distanced themselves from the relations. Elsewhere, it was the introduction of the Constitution article guaranteeing every citizen's right to privacy in 1983 that was decisive. In the experience of Van Mourik, the new law made working with the relations virtually impossible.[110]

---

105 L.M. Horn, O.P.F. Oldenburg & J.H. Scholma-Hofdijk, *Met recht betrokken. Verslag van het eerste lustrumcongres van de Stichting* Labyrint, *gehouden in samenwerking met de sectie gezondheidsrecht van de juridische faculteit van de Vrije Universiteit op woensdag 9 mei 1990* (Utrecht 1991) 47-50.

106 Archive Horn, *Jaarverslag 1990* (Utrecht 1991) 5; Pieter Ippel, 'Rechtspositie van familieleden', *Maandblad Geestelijke Volksgezondheid* 45 (1990) 10, 1087-1090; 'Labyrint wil familieleden van patiënten meer rechten geven', *Dagblad voor Noord-Limburg* 5 May 1990; G. Santing, 'De zorg voor verblijfspatiënten', in: C.J. Slooff & W.M.A. Verhoeven, *Opstellen over ontwikkelingen in en rond de verblijfspsychiatrie* (Leiderdorp 1992) 43-47; Lies Bosscher & Bert Stavenuiter, *Bescherming voor psychotische mensen. Problemen en aanbevelingen rond de wet BOPZ* (Rotterdam, Den Haag 1996) 2-4.

107 Joost Vijselaar, *Het gesticht. Enkele reis of retour* (Amsterdam 2010).

108 Interview Reina van Mourik, 12 May 2021.

109 C.A. van Eijk-Osterholt, *Laten ze het maar voelen... Een verhaal over psychiatrische inrichtingen, belangenbehartiging, acties en de commissie-Van Dijk* (Amsterdam 1981).

110 Interview Reina van Mourik, 12 May 2021.

Building professional relationships

Veldwijk was also the place where from 1978, medical superintendent Henk van Andel and his successor Wout Hardeman were the driving force behind the first successful Dutch family council in a psychiatric hospital.[111] This council comprised a group of family members advocating on behalf of their committed loved ones over issues such as the quality of meals, involuntary transfers or the lack of privacy on the wards. Eugène Poppe, a 'brother-of' who was the backbone of Veldwijk family council from 1979 to 2004, spent a day on its wards every week in order to monitor the circumstances and build a relationship with the staff. That staff, he found, tended to see family members as mere visitors, or even – when such visitors asked questions – a nuisance. Therefore, the council members also took it upon themselves to educate the staff on the ground on how better to deal with their patients' relations.[112] Another kind of family council also originated in the late 1970s: a council that advocated exclusively in the interests of the relations, for example with regard to how they were informed and supported. The family council in Wolfheze, that started in 1979, was the first one of this kind.[113] The family organisations embraced and supported these councils actively – often their local groups initiated family councils in their regional psychiatric hospitals and RIAGGS.[114]

Frontrunners among the mental health care professionals embraced the insights of the family organisations early on. Some, like those in Veldwijk, had already been more family-minded than average, others now discovered the usefulness of the family for their patients' treatment.[115] Initially, the interest of these professionals was largely limited to the interests of the patient, but soon their attention widened to include the burden on the family and they began developing a new attitude and approach to relations. These were

---

[111] W.J. Hardeman & E. de Vries, 'Een familieraad als waakhond voor chronische patiënten', *Maandblad Geestelijke Volksgezondheid* 43 (1988) 12, 1239-1243. Corrie van Eijk-Osterholt was involved in an effort to set up a family council in another institution in the mid-1970s, but that failed as a consequence of the resistance by the institution's management (Corrie van Eijk-Osterholt, 'Familieleden en de psychiatrie (2)', *Maandblad Geestelijke Volksgezondheid* 42 (1987) 2, 172-176).

[112] Personal telephone conversation with Eugène Poppe, 3 September 2019.

[113] UA-GKN-F, inv. no. 1492-1487, Lineke Marseille, 'Verslag van de "familiepraatgroep-bijeenkomst" dd. 4 augustus 1983'; Museum of the Mind, Haarlem, Pandora Library, inv. no. 1036, Linda Horn, 'Van lotgenoot tot bondgenoot', appendices, 'Kontaktgroep Wolfheze en Familieraad Ermelo', *Eigendruk* ([1984]) [1], [3].

[114] Archive Horn, *Jaarverslag 1989* (Utrecht 1990) 15.

[115] Aart Schene, *Thuis bezorgd. Een literatuuronderzoek naar het verschijnsel 'burden on the family'* (Utrecht 1986); Flip Schrameijer (ed.), *Thuis bezorgd: verslag. Een studiedag over de zorg voor psychiatrische patienten in het thuismilieu* (Utrecht 1988) 10-28, 12; *De mantel een zorg. De plaats en de rol van de naaste van de patiënt in de ggz* (Lochem, Gent 1987); Henny Oosterbaan, *Omgaan met gekte. Hoe familieleden de zorg voor psychiatrische patiënten volhouden* (Utrecht 1990); Aart Schene & Bob van Wijngaarden, *Familieleden van mensen met een psychotische stoornis. Een onderzoek onder Ypsilonleden* (Utrecht, Amsterdam 1993).

early adopters, however. For the mainstream of mental health care workers, not used to taking relations into account, coming to regard them as allies was a slow process. The most common reaction Labyrint's Linda Horn remembers was a dismissive: *"Moeten we daar nou ook al aandacht aan besteden?"* ("Do we really have to pay attention to that now as well?")[116] Sometimes the reactions could be downright hostile. Volunteers in Limburg, for example, mentioned that in the Maastricht psychiatric hospital Vijverdal, Ypsilon was painted as *"een vervelende club, die de nek moet worden omgedraaid"* ("an annoying club, whose neck should be wrung").[117]

Some professionals analysed the resistance of their colleagues and confronted them with the result. For mental health care workers who tended to identify with patients, psychiatrist Louk van der Post wrote, it was difficult to replace that unwavering loyalty with the more neutral stance vis-a-vis all the parties involved that came with an awareness of the burden on the family.[118] Ypsilon ally Rigo van Meer was more blunt in stressing that it all came down to a change in mentality, being frank about the limits of what professionals could do, and approaching relations with friendliness, interest and an eye to their problems.[119]

The family organisations had a more nuanced view on the matter. In their experience, mental health and addiction care professionals in general looked favourably upon the mutual support groups set up by the organisations. The resistance came when relations started to voice their opinions on matters of treatment and policy and to make political demands.[120] As Ria van der Heijden saw it:

"Met de eerste doelstelling van Ypsilon [de lotgenotengroepen] *heeft de hulpverlening in het algemeen geen enkele moeite. De problemen ontstaan zodra wij het terrein van de belangenbehartiging betreden. Vanaf het begin hebben wij naar een harmoniemodel gestreefd. Wij hebben de*	("With the first objective of Ypsilon [the mutual support groups], in general mental health care has no problem at all. The problems arise as soon as we enter the field of advocacy. From the beginning, we have striven for a harmonious model. We did not hit the

---

116 Interview Linda Horn & Lineke Marseille, 28 May 2021.

117 'Volop leven in de Ypsilon-regio's', *Nieuwsbrief Ypsilon* (1987) 13, 6-7.

118 L.F.M. van der Post, 'Netwerkbenadering in de sociale psychiatrie', in: Flip Schrameijer (ed.), *Thuis bezorgd: verslag. Een studiedag over de zorg voor psychiatrische patienten in het thuismilieu* (Utrecht 1988) 50-72, 70.

119 C.R. van Meer, 'De benadering van schizofrene patiënten en hun familie', in: Flip Schrameijer (ed.), *Thuis bezorgd: verslag. Een studiedag over de zorg voor psychiatrische patienten in het thuismilieu* (Utrecht 1988) 73-82, 82.

120 Van Amerongen, 'Ouders van drugsverslaafden', 115-120; Ria van der Heijden, 'De psychiater als God?', *Forum* (1989) 2, 3-7.

> *hulpverleners niet om de oren geslagen, maar hebben contact met hen gezocht en geprobeerd op één lijn te komen. De belangenbehartiging voor de patiënt die dat immers zelf niet kan of wil, is voor ons van groot belang. Als het de patiënt goed gaat, dan zijn de familieleden ook gerust. Er is echter geen enkele reden om gerust te zijn. Wij maken ons grote zorgen over de werkwijze van de Riagg's, het opnamebeleid, de attitude van sommige hulpverleners en de wijze van opvang.*”[121]

> mental health care workers over the head, but contacted them and tried to get on the same page. Advocacy for patients who are unable or unwilling to do so themselves is of great importance to us. If the patient is doing well, the family members are also reassured. However, there is no reason to be reassured. We are very concerned about the methods of the Riaggs, the admission policy, the attitude of some mental health care workers and the way support is offered.”)

It was not that professionals did not see that relations were becoming more relevant in light of political moves towards deinstitutionalisation and community care. In fact in 1987, eminent psychiatrist Kees Trimbos linked the newfound interest in the fate of the family directly to the direction mental health care and policy were taking: integrating the psychiatric patient in the community made it inevitable that the family would be considered too. He acknowledged that discontent over mental health care had been the breeding-ground for the activism of the clients' as well as the family movement, and expressed the hope that policymakers, mental health care workers, clients and family members would be able to work together for the good of the patient. However, his welcoming words to the family organisations came with reservations. In the United States, he told his audience, a powerful conservative parent movement had emerged that wanted to turn back the clock on innovations in mental health care that he deemed necessary.[122]

This sort of reaction to the family movement framed it as conservative, or even reactionary, 'anti-anti-psychiatry'.[123] Only Ypsilon can be characterised in this way, though. The fact that there was also a part of the family movement that had risen *from* anti-psychiatry, instead of *in reaction to* it, was noted by some inside the clients' movement,[124] but to many in the mental health care arena the point seems to have been lost. Despite the family organisations' common cause of empowering the relations in

---

[121] Van der Heijden, 'De psychiater als God?', 3.

[122] C.J.B.J. Trimbos, 'Opening', in: Flip Schrameijer (ed.), *Thuis bezorgd: verslag. Een studiedag over de zorg voor psychiatrische patienten in het thuismilieu* (Utrecht 1988) 5-9.

[123] Gemma Blok, *Baas in eigen brein. 'Antipsychiatrie' in Nederland, 1965-1985* (Amsterdam 2004) 168.

[124] UA-GKN-F, inv. no. 1492-1490, Hans Wiegant, 'Toespraak ter gelegenheid van de opening van het kantoor van de stichting "Labyrint" uitgesproken vrijdag 28 november 1986'.

mental health care, the commotion that the rise of Ypsilon brought to the sector resulted in the entire family movement being considered ‘anti-anti’ early on, even though the movement was as multi-faceted as psychiatry was itself.

Managing resistance

It was not surprising that the family organisations met with resistance in mental health care professionals. In particular the invisibility that family members often experienced in psychiatry and the blackening of their character as a result of mother-blaming and family-blaming were the result of deeply-rooted professional attitudes (see Chapter 3). The damage those attitudes had done to relations could even be so great as to hinder efforts by the organisations to convince professionals to enter into a relationship with them. When a psychiatrist or addiction care expert was persuaded to appear before an audience of family members, for example by holding a lecture at one of their regional or national meetings, audience members could turn on them and hold them accountable for every frustration and abuse their family had ever suffered at the hands of professionals. In order to protect the delicate relationships the organisations were trying to build, special measures were taken. Annelies Faber and Cisca Goedhart instructed Labyrint family members before their meetings so that they would treat speakers with respect.[125] But Ypsilon’s Bas van Raaij turned it around:

> *“De psychiaters, de psychologen en andere hulpverleners worden in een zaal gezet en die krijgen een briefing. En die briefing gaat als volgt:* [...] *luister eens, wat er ook gebeurt, je blijft vriendelijk. Je krijgt een storm over je heen, dat ga ik je nou zeggen. Die ouders zijn rázend. Weet dat, en luister gewoon. Wees vriendelijk en vang het op. Je hoeft niks: je hoeft niet ja te zeggen, je hoeft niet nee te zeggen, maar wees vriendelijk. Dit zijn mensen die woest zijn en in nood.”*[126]

> (“The psychiatrists, the psychologists and other mental health care workers are put in a room and they get a briefing. And that briefing goes like this: [...] listen, no matter what happens, you remain friendly. You’re going to get a storm blow over you, I am telling you. Those parents are furious. Know that, and just listen. Be kind and accept it. You don’t have to do anything: you don’t have to say yes, you don’t have to say no, but be kind. These are people who are furious and in need.”)

---

[125] Interview Bas van Raaij, 21 June 2018; interview Annelies Faber, Els Borgesius & Paul Baart, 13 January 2022; interview Cisca Goedhart, 18 November 2022.

[126] Interview Bas van Raaij, 21 June 2018.

Apparently, Labyrint and Ypsilon were able to channel these outbursts, but in the case of the LSOVD, repeated confrontations seem to have stood in the way of building fruitful relationships with addiction care professionals.[127] Bob van Amerongen, as always, kept trying to smooth things over, as is clear from this almost casual closing remark from a long speech of 1991, summarised in an article in the LSOVD newsletter as:

> *“Van Amerongen besluit zijn verhaal om er* [als LSOVD-ouders] *toch vooral niet vanuit te gaan dat de drugshulpverlening een maffia-instelling is, en vraagt aan deze zelfhulpverlening om (groot)ouders niet belachelijk te maken.”*[128]

> (“Van Amerongen concludes with [the request to the LSOVD parents] not to assume that drug addiction care is a mafia institution, and asks care workers in return not to ridicule self-help for (grand)parents.”)

The crusade of LSOVD ‘father-of’ Douwe Bartstra against family-blaming theories and family therapy for addiction in previous years (see Chapter 3) may have played a part here. Under the pseudonym Jan Woelre, Bartstra published a series of furious articles in newspaper *Het Parool* in December 1983, documenting his experiences with his addicted son and the therapists they encountered, and a book based on the articles in 1985.[129] Among his main issues were family-blaming theories and the family therapies based on them that were spreading internationally as well as in Dutch addiction care practice in the early 1980s. This development was helped along by the special section for family therapy set up by the International Council on Alcohol and Addictions in 1979,[130] but most of all by publications by American psychologists Duncan Stanton and Thomas Todd. Their 1982 book on family therapy for drug addiction in particular[131] found its way to addiction care workers all over the Netherlands. Coming from a systems approach, Stanton and Todd made the familiar claim that the function of the addicted ‘identified patient’ in the family was to distract from conflicts between the parents. Many LSOVD

---

[127] Jansen, ‘Openingswoord’; R. van Amerongen, ‘Inleiding van drs. R. van Amerongen op de Provinciale Dag op 16 april 1988 te Amersfoort’, *Info* (1989) 29, 6-11; Van Amerongen, ‘Ouders van drugsverslaafden’.

[128] M. Colijn, ‘Landelijke Dag op 6 april. De OVD in al zijn facetten’, *Info* (1991) 6, 16-19, 19.

[129] Jan Woelre, ‘Heroïne trekt in gezin een vernielend spoor. Ontdekking, woede, verdriet en onmachtige hulpverleners’, *Het Parool* 24 December 1983; Jan Woelre, ‘Een heroïnekind ziet eruit als iemand die kanker heeft’, *Het Parool* 27 December 1983; Jan Woelre, ‘Heroïne en het dogma van de vrije wil’, *Het Parool* 30 December 1983; Jan Woelre, *Mijn zoon is verslaafd. Een lijdensweg door de hulpverlening* (’s-Gravenhage 1985).

[130] P. Crowley, ‘Family therapy approach to addiction’, *Bulletin on Narcotics* 40 (1988) 1, 57-62, 58.

[131] M. Duncan Stanton & Thomas C. Todd, *The Family Therapy of Drug Abuse and Addiction* (New York 1982).

parents were confronted with this kind of thinking in their encounters with addiction care professionals. Initially, it seemed to bring them closer together, but soon systems therapy turned out to be very painful for the parents.[132]

Sociologist Bartstra meticulously scrutinised the scientific literature, and, just like René Sieders of the Stichting Anorexia Nervosa (see Chapter 2), he used every opportunity to publish his dissections of scientific publications that 'proved' that parents and families were to blame and dismissed those publications on account of their questionable methodology.[133] In this case, too, that critical position created tensions in his organisations' relationship with professionals. Apparently, family-blaming needed to go out of fashion before family organisations could make headway in collaborating with the professionals. Around 1990, Bob van Amerongen was hopeful that the hostile approach to the family in addiction care was on its way out.[134] In an LSOVD publication from 1996, it still proved persistent, but by then was less of a problem than the inner feelings of guilt that parents struggled with or the critical attitudes in their environment. In addition, this time, family-blaming theories were refuted by a professional ally the foundation had finally acquired: psychiatrist Els Noorlander.[135]

In order to promote the development of new, alternative scientific insights, Ypsilon took matters into its own hands: in collaboration with psychiatrist Cees Slooff and other mental health care professionals, they set up the Stichting Schizofrenie Nederland (SSN, Schizophrenia Foundation of the Netherlands) in 1989. With this new foundation, they wanted to give a boost to improvements in mental health care for schizophrenia patients and their families, improve education on schizophrenia for lay people as well as professionals, and stimulate research.[136] Although Ria van der Heijden and Bas van Raaij later looked back on the initiative with mixed feelings – regretting how, in their eyes, a lot of money went to professionals instead of directly benefiting patients[137] – in 2012 Ypsilon made Slooff an honorary member for his contributions to their cause.[138] Today operating under the name Phrenos, the SSN has become the leading knowledge institute

---

[132] Van Amerongen, 'Ouders van drugsverslaafden', 118-121.

[133] Jan Woelre, 'De helpers bijeen: "Drugs? Kwestie van onbehagen"', *Het Parool* 15 September 1984; Douwe Bartstra, '8^{e} Wereldcongres van Therapeutische Gemeenschappen in Rome', *Info* (1985) 13, 13-17; Van Amerongen, 'Ouders van drugsverslaafden', 120; D.S.J. Bartstra, 'The peculiar relations between professionals and victims', in: Charles D. Kaplan & Martien Kooyman, *Proceedings of the 15th International Institute on the Prevention and Treatment of Drug Dependence, April 6-11 1986 Amsterdam/Noordwijkerhout (The Netherlands)* (Rotterdam 1987) 332-334.

[134] Van Amerongen, 'Ouders van drugsverslaafden', 121.

[135] Colijn, *De droom van Mary*.

[136] 'Stichting zet zich in voor schizofreniepatiënten', *de Volkskrant* 2 November 1989.

[137] Ria van der Heijden, 'Werk aan de winkel in de psychiatrie', *Ypsilon Nieuws* (2002) 97, 14-15, 14; interview Bas van Raaij, 21 June 2018.

[138] 'Cees Slooff benoemd tot lid van verdienste van Ypsilon', https://www.ypsilon.org/actueel-ypsilon/nieuws/cees-slooff-benoemd-tot-lid-van-verdienste-van-ypsilon/ accessed 5 April 2023.

in the Netherlands advancing the rehabilitation, participation and destigmatisation of people with severe mental health issues.[139]

New laws and policies at work

After having been test-driven for years,[140] the *Wet Bijzondere Opnemingen in Psychiatrische Ziekenhuizen* (*Wet BOPZ*, Law on Special Admissions to Psychiatric Hospitals), the new law regulating involuntary commitment in psychiatric hospitals, became officially effective in 1994. When three years later the new law was evaluated for the first time, Ypsilon, under the leadership of chairwoman Lies Bosscher, did its own survey into its effects. The dozens of cases it collected substantiated the fears the association had expressed since its earliest days. With dozens of detailed case histories, it showed how people experiencing psychosis could reject all care, end up dangerously uncared for, homeless, or jailed because of a crime committed in a psychotic state.[141]

Sadly, this was already becoming public knowledge. Several shocking events involving people with severe mental health issues made the news in the mid-1990s: from homeless people with severe mental health issues freezing to death on cold winter nights, to the murder of a vulnerable and isolated former client in his own apartment in Eindhoven, and the murder of a twelve-year-old school girl on the Amsterdam street where she lived by a neighbour whose psychotic behaviour escalated that day to the fatal point the community had feared for a long time.[142]

To the doctors who assessed patients for involuntary commitment, the new law came with harrowing dilemmas.[143] Mental health care professionals who were responsible for assessing the extent to which these people were a danger to themselves or others often interpreted the law so narrowly that many seriously troubled people were left to their own devices. From the late 1980s, case law going up to the High Court had shown that the danger criterion could be interpreted much more broadly, and the Mental Health Care Inspectorate even published a brochure in 1995 to educate professionals on this point.[144] But lower courts had repeatedly dismissed appeals to the danger criterion if the mental health care worker responsible for the assessment could not argue beyond doubt that a person was a danger to themselves or others.[145] As a result, many of them played it safe, as Ypsilon observed:

---

[139] Homepage Kenniscentrum Phrenos, https://kenniscentrumphrenos.nl/ accessed 19 December 2023.

[140] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 1104.

[141] Bosscher & Stavenuiter, *Bescherming voor psychotische mensen.*

[142] NISV-SVTA, *Brandpunt,* 4 February 1996.

[143] Marjon van Royen, ' "Niet de voordeur zit dicht, maar de achterdeur staat open". De dilemma's van de crisispsychiatrie', *NRC Handelsblad* 24 July 1993.

[144] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 1104-1105.

[145] UA-GKN-F, inv. no. 1492-1490, Louk van der Post, 'Wat kan de RIAGG doen bij dwangopname…', *Eigendruk* (April 1990) 14-16.

"Elke hulpverlener kan erop worden aangesproken als hij of zij achteraf ten onrechte geoordeeld heeft dat sprake is van gevaar. Anders gezegd: wie nu overgaat tot opname, steekt zijn nek uit, want loopt altijd het risico erop te worden 'gepakt'. Het omgekeerde kan echter niet: wanneer iemand ten onrechte oordeelt dat opname niet nodig is, blijft de betrokkene van hulp verstoken zonder dat er iemand op aanspreekbaar is. Bij de geringste twijfel zal de hulpverlener dan ook negatief oordelen over een gedwongen opname."[146]

("Any care worker can be held accountable if he or she has made the wrong judgement that there is a danger. In other words, anyone who decides in favour of commitment now sticks their neck out, because there is always the risk of being 'caught' for it. However, the reverse is not possible: if someone wrongly judges that commitment is not necessary, the person concerned is deprived of help without anyone being held accountable. If there is the slightest doubt, the care worker will therefore deny involuntary commitment.")

Closely related to this situation were the now-noticeable effects of the Dutch deinstitutionalisation policy. In 1987, the country's largest psychiatric hospital Meerenberg in Santpoort started to move its patients out, in particular to smaller and more independent facilities in Amsterdam, a process that would continue slowly but surely until in 2002 the hospital was closed for good.[147] In the long run, more institutions would follow.[148] In most places, deinstitutionalisation was limited to the closing of individual wards or pavilions where chronic patients had spent their lives, while new developments in urban areas only offered 'beds' for short-term stays: increasingly, chronic patients were discharged when their treatment ended and returned to the community and outpatient care. This is how, over the course of the 1990s, Dutch deinstitutionalisation policy slowly became a reality.[149]

Meanwhile, the number of people requiring mental health care services was growing fast. Elderly people with dementia and people with a mental handicap had by then been moved to specialised institutions, their places being taken by patients who were suffering from severe psychotic disorders, personality disorders or addiction.[150] But for new as well as most old patients, spending their lives on a ward was no longer a prospect.[151] However,

---

[146] Bosscher & Stavenuiter, *Bescherming voor psychotische mensen,* 5.

[147] Gemma Blok, 'Enkele reis op z'n retour. Santpoort en het Amsterdamse Model', in: Joost Vijselaar (ed.), *Gesticht in de duinen. De geschiedenis van de provinciale psychiatrische ziekenhuizen van Noord-Holland van 1849 tot 1994* (Hilversum 1997) 238-267; Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 1086.

[148] E.g. the Sint-Franciscushof in Raalte. See: Miek Smilde, *Raarhoek* (Amsterdam, Antwerpen 2011).

[149] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 1085-1100.

[150] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 1098-1099.

[151] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 1053-1055.

construction of the promised half-way housing and community care lagged behind.[152] Upon discharge from a psychiatric hospital, many patients were directly referred to the streets, according to a social worker for the Utrecht police.[153] Half of the thirty thousand homeless people in the Netherlands, it was estimated in 1990, had a psychiatric disorder.[154]

The family organisations all agreed that mental health care policy and practice in the 1990s left a lot of people out in the cold. But they had very different views on how to change the situation for the better. According to Ypsilon, the new laws and regulations on patients' rights and deinstitutionalisation had resulted in a serious lack of care, leading to staggering numbers of patients ending up in jail for a crime committed in a state of psychosis. The organisation was aware of how deinstitutionalisation had derailed abroad and took that as a warning not to copy the model in the Netherlands. Ypsilon continued to plead for assuring care and protection to overrule considerations of a patients' autonomy if that patient displayed an unawareness of their illness, in particular in cases of psychosis. For the same reason, Ypsilon felt involuntary treatment should be made possible for this group. To that end, they drew up a model for a declaration of intent that people who were susceptible to psychosis could use to specify circumstances under which they wanted to be treated even if they denied that when in a psychotic state.[155]

But to Labyrint~In Perspektief, treating people against their will was not care; it was a sign that professionals had not picked up on signals from those with severe mental health issues or their relations in time, that no adequate care had been offered at an earlier stage. That people in crisis refused to be treated was not because they failed to see the severity of their situation, Annelies Faber wrote, but because their previous experiences with mental health care were so bad. To Labyrint~In Perspektief, only outreach care services were the solution, not force.[156]

Slowly but surely moving forward

That the family organisations were able to enter national mental health care debates at this level in the 1990s shows how they had developed. Having focused initially on laying their organisational foundations and building up their mutual support activities, the fact

---

[152] Gerrit Tulp, 'Psychiatrische hulp in Amsterdam deugt niet', *Nieuwsbrief Ypsilon* (1993) 42, 44-47.

[153] 'Voorspelling: "Stations en grote winkelcentra worden gekkenhuizen" ', *Nieuwsblad van het Noorden*, 9 September 1994.

[154] 'Gestoorde dakloze helder in beeld', *Nieuwsbrief Ypsilon* (1990) 29, 36-39, 38.

[155] Gerrit Tulp, 'Column', *Nieuwsbrief Ypsilon* 27 (1990) 13-16, 15; Marjolein Schipper, ' "Om zélf gek van te worden". Duizenden gestoorde medeburgers dagelijkse bron van onzekerheid", *De Telegraaf* 27 March 1993; Gerrit Tulp, 'Column', *Nieuwsbrief Ypsilon* 44 (1993) 12-14, 14; Bosscher & Stavenuiter, *Bescherming voor psychotische mensen,* 7-12; NISV-SVTA, *Reporter,* 16 April 1993; interview Bert Stavenuiter, 27 January 2022.

[156] Annelies Faber, 'De Wet BOPZ bijgesteld… maar hoe zit het met de zorg?', *Relatief* 1 (1997) 4, 3-4.

that they became increasingly politically active testifies to their growing assertiveness and expertise. At the same time, the organisations noticed that efforts to embed the family work in the mental health care organisations were stagnating. Labyrint had successfully built up relationships with RIAGG prevention workers who facilitated mutual support groups for relations, but these professionals did not refer group participants to the family organisation, nor guide them on the way to empowerment.

In addition, the relationships with RIAGG professionals were fragile. They remained unknown beyond the prevention departments and were often broken off because of cutbacks, a change in priorities or a key contact leaving. And if the staff involved in care and treatment did not know, neither did the patients and their families.[157] The LSOVD experienced the exact same thing in its alliance with the CADs. At the ten-year anniversary of the LSOVD in 1990, an addiction care professional concluded that the novelty of the family mutual support groups had worn off inside the CADs, that they were not sure how to move on, and that he hoped that family therapy would offer solace...[158]

It was a matter of perseverance and patience. Labyrint continued to educate mental health care workers about the situation of the family members. To staff members of psychiatric hospital Vogelenzang in Bennebroek, for example – the institution where, by then, Corrie van Eijk-Osterholt might have been a well-known advocate for the case of the relations, as her twin sister Mies Osterholt had moved there in 1978[159] – a meeting with Labyrint volunteers in 1993 was an eye-opening experience. The psychiatric nurses who attended the meeting admitted that they never took the relations into account, or looked at things from their point of view, but the Labyrint volunteers had made them aware that they should involve the family structurally in their work.[160] In addition to educating professionals, Ypsilon launched a charm offensive: publishing guides to best practices, awarding the *Kwaliteitsprijs Schizofrenie* (Quality Prize Schizophrenia) to mental health care organisations which did exceptionally good work for people with schizophrenia, and giving presents to the psychiatric nurses who were so important for the welfare of their loved ones.[161]

Labyrint board member and mental health care researcher Els Borgesius noted in a book she wrote for professionals in 1994 that the message that the relations were important to pay attention to, was slowly getting through to the staff on the workfloors. The contribution of relations to the care of their loved ones with severe mental health

---

[157] Archive Horn, *Jaarverslag 1990* (Utrecht 1991) 15.

[158] A. van de Voort van der Kley, 'Een verslaafde in het gezin', *Info Special* (1990) 16-19, 19.

[159] Corrie van Eijk-Osterholt, *Uitbehandeld. Een kroniek* (Rotterdam 2002) 239.

[160] Maria van Rooijen, ' "Van die kant bekijken wij het eigenlijk nooit" ', *Maandblad Patiëntenbeweging* (1993) 5, 9.

[161] Mary Thewissen-van Velzen, *Witboek over de zorg voor mensen met schizofrenie* (Rotterdam 1992); Grietje Santing, 'Van 't bestuur', *Nieuwsbrief Ypsilon* (1992) 40, 3; Bert Stavenuiter, 'Hulpverleners zoeken oplossing voor "uitvallers". Op de grens van zorg en bewaking', *Ypsilon Nieuws* (1999) 80, 5-9, 9.

issues could no longer be ignored, and neither could the fact that the burden of that care could result in relatives developing mental health problems of their own. As a result of the actions of the family organisations, Borgesius concluded, the relations had become more and more assertive in these matters and professionals had been shown the importance of educating them and involving them in decisions about care.[162]

The actions of the family organisations were increasingly supported by new science. Instead of blaming relations for causing or maintaining their loved one's mental health problems, theories and practices were introduced that left open the question of what caused a person's mental health problems, and focused pragmatically on dealing with them more effectively. In particular, the theory of 'expressed emotion' or 'EE' was gaining ground: the idea that expressing strong emotions to a person with a history of psychosis heightened the risk of relapse (see Chapter 3). Instead of blaming relations for showing such strong emotions, there was a growing understanding that their situation could bring on stress, pain, anger and grief, and a solution was found in training them to handle those emotions in a different way. That cleared the way for professionals to see relations as allies in care, who could help to keep the stress levels of their client down.[163] Borgesius was often invited to give lectures based on her book, and met interested professionals who found it eye-opening that it was possible to collaborate with relations and even benefit from this.[164] The importance of involving the relations in matters of care was underlined increasingly in mental health care organisations' policy documents too.[165]

In the eyes of the family organisations, however, it took a long time for such policies to be put into practice. In the early 1990s, they found, too many mental health care organisations lacked a family council, many professionals were still uninformed when it came to the importance of paying attention to the relations of their patients and all too often relations were not referred to family organisations that had important support to offer. The continuing neglect of the family was particularly poignant in the context of the increasing responsibility that society placed on the family of people with mental health problems, now that patients were admitted to psychiatric hospitals less often and discharged sooner.[166] The concerns of relations with loved ones inside those hospitals

---

[162] Els Borgesius, *Hulpverleners en familie: partners in de zorg. Een handleiding voor hulpverleners in de ggz* (Assen 1994) 1-2.

[163] Borgesius, *Hulpverleners en familie,* 1-2; Oosterbaan, *Omgaan met gekte,* 17-18; John Neill, 'Whatever Became of the Schizophrenogenic Mother?', *American Journal of Psychotherapy* 44 (1990) 4, 499-505; Mary V. Seeman, 'The Changing Role of the Mother of the Mentally Ill: From Schizophrenogenic Mother to Multigenerational Caregiver', *Psychiatry – Interpersonal and Biological Processes* 72 (2009) 3, 284-294.

[164] Interview Annelies Faber, Els Borgesius & Paul Baart, 13 January 2022.

[165] P.C. Baart, 'Familieorganisaties moeten erkenning krijgen', *Maandblad Patiëntenbeweging* (1993) 4, 19; Dercksen & Van 't Hof, *Erkenning gevraagd,* 13.

[166] Baart, 'Familieorganisaties moeten erkenning krijgen', 19; Dercksen & Van 't Hof, *Erkenning gevraagd,* 13.

were also far from over; although the government reported significant progress,[167] the Mental Health Inspectorate's reports showed that the circumstances in many institutions were still a lot worse than those in general hospitals.[168] In addition, the opposition by mental health care providers to seeing the clients' and family organisations play a role as the 'third market player' in the new national health care system under creation by the government was telling.[169]

At the same time, it was also becoming clear that the family organisations were gaining confidence in their dealings with the mental health care field. The empowerment their activities brought to family members was starting to have a noticeable effect. Whereas relations used to feel too guilty or intimidated to ask anything, more and more of them were now confident enough to address their loved one's therapists and nurses.[170] Mother- and family-blaming were still palpable in mental health care and especially in addiction care, but the family organisations were informing their constituents about new developments in psychiatry that promoted working with the family instead, and this may also have helped relations develop a new assertiveness.[171] Improvements were also felt when new members joined with experiences that differed from the 'old' ones: experiences of being heard, being informed and being involved. In the words of Bas van Raaij:[172]

> *"Naarmate mensen eerder op de hoogte zijn van de ziekte en het sneller wordt ontdekt, zie je dat traumatische ervaringen met de hulpverlening, zoals vroeger vaak het geval was, achterwege blijven en* burnout *van familieleden minder voorkomt. Als je vroeger een schizofreniepatiënt in je gezin had, was je in* big trouble. *Ten eerste had je de schuld en ten tweede moest je in gezinstherapie. Dat heeft er volgens mij maar al te vaak toe geleid dat de patiënten*

> ("The sooner people are aware of the illness and the faster it is detected, the more traumatic experiences with care are avoided, and burnout of family members is less common. In the past, if you had a schizophrenia patient in your family, you were in big trouble. First, you were to blame, and second, you had to go to family therapy. All too often, I think, this has led to patients being ostracised because, quite

---

[167] *Onder anderen,* 13.

[168] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 1090.

[169] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 1065-1066; Dercksen & Van 't Hof, *Erkenning gevraagd,* 70-71.

[170] Popkje van der Ploeg, ' "Goed dat psychiaters nu ook onze stem horen" ', *Leeuwarder Courant* 2 September 1989; 'Ouders uit stoel', anonymous letter from 'parents with a life sentence' to the editor of the *Leeuwarder Courant* 14 September 1989.

[171] Santing, 'De zorg voor verblijfspatienten'.

[172] Bert Stavenuiter, 'Bestuur en beleid', *Ypsilon Nieuws* (1995) 55, 28-29; Dercksen & Van 't Hof, *Erkenning gevraagd,* 15.

werden uitgestoten omdat de familie het, heel begrijpelijk, niet meer aankon. Zodoende kwamen veel patiënten op verblijfsafdelingen terecht. De familieleden van patiënten die een goede behandeling krijgen en goed worden geïnformeerd, staan doorgaans veel meer open voor de mogelijkheden van rehabilitatie op het gebied van werken, wonen en opleiding. Ze gaan ook totaal anders met hulpverleners om. Veel gelijkwaardiger, veel geïnformeerder, veel mondiger. Daar heeft Ypsilon een rol in gespeeld, denk ik."[173]

understandably, the family could no longer cope. As a result, many patients ended up in residential wards. The relations of patients who receive good treatment and are well informed are usually much more open to the possibilities of rehabilitation in terms of work, housing and education. They also deal with social workers in a completely different way. Much more equal, much more informed, much more empowered. I think Ypsilon played a role in that.")

The increased confidence was not exclusive to Ypsilon and its members. For example, in the eyes of the family organisations, all psychiatric hospitals and outpatient care organisations in the country should have family councils – just like they had clients' councils, that would be compulsory by law from 1996. Since family councils remained rare, however, in 1993 Labyrint and In Perspektief created an umbrella organisation, the Stichting Landelijke Kamer Familieraden in de GGZ (SLKF, Foundation National Chamber Family Councils in Mental Health Care), making room for it in their own shared office. The SLKF's aim was to help set up and strengthen family councils by offering advice, support and training. It made model agreements available that councils could sign with the boards of institutions, and educated and supported council members with annual meetings, training and newsletters.[174] This brought results: in 1997, more than half of all psychiatric hospitals had a family council.[175]

Another sign of the increasing strength of the family movement was how it was able to gain broad support for the guidelines it developed for mental health care professionals. Labyrint was the leader in this, figuring out solutions that helped the relations, while leaving patients' rights untouched. For example, many professionals shut the family out completely for fear of violating the patient's privacy, but the guidelines explained to them how relations could be supported with general information on the workings of the institution, severe mental health issues and how to cope with the symptoms without jeopardising patient confidentiality. Guidelines showed how to communicate and collaborate with the family in the interest of patient and family alike, while navigating

---

[173] Dercksen & Van 't Hof, *Erkenning gevraagd,* 15.

[174] Personal archive Karin Groen, Karin Groen, 'Terugblik 20 jaar SLKF' (2013).

[175] M.I. Bosma, 'Brief aan minister Borst', *Relatief* 1 (1997) 1, 25.

the precarious balance between the autonomy of clients and advocacy for relations. Despite the continuing frictions between Labyrint, In Perspektief and Ypsilon, they co-published the first set of guidelines in 1992.[176]

That same year, the LSOVD settled its own agreement with three umbrella organisations in addiction care.[177] Upon later evaluation, this turned out to have had a limited effect in the addiction care organisations it was aimed at, but it had been effective in empowering relations in their dealings with professionals.[178] That may have been the primary effect of the mental health care guidelines, too.[179] What also mattered was that the consecutive guidelines brought ever more parties together. Towards the end of the decade, the *Modelregeling Betrokken Omgeving* (Model Agreement Involved Environment), was not only the product of collaboration between Labyrint~In Perspektief, Ypsilon and the LSOVD, but with the Cliëntenbond, the LPR (Landelijke Patiëntenraden, National Patient Councils) and GGZ Nederland (the umbrella organisation of the mental health care providers) as well.[180] Such collaboration on guidelines is illustrative of the way that, in the 1990s, the first seeds of a development towards a more coherent family and clients' movement were slowly but surely sown.

The clients' movement

The young family organisations of the early 1980s entered a field where, as we have seen, clients' organisations in mental health care had established themselves since the 1960s and 70s. There were the diagnosis-oriented organisations – like AA and Al-Anon, the Fobieclub, the Nederlandse Vereniging voor Autisme (NVA, Dutch Association for Autism) and the Stichting Anorexia Nervosa – each working in its own specialised field. There were the undifferentiated organisations like the Cliëntenbond, Pandora and the recent addition of De Wegwijzer (The Signpost, 1981), a Reformed-Church organisation for patients with any type of mental health problems and their relations that arose almost simultaneously with In Perspektief, but in a different branch of Reformed Christianity.[181]

There were also local and regional initiatives that were influential on the national level, like the Rotterdam Junkiebond (Junkie League). Wearing the derogatory term

---

[176] Pieter Ippel & Linda Horn, *Richtlijnen voor een zorgvuldige communicatie tussen hulpverleners en familieleden van psychiatrische patiënten* (Utrecht 1992).

[177] M. Fris & J.E. de Leeuw den Bouter, *Ouders Van Drugverslaafden en de hulpverlening. Evaluatie van het convenant* (Utrecht 1994) [1].

[178] Fris & De Leeuw den Bouter, *Ouders Van Drugverslaafden en de hulpverlening,* 27.

[179] Interview Linda Horn & Lineke Marseille, 28 May 2021.

[180] 'Modelregeling GGZ-instelling / familie en naastbetrokkenen', *Relatief* (1998) 1, 32.

[181] Erik Koning, 'De eerste jaren', *De Wegwijzer* (2013) 2, 8-17.

'junkie' as a badge of honour, this was the first association of drug users, established in 1980 just like the LSOVD. Its example was soon followed in other cities.[182] Other influential local and regional initiatives brought together clients or users with relations and professionals, notably the Medisch-sociale Dienst Heroïne Gebruikers (MDHG, Medico-social Service Heroin Users, 1977) in Amsterdam,[183] the Rotterdam Basisberaad GGZ Rijnmond (Rijnmond Mental Health Care Base Council, 1980)[184] and the Platform GGZ Amsterdam (Amsterdam Mental Health Care Platform, 1983).[185] But dominant in the early 1980s clients' movement were the national, undifferentiated 'big three': the Cliëntenbond, Pandora and the Landelijke Patiëntenraden (LPR, National Patient Councils), the national umbrella of the clients' councils in mental health organisations.

The reception of the undifferentiated family organisations

As we saw in Chapter 3, by the early 1980s, Pandora's years as an elitist educational foundation that promoted the biomedical model were in the past, and it had developed into one of the most fervent supporters of the social explanatory model. The Cliëntenbond was increasingly moving beyond merely protesting poor practices and mistreatment towards formulating its own alternative views on how mental health care should move forward. The LPR entered the scene in 1981, and so did the Stichting Patiëntenvertrouwenspersoon (Stichting PVP, Patient Advocate Foundation), the independent employer of patient advocates in the institutions.[186] Despite their mutual differences, Pandora, the Cliëntenbond and the LPR co-ordinated their actions and were increasingly involved in the development of new laws and policies. At the same time, parts of their constituencies – mainly the Cliëntenbond's – were radicalising because of their disappointment with the changes in mental health care.[187]

In this radicalising part of the clients' movement, the family organisations entering the arena were a touchy subject. As we saw in Chapter 2, in the clients' movement of the early 1970s, loyal relations had generally been regarded as victims of psychiatry just like

---

[182] Dercksen & Van 't Hof, *Erkenning gevraagd,* 40-42; Blok, *Ziek of zwak,* 213; Gemma Blok, 'The politics of intoxication. Dutch junkie unions fight against the ideal of a drug-free society, 1975-1990', in: Martin Dinges & Robert Jütte (eds.), *The transmission of health practices (c. 1500 to 2000)* (Stuttgart 2011) 69-88.

[183] Blok, *Ziek of zwak,* 213-214; the MDHG archive shows that, in the early 1980s, there were even some activities specifically focused on parents of people with an addiction (International Institute of Social History, Amsterdam, ARCH01540 Archive MDHG Amsterdam, box 20 Stukken betreffende: kinderen van verslaafde ouders/ouders van verslaafde kinderen (E/1)).

[184] Hunsche, *De strijdbare patiënt,* 206, 211.

[185] Marian Vink & Daan Stremmelaar, *Krachtige mensen in beweging. Geschiedenis van de patiënten- en cliëntenbeweging in Amsterdam* (Amsterdam 2022) 40-44.

[186] Stichting Patiëntenvertrouwenspersoon Geestelijke Gezondheidszorg, *Verslag 1981-83* (Utrecht 1983).

[187] Hunsche, *De strijdbare patiënt,* 83, 134.

patients. That is how in the Cliëntenbond, some of the founding 'parents-of' remained pillars of the organisation for many years. By the end of the 1970s, however, as we saw in Chapter 3, their involvement had become a matter of debate, resulting in 'father-of' Arie Groot handing over the chair of the league to Hans van der Wilk in 1979.

Activist Jan van den Berg, whose critical words towards the new family organisations closed Chapter 3, called the relations *'de nieuwe zaakwaarnemers'* ('the new meddlers'), referring to the term that had been used to exclude professional sympathisers from the Cliëntenbond ten years earlier. He accused the family members of whining about their imaginary suffering, and bonding with mental health care professionals against the clients, whom he, in classical anti-psychiatry terminology, referred to as the 'weak', 'hollowed out', 'torn apart', as people who were unable, with their 'maimed identity', to resist and speak out.[188] In response to Van den Berg's criticism, Labyrint's Linda Horn explained that she shared his worries about a new alliance between psychiatrists and relations against clients and therefore saw a place for her organisation *alongside* the clients' movement, not opposite. She intended to cherish the contacts the family organisation had with Pandora, the Cliëntenbond and the LPR.[189]

The feeling was mutual. In fact, the office space Labyrint moved into in Utrecht in 1986 had previously been occupied by the Cliëntenbond, and was a few doors down from the headquarters of the Stichting PVP, where the family organisation was welcome to use the meeting room.[190] In addition, Labyrint invited Corrie van Eijk-Osterholt, the renowned 'twin sister-of' who epitomised the clients' movement of the 1970s (see Chapter 2), to become the organisation's honorary chairwoman.[191] She accepted, but was critical towards it too – in fact, she targeted its most fundamental position and repeatedly spurred Labyrint on to advocate in the interests of patients too, especially for those who lived in institutions where circumstances were still dire. With that position, Van Eijk-Osterholt actually came much closer to Ria van der Heijden's and Ypsilon's position, than to Labyrint's main stance.[192]

---

[188] Jan van den Berg, 'Familieleden en de psychiatrie', *Maandblad Geestelijke Volksgezondheid* 42 (1987) 1, 60-63.

[189] Interview Linda Horn & Lineke Marseille, 28 May 2021.

[190] Interview Linda Horn & Lineke Marseille, 28 May 2021; interview Annelies Faber, Els Borgesius & Paul Baart, 13 January 2022.

[191] UA-GKN-F, inv. no. 1492-1490, 'Congres Met Recht Betrokken', *Eigendruk* (July 1990) 2-4, 2.

[192] Van Eijk-Osterholt, 'Familieleden en de psychiatrie (2)'; C.A. van Eijk-Osterholt, ' "When we are born, we cry that we are come to this great stage of fools" ', in: L.M. Horn, O.P.F. Oldenburg & J.H. Scholma-Hofdijk, *Met recht betrokken. Verslag van het eerste lustrumcongres van de Stichting* Labyrint, *gehouden in samenwerking met de sectie gezondheidsrecht van de juridische faculteit van de Vrije Universiteit op woensdag 9 mei 1990* (Utrecht 1991) 59-66, 62-63.

The reception of the diagnosis-oriented family organisations

The diagnosis-oriented organisations of the 1970s were meanwhile operating in their own particular fields, away from the tensions in the mainstream clients' movement. The parents in the NVA (Nederlandse Vereniging voor Autisme, Dutch Association for Autism) continued to advocate in the undivided interests of their severely autistic children and themselves, and achieved a major success when in 1984, the *Nota Autisme* (Autism Memorandum) was published by State Secretary of Health Joop van der Reijden.[193] Even though the document was criticised for not allocating enough money to improving care for autistic children, for the NVA it was a turning point.[194] Likewise, the needs the Stichting Anorexia Nervosa had exposed were acknowledged when, in 1984, the Gezondheidsraad (Health Council) was ordered by the Ministry of Welfare, Health and Culture to survey the state of Dutch anorexia care. It would take five years for the survey to be published, but it would confirm everything the foundation had protested against and be followed up by policies that would result in improved practices for these patients and their families.[195]

In 1987, a new foundation in mental health care was set up for people with severe mental health problems and their relations: the Nederlandse Stichting voor Manisch Depressieven (NSMD, Dutch Foundation for the Manically Depressed). Despite the fact that the Fobieclub, the NVA, the Stichting Anorexia Nervosa, the LSOVD and Ypsilon had preceded it, the NSMD is often considered the first Dutch diagnosis-oriented mental health clients' and family organisation[196] – or more generally speaking, the 1980s are considered the decade when diagnosis-oriented organisations first appeared in the Netherlands.[197] The previous chapters have amply shown that that is not the case. What is clear, is that the start of the NSMD can be considered the start of a wave of new diagnosis-oriented organisations that would mark the 1990s.

For the LSOVD, however, being diagnosis-oriented was not just a matter of choice – joining an undifferentiated family organisation was no option for the relations of people with an addiction. This situation echoed what they encountered in the care system. Although many people with an addiction also struggled with other severe mental health issues, addiction care would not help them because of those issues, while mental health care would not help

---

[193] 'Hulpverlening aan autistische kinderen laat te wensen over', *de Volkskrant* 30 November 1984; 'Beleidsnota autisme van de Interdepartementale Stuurgroep Gehandicaptenbeleid (ISG)', *Engagement* 12 (1985) 1, 19-43; 'De ISG-nota "Autisme", een commentaar van dr. H. Baartman, secretaris bestuur NVA', *Engagement* 12 (1985) 1, 45-51.

[194] 'Van der Reijden botst met Tweede Kamer over autisme', *NRC Handelsblad* 28 March 1985; interview Willem Momma, 29 November 2018,

[195] René Sieders, '20 jaar', *ANtenne* (October 1998) 107, 4-7, 5.

[196] Hunsche, *De strijdbare patiënt,* 145.

[197] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 929.

them if they were not clean.[198] Chapter 3 outlined how in those early years, the other family organisations did not consider addiction to be something that concerned them, making them keep their distance from the LSOVD. As a consequence, Bob van Amerongen noted with regret in 1989, no mutual relationships developed between the LSOVD and Labyrint and Ypsilon. To him, that added to the isolation of parents of people with a drug addiction.[199]

By contrast, the diagnosis-oriented Ypsilon was received as part of the new family movement and grouped together with Labyrint and In Perspektief – despite the fact that the organisations had very different ideological backgrounds and, indeed, Ypsilon was actually focused on a single diagnosis. The simultaneous start of the organisations in the early 1980s will have played a role in that. But it will also have had something to do with Ypsilon's focus on 'schizophrenia', which – even though the term had been banned – was a central concern in mainstream psychiatry and in anti-psychiatry in particular.[200] Other severe mental health issues, such as autism and anorexia nervosa, as we have seen, were not. The problem of the organisations active in those fields was the lack of specialised expertise and care. Ypsilon's problem was that there was an abundance of expertise regarding psychosis and schizophrenia, but that, in their eyes, it was the wrong kind of expertise, the anti-psychiatry, family-blaming kind of expertise. As a consequence, there was also nothing to be gained for Ypsilon in the mainstream clients' movement of the 1980s, which was still rooted in anti-psychiatry and dominated by the Cliëntenbond and Pandora. The feeling was mutual.

To collaborate or not to collaborate

Despite the reservations of those in the clients' movement towards the family organisations, there were opportunities for collaboration. That was of course quite natural in the case of Labyrint. Linda Horn and Lineke Marseille, each with one foot in Pandora and the other leg in Labyrint, carefully carved out ways to work together without crossing the line where the family organisation's involvement would turn into the 'meddling' that both sides despised. Departing from the idea that information about mental health care was in the interest of both clients and relations, one of the first projects they undertook was to compile a two-part guidebook: one part for the client, one for the relations.[201] Labyrint would always coordinate its advocacy actions with the clients' movement, careful never to go over its head or behind its back.[202]

---

[198] Dercksen & Van 't Hof, *Erkenning gevraagd,* 75.

[199] Van Amerongen, 'Ouders van drugsverslaafden', 123.

[200] Blok, *Baas in eigen brein,* 48-52.

[201] Archive Horn, *Jaarverslag 1989* (Utrecht 1990) 13.

[202] Interview Linda Horn & Lineke Marseille, 28 May 2021; interview Annelies Faber, Els Borgesius & Paul Baart, 13 January 2022.

The LSOVD was in contact with the local Junkiebonden (Junkie Leagues) from the start,[203] but disagreements on addiction policies and practices seem to have divided them too deeply to work together. On the issue of methadone treatment, for example, the LSOVD felt in its early years that this could only be a first step towards abstinence,[204] while the Junkiebonden saw it as the best way to free users from the perpetual fear of having to go cold turkey.[205] After the LSOVD lost its first chairman Rinus Jansen in 1985, it seems to have lost touch with the Junkiebonden, too.

Surprisingly, a collaboration developed also between the family organisation and the clients' organisation that found themselves in radically opposed corners of the activist field. As early as March 1986, vice-chairman of the Cliëntenbond Paul van Trigt shared the stage of the *Breingeindag* (Brain Fun Day), the opening day of the annual *Week van de Psychiatrie* (Psychiatry Week), with Ypsilon chairwoman Ria van der Heijden. For Van Trigt, working together with the family organisation was a highlight, a new step in empowering clients and relations. But local contacts between Ypsilon and the Cliëntenbond in Rotterdam were met with such negative reactions from other members of the Cliëntenbond that their local collaboration had to go underground.[206] Ypsilon's Bas van Raaij remembers that they all had to be careful:

> "*... dat was geheim. Omdat op het moment dat dat uit zou lekken, dan zou de pleuris uit zijn gebroken.* [...] *wij* [Ypsilon] *waren om het maar kort door de bocht te zeggen, en misschien waren het wel beelden, maar wij waren vijanden van de stichting Pandora en van de Cliëntenbond.*"[207]

> ("... that was a secret. Because the moment that that might come out, the shit would have hit the fan. [...] we [Ypsilon] were, to put it bluntly, and maybe these were images, but we were enemies of the Pandora foundation and of the Cliëntenbond.")

Between September 1986 and the autumn of 1988, representatives of the Rotterdam Cliëntenbond chapter, Ypsilon, the Deltaziekenhuis psychiatric hospital and local RIAGGS met regularly at the hospital.[208] Working side by side, Van Trigt and Van der Heijden also

---

[203] Q.A. Jansen, 'De driehoek verslaafde-ouder-hulpverlener', *FZA Kwartaalberichten* 6 (1981) 4, 8-10, 10; Charles Langeveld, 'We zijn moe, maar wel strijdlustig', *FZA Kwartaalberichten* 6 (1981) 4, 11-12, 12.

[204] 'Vervolg Verslag van de Eerste Regionale Oudercontactdag van de Landelijke Stichting "Ouders van Drugverslaafden" ', *Info* (1984) 11, 3-10, 9.

[205] Blok, *Ziek of zwak,* 214.

[206] Interview Paul van Trigt, 30 November 2021.

[207] Interview Bas van Raaij, 21 June 2018.

[208] Rotterdam City Archive, Archive Psychiatrische Inrichting Maasoord later Deltaziekenhuis, access no. 230-04, inv. no. 250: letter from M.H. Cohen Stuart to J. Hardon et al., 12 September 1986,

developed thematic guides for moderators of Ypsilon's mutual support groups.[209] Van Trigt envisioned a reformist course for the league, aimed at collaboration with mental health care workers and family members. But opposed to the reformers in the Cliëntenbond stood the radical abolishers: chairman Ed van Hoorn, who had succeeded Hans van der Wilk in 1982, and other prominent members who were radically opposed to any reform of mental health care and pursued its complete abolition.[210]

The opposition between radicals and reformers in the Cliëntenbond must have reminded more than a few of its members of similar struggles that were going on in the Dutch women's movement at the time. There, throughout the 1970s, a heated debate arose on whether or not to participate in the channels that were opening up for implementing feminist ideals, like government commissions and ministerial emancipation departments. Reformers who wanted to take these opportunities found themselves heavily criticised by radicals who felt that such a course would lead to being swallowed up by the very system that they were so opposed to. While reformers moved ahead within the system and made use of the subsidies it offered, radicals set up independent volunteer initiatives based on self-help, like women's social and care services. When in the long run, the continuity of those services was jeopardised, a turn was made towards subsidised professionalisation after all. Heavily criticised by the radicals in the movement, this 'paid revolution' symbolised how over the 1980s in the Dutch women's movement a pragmatic, reformist approach took precedence.[211]

In the Cliëntenbond, however, the radical spirit prevailed. Despite the fact that chairman Van Hoorn saw the league increasingly being sucked into conference rooms, and saw its members – including himself – develop into professional participants because they needed to make a living, the radical spirit remained alive even after he stepped down in 1986. At least, that is what Van Trigt experienced when he became the next national chairman and tried to get the Rotterdam example accepted on the national level. In his eyes, the Cliëntenbond was not a union that was against psychiatry, but a union of users of psychiatry, and there should be room for both radicals and reformers.[212] But instead, in an atmosphere of disappointment with the direction the restructuring of the mental health care sector was taking, the Cliëntenbond started moving away from allies and increasingly

---

C.S.[Cohen Stuart], 'Persoonlijk verslag van de 1e Ypsilon – Cliëntenbond – Psychiatrie – ontmoeting op 28 oktober 1986', and untitled note from M.H. Cohen Stuart to De Visser, 1 Augustus 1988.

[209] Interview Paul van Trigt, 30 November 2021, interview Bas van Raaij, 21 June 2018; personal archive Paul van Trigt, handwritten notes thematic guides, ca. 1985, handwritten notes Breingeindag 1986.

[210] Hunsche, *De strijdbare patiënt,* 116-119.

[211] Joyce Oudshoorn, 'Half werk. Vrouwenbeweging, emancipatie en politiek, 1950-1990', *Leidschrift* 17 (2002) 9, 35-52.

[212] Interview Paul van Trigt, 30 November 2021.

alienated the reformers in its own constituency.[213] In the eyes of Van Trigt, the league pulled away just as possibilities opened up for getting what they had always asked for. Disillusioned, he left the organisation, and indeed the entire clients' movement in 1988:

"Ik ben eruit gestapt. Ik was uit-, ik was uitgepraat. En niet alleen ik hoor, ook dat strominkje zeg maar. We waren uitgepraat. [...] *We kregen niet... er was niet de ruimte om door te gaan op dit spoor."*[214]	("I got out. I was done, I was done talking. And not only me, but also that small current, so to speak. We were done talking. [...] We didn't get... there was no space to continue on this track.")

The boom in diagnosis-oriented organisations

"Patiënten met ziekte-inzicht zitten bij Anoiksis, anders word je geen lid van zo'n club. Bij Ypsilon zitten vooral ouders van patiënten die medicatie weigeren. Dat maakt ook dat [die ouders] *vaak van die radicale standpunten hebben. Dat ze sowieso dwang voorstaan in de psychiatrie, veel meer dan de andere partijen eigenlijk."*[215]	("Patients with illness-awareness are in Anoiksis, otherwise you would not become a member of a club like that. At Ypsilon, there are mainly parents of patients who refuse medication. That is also why [those parents] often have such radical views. Why they advocate coercion in psychiatry, much more than the other parties.")

Looking back in this quote, Maarten Vermeulen drew clear lines between Ypsilon and Anoiksis, the association he initiated in 1993 for people who, like himself, had experienced psychotic episodes and received a schizophrenia diagnosis. It was not an initiative against Ypsilon – in fact, it had originated there. After Ria van der Heijden had stepped down as Ypsilon's chairwoman in 1989, one of the many things she kept doing for the organisation was to host annual meetings for schizophrenia patients in her living room.[216] Vermeulen was among the first participants. At the second meeting, in 1992, he announced that he intended to set up an association of schizophrenia patients. Afterwards, Van der Heijden and her son Bas van Raaij danced with joy. Although Ypsilon had never shied away from

---

[213] Hunsche, *De strijdbare patiënt,* 116-119, 134; cf. Vink & Stremmelaar, *Krachtige mensen in beweging,* 38-39.

[214] Interview Paul van Trigt, 30 November 2021.

[215] Hunsche, *De strijdbare patiënt,* 174.

[216] 'Ledenvergadering op Landelijke Dag Ypsilon', *Nieuwsbrief Ypsilon* (1990) 24, 5-6.

speaking for 'their patients', they supported those who were able to advocate for their own interests, like Vermeulen, in organising for themselves.[217]

Although Anoiksis deserves special mention here because it was born from Ypsilon, so to speak, at the same time it was a typical example of the dozens of new, diagnosis-oriented organisations that emerged through the 1990s.[218] In 1996, researchers counted thirty-five diagnosis-oriented and eighteen undifferentiated patient and hybrid organisations, and twelve family organisations, that were, on closer inspection, almost all diagnosis-oriented.[219] Six years later, a follow-up study counted thirty diagnosis-oriented, four undifferentiated and ten family organisations.[220] The tendency was clear.

The clients' movement of the 1990s, however, was still dominated by the organisations of the 1970s and 80s – in fact, the Cliëntenbond, the LPR and Pandora saw themselves and were seen by others as *the* clients' movement. That movement and the diagnosis-oriented organisations were worlds apart. Rooted in the social perspective of the previous decades, those in the clients' movement abhorred the now-popular idea that mental health problems were illnesses, and that such problems should be dealt with by doctors, in institutions, with medication. In 1987, Labyrint's Linda Horn had already noticed this development with concern:

> *"Wat ik zo ontzettend eng vind is dat het zo in de medisch-diagnostische hoek getrokken wordt* [...]. *Persoonlijk zou ik het liefste zien dat ze allemaal bij de Cliëntenbond zouden horen, maar dat*

> "What I find so incredibly scary is that it is pulled into the medical-diagnostic sphere so much [...]. Personally, I would prefer that they all belonged to the Cliëntenbond, but apparently that does

---

[217] Hunsche, *De strijdbare patiënt,* 173; interview Bas van Raaij, 21 June 2018.

[218] Hunsche, *De strijdbare patiënt,* 162; Dercksen & Van 't Hof, *Erkenning gevraagd,* 40.

[219] Dercksen & Van 't Hof, *Erkenning gevraagd,* 19. The twelve family organisations Dercksen and Van 't Hof listed (under the heading *mantelzorgorganisaties*, informal caregiving organisations) in 1996 were: In Perspektief, Labyrint, Ypsilon, the Alzheimerstichting, Al-Anon ACA, Al-Anon Alateen, the LSOVD, De Cirkel (oudervereniging van bodemloze kinderen, association of parents of children with attachment disorder), Vereniging Bas (Nederlandse Vereniging voor Hyperactiviteit, Dutch Association for Hyperactivity), Balans (Landelijke Vereniging voor Gedrags- en Leerproblemen, National Association for Behavioural and Learning Problems), the Nederlandse Vereniging voor Autisme and the Stichting Partners van Oorlogsgetroffenen (Foundation Partners of Victims of War). They seem to have considered all family organisations as diagnosis-oriented (Dercksen & Van 't Hof, *Erkenning gevraagd,* 39).

[220] Sonja van 't Hof & Tamara Verstegen, *Ervaring gebundeld. Organisaties van patiënten, cliënten en hun familie in de geestelijke gezondheidszorg* (Houten, Diegem 2002) 17. The ten family organisations Van 't Hof and Verstegen listed in 2002 were: Al-Anon, Alateen & Al-Anon ACA, Algemene Oudervereniging De Knoop (General Parents' Organisation The Knot, for parents and caretakers of children with attachment disorders), Alzheimer Nederland (the former Alzheimerstichting), Balans, De Cirkel, Labyrint~In Perspectief, the LSOVD and Ypsilon.

gebeurt kennelijk niet. [...] *Ik heb ook het idee dat ze zich toch wel als echt ziek zien en dat vind ik nog veel enger.*"[221]

not happen. [...] I also have the idea that they really see themselves as ill and I find that even scarier."

The Cliëntenbond was holding on to its social perspective, now focusing its protests on coercion and compulsion practices, in particular on the use of electroshock therapy.[222] But an increasing number of people with mental health issues did not feel comfortable with that perspective. Partly as a result of the improvements in mental health care, however imperfect and incomplete, their experiences were different: the antagonism between people with mental health issues, doctors and relations was diminishing, while the biomedical explanation model had also reached the lay public. Some people who had experienced psychosis, for example, referred to themselves as patients and spoke out about how they felt it was a good thing to have been involuntarily committed and treated with medication or even stronger methods against their will.[223]

These patients did not connect with the radical atmosphere in the undifferentiated clients' movement. Reciprocally, it did not go unnoticed to some inside that movement that it was losing touch with a new generation of clients who accepted the idea that they had a mental illness, and chose to work with psychiatry instead of against it.[224] Cliëntenbond member Doke Oosterholt saw this happening and urged the league to move with the times, to allow a much broader spectrum of beliefs, to engage with patients who felt more comfortable with the biomedical interpretation of their mental health issues than with the uncompromisingly social view of the Cliëntenbond.[225] In the eyes of fellow member Marlieke de Jonge, however, the problem was that Oosterholt had gotten stuck in 'anti-anti-psychiatry'.[226] Despite continued debates between 'reformers' and 'radicals' that left both sides feeling misunderstood,[227] the atmosphere in the Cliëntenbond and Pandora remained hostile towards the biomedical perspective and those who embraced it. There was no room for people who had positive experiences with their therapists, or who considered themselves mentally ill.[228] As a result, for example, Fred Bos, the founder of the NSMD, never even got in touch with the Cliëntenbond.[229]

---

[221] Quoted in Dercksen & Van 't Hof, *Erkenning gevraagd,* 74-75.

[222] Hunsche, *De strijdbare patiënt,* 161.

[223] Bert Stavenuiter, 'Een uniek moment; letterlijk...', *Ypsilon Nieuws* (1994) 50, 20-22.

[224] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 1108.

[225] Doke Oosterholt, 'Genezen van jezelf (2)', *Maandblad Geestelijke Volksgezondheid* 45 (1990) 2, 183-184.

[226] Marlieke de Jonge, 'Antwoord', *Maandblad Geestelijke Volksgezondheid* 45 (1990) 2, 184-185.

[227] Hunsche, *De strijdbare patiënt,* 116-117.

[228] Dercksen & Van 't Hof, *Erkenning gevraagd,* 38.

[229] Hunsche, *De strijdbare patiënt,* 158.

In short, with the rise of the diagnosis-oriented organisations, the biomedical turn in psychiatry over the 1990s also trickled down to the clients' movement. Perhaps, Dercksen and Van 't Hof suggest, the clients' movement had brought that on by their own actions:

"Wellicht waren de acties van de cliëntenbeweging in de zeventiger jaren een voorwaarde voor het ontstaan van zovele ziektegebonden organisaties in de jaren tachtig en negentig. Omdat de houding van de overheid en de hulpverleners tegenover cliënten in het algemeen is veranderd, kon aandacht ontstaan voor de verschillende behoeften van bijvoorbeeld mensen met schizofrenie, met een geschiedenis van fysieke, emotionele of seksuele mishandeling, of met eet- of gokproblemen."[230]	("Perhaps the actions of the clients' movement in the 1970s were a prerequisite for the emergence of so many diagnosis-oriented organisations in the 1980s and 1990s. Because the attitude of the government and the care providers towards clients in general has changed, attention could arise for the different needs of, for example, people with schizophrenia, with a history of physical, emotional or sexual abuse, or with eating or gambling problems.")

For family members, the rise of the diagnosis-oriented organisations also signified change. Whereas the undifferentiated clients' movement was suspicious of them or even hostile towards them, the new diagnosis-oriented clients' organisations saw them as allies and often welcomed them as members, just as the NVA and the Stichting Anorexia Nervosa had always been open to patients and relations alike. The LSOVD would move in the same direction, redefining itself as an organisation for both people with a drug addiction and their relations in 1996.[231]

For Ypsilon, the rise of the diagnosis-oriented organisations brought a new ally, Anoiksis. Even if they did not always agree on specific issues, the fact that they looked at things from a similar perspective made it easy and natural for them to collaborate. For Labyrint~In Perspektief, the development went against everything they believed in. Even though their constituents started asking for mutual support groups based on diagnosis around the turn of the century, board member Margriet Mannak would not hear of it, as to her, the similarities in the experiences of patients and relations were more prominent than the differences.[232] As a result, Labyrint~In Perspektief's relationship with

---

230 Dercksen & Van 't Hof, *Erkenning gevraagd,* 88-89.
231 'Van het bestuur', *Info* (1996) 59, 3-4.
232 Interview Margriet Mannak, 21 September 2021.

the undifferentiated, mainstream clients' movement remained better than Ypsilon's.[233] But like in Rotterdam in the late 1980s, if there was a personal connection, close local collaborations that were the exception to the rule could still blossom. In Amsterdam, for example, Ypsilon's Kees Zwarthoed and Anneke Bolle of the Cliëntenbond operated in remarkable unity for many years.[234]

Representation and inclusion

In 1996, four hundred thousand patients were registered in some form of mental health care in the Netherlands, including psychogeriatric and addiction care.[235] That same year, just how many Dutch people encountered psychiatric problems at some point in their lives was brought to light by the first systematic study on the subject: an impressive 41.2%, in a population of fifteen and a half million people.[236] It was more and more obvious that the potential of the clients' and family movement was enormous, even for the organisations that had specific target groups. But the size of the family organisations' constituencies remained modest. In 1994, Ypsilon had four thousand two hundred members, an estimated one thousand regular participants in mutual support groups and at least a hundred active volunteers.[237] Slowly continuing to grow, it would count about six thousand five hundred members towards the end of the century.[238] In Perspektief, Labyrint and the LSOVD were foundations, making it harder to quantify their constituencies. In 1994, In Perspektief brought together an estimated one hundred fifty to two hundred relations and volunteers who participated regularly in mutual support groups,[239] Labyrint had eighty volunteers and four hundred donors,[240] while in 1996 the LSOVD counted six hundred constituents.[241]

It puzzled the family organisations of the 1980s why more people did not join them.[242] Was stigma the main cause, as the experiences of the LSOVD with the media suggest? Were relations too overburdened to join, because they felt obliged to volunteer but did not have time or energy to spare? Were membership fees or newsletter subscription prices

---

[233] Interview Annelies Faber, Els Borgesius & Paul Baart, 13 January 2022.

[234] Interview Bert Stavenuiter, 27 January 2022.

[235] Dercksen & Van 't Hof, *Erkenning gevraagd,* 17, 19-21.

[236] R.V. Bijl, A. Ravelli & G. van Zessen, 'Prevalence of psychiatric disorder in the general population: results of the Netherlands Mental Health Survey and Incidence Study (NEMESIS)', *Social Psychiatry and Psychiatric Epidemiology* 33 (1998) 12, 587-595.

[237] Elias & Van Santen, *Drie familie-organisaties GGZ,* 10.

[238] E-mail Bert Stavenuiter, 27 January 2022.

[239] Elias & Van Santen, *Drie familie-organisaties GGZ,* 5-6.

[240] Elias & Van Santen, *Drie familie-organisaties GGZ,* 8.

[241] 'Van het bestuur', *Info* (1996) 59, 3-4, 3.

[242] 'Van het bestuur', *Info* (1996) 59, 3-4, 3; interview Linda Horn & Lineke Marseille, 28 May 2021; interview Bert Stavenuiter, 27 January 2022.

a deterrent, even when all organisations had arrangements in place for those who could not afford them? Or was it because the organisations offered a lot of their information and activities without cost or obligation, and thus there was no need for people to become a member or a donor if they wanted to make use of them?

We can only speculate about the answers, but it is possible to shed a different light on the matter. A 1996 survey of the Dutch clients' and family organisations showed that it was quite normal for all of them to represent only a fraction of their potential constituencies. At that point in time, the boom in the number of organisations was already underway, and dozens of predominantly diagnosis-oriented organisations now dotted the landscape. Researchers Adrianne Dercksen and Sonja van 't Hof compared the organisations' estimated combined constituencies of fifty three thousand people (about half of them clients, the other half family members) to the number of four hundred thousand registered patients, and concluded that only 7% of mental health care clients joined an organisation, and even smaller proportions of the relations.[243] More recent research confirms that this is the participation percentage in patients' and family organisations across the whole range of health care, including mental health care.[244] In other words, the combined formal memberships and constituencies of the family organisations were small, but quite normal.

The small size of the family organisations had the consequence that their human resources, financial means and advocacy power remained limited. However, that did not mean that their significance was limited. In addition to their importance for individuals who found support in an organisations' activities, Dercksen and Van 't Hof wrote, the continued advocacy of clients' and family organisations benefited all clients and relations. They had broken taboos, protested against poor circumstances and inadequate medical and interpersonal treatment of patients in mental health care organisations, and demanded a voice in decision-making. As a result, a lot had changed. The situation in Dutch mental health care around the turn of the century was not comparable with that of thirty years before. Despite its small size and shortcomings as far as representativity was concerned – who the true client representative was, was impossible to answer – the clients' and family organisations were the closest thing to a united voice of clients and relations.[245]

A particular concern of the family organisations with regard to representation was that the people who turned up to their groups and their meetings did not resemble the range

---

[243] Dercksen & Van 't Hof, *Erkenning gevraagd,* 20-21.

[244] Anne Brabers, Wouter van der Schors & Judith de Jong, *Zorggebruikers zien patiëntenorganisatie als belangrijke bron voor lotgenotencontact* (Utrecht 2017) 4, https://www.nivel.nl/sites/default/files/bestanden/Factsheet_Zorggebruikers_zien_patientenorganisatie_als_belangrijke_bron_voor_lotgenotencontact.pdf accessed 25 February 2024.

[245] Dercksen & Van 't Hof, *Erkenning gevraagd,* 79-80, 86-90.

of people they saw in psychiatric hospitals or in RIAGG waiting rooms. In particular, they all noticed, there was a painful lack of ethnic diversity in their ranks, while increasingly, patients in mental health care had a *migrant* (immigrant) – as the politically correct Dutch term was at the time – background.[246] Being aware of this problem was one thing, but successfully tackling it was quite another matter.[247] The LSOVD board, for example, reported early on that it was actively in touch with representatives from ethnic groups in the Netherlands who were dealing with a disproportionate heroin problem, in particular with the Moluccan community.[248] A decade later, however, they had to conclude that they had not succeeded in getting the parents involved in their organisation.[249] In the other family organisations, the situation was no different.[250]

When in 1997, Ypsilon volunteer Juanita Slengard offered to set up a group for immigrant parents of people with schizophrenia, her ideas were received in the organisation with enthusiasm. Slengard first set up an Ypsilon branch in Surinam, the country she and her son had left to seek better care for him in the Netherlands.[251] Back in Rotterdam in 1998, she started Ypsilon Migranten (Ypsilon Migrants), a mutual support group for immigrant parents. She reached out to them by talking about mental health problems on immigrant radio channels and leaving flyers in waiting rooms. Combining her personal experience with her professional experience as a protocol officer at the Surinamese Ministry of Foreign Affairs, she was able to attract people from various ethnic backgrounds, and soon had eighty to a hundred participants on her address list who regularly attended the Ypsilon Migranten meetings.[252]

Slengard's activities were much appreciated by the national organisation – in 2006, she was awarded the Ypsilon honorary gold brooch for her work. When Ypsilon founder Ria van der Heijden passed away that year, Slengard was asked to take over the Rotterdam mutual support group that Van der Heijden had led from the very beginning in the early 1980s to the very end. When Slengard accepted the new position, she gave up the immigrant group, taking many participants with her to Van der Heijden's former group. But Slengard's rise in the organisation also caused friction. When that escalated,

---

[246] Interview Bert Stavenuiter, 27 January 2022; interview Cisca Goedhart, 18 November 2022; Van Amerongen, 'Ouders van drugsverslaafden', 117.

[247] Vink & Stremmelaar, *Krachtige mensen in beweging,* 220; interview Bert Stavenuiter, 27 January 2022; interview Cisca Goedhart, 18 November 2022.

[248] Q.A. Jansen, 'Voorwoord', *Info* (1983) 8, 2; 'Verslag van de Provinciale Dag Zeeland van de Landelijke Stichting "Ouders van Drugverslaafden" ', *Info* (1985) 14, 4-18, 12.

[249] Van Amerongen, 'Ouders van drugsverslaafden', 117; Bob van Amerongen, 'Ouders als medewerkers', *Info* (1991) 6, 11-15, 14; Fris & De Leeuw den Bouter, *Ouders Van Drugverslaafden en de hulpverlening,* 24.

[250] Interview Bert Stavenuiter, 27 January 2022; interview Cisca Goedhart, 18 November 2022.

[251] Juanita Slengard, 'Dagboek van een werkbezoek aan Suriname', *Ypsilon Nieuws* (2000) 89, 13-14.

[252] 'Gespreksgroep voor Surinaamse familieleden', *Ypsilon Nieuws* (1998) 78, 23; interview Juanita Slengard, 22 October 2021.

she chose to leave the organisation in 2007. And with her, the culturally diverse group she had brought to Ypsilon also disappeared.[253]

Meanwhile, in 2004, Gina Braafheid, another 'mother-of', had started an Ypsilon group for people with a Surinamese background in Amsterdam. But by 2006, she had also left Ypsilon, establishing her group as the independent Stichting Sriebie Wiekie (Foundation I Slept But Now I Am Awake).[254] In a White organisation, she felt, it was impossible for immigrant parents to feel at home and share their feelings about experiences that touched them so deeply. But Braafheid's priorities were different, too: she intended not only to educate and empower Surinamese relations, she also wanted to prompt mental health care professionals to tailor the help they offered to the needs of immigrants.[255] However, her organisation did not last either.

Not knowing how to reach immigrants was not just a problem for the family organisations in mental health care. It was the same for patients', clients' and family organisations in all sectors of health care, and mental health care organisations and professionals had a hard time connecting with their increasingly culturally mixed clientele too.[256] A survey published in 2000 concluded that mental health care and the clients' movement overall had the same problem. It was caused by a combination of factors: the unfamiliarity of immigrants with the Dutch mental health care system, a lack of understanding of each other's norms and values, language problems, shame and taboos, particularly with regard to cultural differences regarding what constitutes a mental health problem, what causes them, and what should be done about them.[257] Medical anthropologists Ronald May and Rob van Dijk, both actively involved in efforts to make Dutch mental health care more multicultural from the mid-1980s, saw it like this:

RM: "Aan de ene kant zat je met een enorm taboe, aan de andere kant met de andere verklaringsmodellen zoals winti en djinn. Daar wist de ggz zich geen raad mee. Je moet altijd vertaalslagen maken:

("On the one hand, you had a huge taboo, on the other hand you had the other explanatory models such as Winti and jinn. The mental health care system didn't know what to do with that. You always

---

[253] Interview Juanita Slengard, 22 October 2021.

[254] Eveline van de Putte, *Het zwijgen voorbij. Portretten van Surinaamse mantelzorgers van familieleden met ggz-problematiek* (Utrecht 2012) 10-18.

[255] Personal archive Ronald May, correspondence between Gina Braafheid and Ronald May, 28 October 2005, copy of Tara Oedayraj Singh Varma, 'Opvang Sur. psychiatrische patiënten niet voldoende', *De Volkskrant Suriname*, [April 2006].

[256] Vink & Stremmelaar, *Krachtige mensen in beweging,* 220; Van 't Hof & Verstegen, *Ervaring gebundeld,* 30-31; Hunsche, *De strijdbare patiënt,* 212-217.

[257] Basisberaad ggz, *Thuis is waar de ander is. Allochtone cliënten in de geestelijke gezondheidszorg en de cliëntenbeweging* (Rotterdam 2000).

in de zorg, binnen de patiënten, binnen de familie. Maar die vertaalslagen werkten niet, er was onbegrip aan beide kanten. Er was geen vertrouwen."

have to make translations: in health care, within the patients, within the family. But those translations didn't work, there was a lack of understanding on both sides. There was no trust.")

RvD: "In de Nederlandse verenigingen waren patiënten en naasten rond een diagnose bij elkaar gebracht, die zochten elkaar ook op die manier op. Maar winti varieert van pech tot jaloezie tot epilepsie tot krankzinnigheid. Je gaat niet vanuit een djinn een vereniging oprichten. Zo'n label van een diagnose werd dus ook niet door de mensen herkend."[258]

("In the Dutch associations, patients and relations were brought together around a diagnosis, and they also sought each other out in that way. But Winti ranges from bad luck to jealousy to epilepsy to insanity. You are not going to set up an association from a jinn. So such a diagnosis label was not recognised by people.")

Both Slengard and Braafheid had been able to bridge the cultural gap: offering migrant parents the opportunity to share their experiences in their own language, literally and figuratively, as well as to familiarise themselves with Western views on mental illness and the Dutch mental health care system.[259] But the divide ran deeper: not only the perception of mental illness, the concrete experiences of family members of colour in Dutch society differed with those of White relations too. To pinpoint just one aspect: their children were four times as likely to end up in a police cell instead of a hospital ward because Black people in a psychotic state were perceived as more dangerous than White fellow-sufferers.[260] "*Onze kinderen komen niet in aanraking met de politie,*" ("Our children don't get in trouble with the law"), a White mother had said to Braafheid when the latter had spoken about her and her son's difficulties with the police.[261] The remark illustrates the way that the mutual support groups' promise of acknowledgment and recognition could prove very disappointing indeed to immigrant parents.

From empowered to united

Despite the family organisations' shortcomings – that were not unique to them, as we have seen – they made serious headway towards their common goal: getting a say in matters

---

[258] Interview with Ronald May & Rob van Dijk, 12 March 2019.

[259] Interview Juanita Slengard, 22 October 2021.

[260] Hunsche, *De strijdbare patiënt,* 216; interview Juanita Slengard, 22 October 2021; Van de Putte, *Het zwijgen voorbij,* 10-18.

[261] Van de Putte, *Het zwijgen voorbij,* 13; Hunsche, *De strijdbare patiënt,* 215-216.

of mental health care. That happened largely thanks to the new health care policy under development by the Ministry of Welfare, Health and Culture: the system of *marktwerking*, government-regulated competition. In the future, the government envisioned, the decisions over health care would be made in the negotiation between three main market players in the field: the health care providers, the health insurers and the health care consumers. As representatives of the mental health care consumers, the collective of clients' and family organisations would be right up there with the mental health care providers and insurers. Even if the clients' and family organisations were far from the strongest player in this market, and deeply divided in addition, this was where the decisions were going to be made. And in order for the system to work, the Ministry needed all three market players on board. Whereas the rise of the family organisations in the early 1980s had been a sign of the empowerment of the relations in their own right, towards the end of the century these developments would bring the interests of clients and relatives closer together again.[262]

Getting a say in matters of mental health care was one thing, however, *how* they were going to have that say was quite another for the small, vulnerable, largely volunteer-driven family organisations. That they were invited to join meetings, platforms and networks could be considered a sign of their increasing influence, but also as a sign of them being swallowed up and rendered toothless. In comparison with the clients' movement, the family movement seems to have worried less about the latter issue. Their concerns were pragmatic in the first place: the amount of work involved in the position as 'third party' threatened to overshadow their own activities and agendas, while it remained to be seen to what extent that work would contribute to the organisations' own goals. The regional patient/clients' platforms (RP/CPs), for example, that were set up in the 1990s as the principal forum where the three market players would negotiate health arrangements, were a headache for clients' and family organisations to participate in – Ypsilon even advised their local groups not to do so, unless there were very clear benefits.[263] In addition, the clients' and family organisations in mental health care resisted participating because they worried that patients' organisations from outside the mental health field would dominate the platforms, that they would have to make enormous efforts for which they did not have the means, and that in the end, all that energy would not be spent in their interests. But if they wanted to retain their influence, somehow the organisations had to comply.[264]

By making (some) financial means available to the clients' and family organisations and by putting pressure on them, the Ministry slowly but surely moved things forward. One of the things the government did to help organisations acquire more funding was to

---

[262] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 1082; Dercksen & Van 't Hof, *Erkenning gevraagd,* 74-80, 89-90.

[263] Van 't Hof & Verstegen, *Ervaring gebundeld,* 74.

[264] Oosterhuis & Gijswijt-Hofstra, *Verward van geest,* 1082; Dercksen & Van 't Hof, *Erkenning gevraagd,* 74-80, 89-90.

make subsidies for *zorgvernieuwingsprojecten* (care innovation projects) in mental health care available to projects that involved a clients' or family organisation. In particular, a new offshoot of the undifferentiated clients' movement, the *herstelbeweging* (recovery movement), used this opportunity well. Inspired by mainly British examples of rehabilitation methods, the recovery movement developed local and regional initiatives, based on the principle of using clients' experiences as sources of strength, self-esteem and mutual support.[265]

The Ministry added greater pressure by continuing to demand collaboration. In 1994, it forced In Perspektief, Ypsilon and Labyrint to work together in the collective publicity campaign *Keerpunt* (Turning Point),[266] which became a fiasco because of the intense unwillingness of the partners. Along the same lines, it tried to get Pandora, the Cliëntenbond and the LPR to merge. Health minister Els Borst even appointed an expert to facilitate the process: Hans van der Wilk, who had left Pandora and the Cliëntenbond in 1983 to become director of the Nederlands Patiënten/Consumenten Platform (NP/CP, Dutch Patient/Consumer Platform), and had been professionally involved in the *marktwerking* developments since then.[267] But the merger, which should have taken place in 1997 – like the one between Labyrint and In Perspektief – fell through.[268]

Elsewhere, the family organisations seemed more successful in collaborating on their own account. Labyrint, In Perspektief and Ypsilon had become active in Eufami, the European Federation of Family Organisations in Mental Health Care. Eufami had been started by Gusta Frooninckx of the Belgian family organisation Similes, but volunteers from Ypsilon, Labyrint and In Perspektief had prepared its legendary founding congress in De Haan, Belgium in 1990. Subsequently, In Perspektief's Reina van Mourik served on Eufami's board and general committee from 1992 to 2002, and then served another six years as secretary of its executive committee. Bas van Raaij, who was employed by Ypsilon from 1990,[269] succeeded Frooninckx as president in 1996 and energetically built up the European organisation over the next five years. That did not mean, however, that the two sides of the Dutch family movement warmed to each other.[270]

The continuing coldness between the family organisations did not stop the government from pushing for more collaboration. Around the turn of the century, the subsidised family and clients' organisations were expected to take part in developing protocols, guidelines

---

[265] Hunsche, *De strijdbare patiënt,* 207-208, 221-222, 233-237; Vink & Stremmelaar, *Krachtige mensen in beweging,* 35; Petra Hunsche, *Herstel in beweging. De cliëntenbeweging in de 21^{e} eeuw* (Amsterdam 2022).

[266] 'Keerpunt', *Welzijnsweekblad* (1994) 5, 3.

[267] Dercksen & Van 't Hof, *Erkenning gevraagd,* 70-74.

[268] Van 't Hof & Verstegen, *Ervaring gebundeld,* 27-28.

[269] Interview Bas van Raaij, 21 June 2018.

[270] Oksana Last & Rex Last (eds.), *10 years Eufami: 1992-2002* [Brussels 2002] 7-9, 28; interview Bas van Raaij, 21 June 2018; interview Reina van Mourik, 12 May 2021; interview Margriet Mannak, 21 September 2021. In Perspektief's Cor van Oosten was part of that organising committee; Ypsilon's Kees Zwarthoed was on the committee before Van Mourik.

and programmes aimed at standardising diagnosis, care and treatment practices. On the one hand, this was the ultimate form of recognition for patient and family experience and expertise; on the other hand, it was still a lot to ask of the organisations. The Ministry now started to acknowledge the lack of expertise, experience and financial means in the organisations compared to the mighty insurers and mental health care providers. But it took them years to overcome the opposition of these two other market players against subsidising the organisations structurally to enable them to play their part. In 1997, a separate fund was finally created for them, the Patiëntenfonds (Patients' Fund), which took over the administration of government grants to the Cliëntenbond, Pandora, the LPR, Ypsilon and Labyrint~In Perspektief.[271]

Meanwhile, both clients' and family organisations insisted that mergers and other forms of structural formal collaboration were impossible because of their differences of opinion, their different identities and their different tasks in the field.[272] It was so crucial to the Ministry to have the organisations come together somehow, however, that it stepped back, hired independent advisers to work with the organisations and gave them space to explore their own approach. Gee de Wilde, who in 2003 was brought in as an independent chairman of the budding collaboration that resulted, remembers how the organisations boldly chose to organise a conference together on the hottest issue between clients' and relations: *dwang en drang* (coercive measures) in mental health care. Changes in the *Wet BOPZ* had been proposed that made the matter extra urgent:

"De inzet was: 'Als cliënten en familie het eens zouden kunnen worden over het thema dwang, dan kunnen we het overal over eens worden'. Familie werd door cliënten immers vaak gezien als de aanstichters van repressieve maatregelen: 'Zijn we eindelijk van die lastige situaties in ons gezin af'. Onzin natuurlijk. Maar als het water je aan de lippen staat, en je keer op keer nul op het rekest van de hulpverlening hebt gehad, ben je blij dat er eindelijk eens iets gebeurt."[273]

("The goal was: 'If clients and family could agree on the topic of coercion, then we could agree on everything'. After all, family was often seen by clients as the instigators of repressive measures: 'Good riddance to those difficult situations in our family'. Nonsense, of course. But when you're at your wits' end, and time and time again you've had no response from the care services, you're glad that something is finally happening.")

---

[271] Van 't Hof & Verstegen, *Ervaring gebundeld,* 72, 89.

[272] Gee de Wilde, 'De prehistorie van MIND' (s.l. 2017) 1, https://www.canonsociaalwerk.eu/1998_clientsturing/2017-01-Gee-de-Wilde-De%20prehistorie%20van%20MIND.pdf accessed 5 March 2024.

[273] De Wilde, 'De prehistorie van MIND', 2.

In the eyes of De Wilde, the 2004 conference was a cathartic experience. Prepared in harmony by Pandora's Lise Broekaar, Ypsilon's Marijke Luif and the SLKF's Ria Trinks, it ended in an agreement to work together towards the reduction of coercive measures in mental health care. Despite the continuing differences of opinion on how exactly to go about that, all parties agreed that good and timely care was the key, and that this goal united them. This experience showed the organisations the way forward: discussing important issues despite well-known disagreements, figuring out where they could find common ground while respecting their differences.[274] As Ypsilon director Bert Stavenuiter sees it, this requires an attitude that is familiar to many relations who have a loved one with mental health issues:

> *"Agree to not agree, dat is waar het in de psychosewereld heel vaak over gaat. Okee, jij zegt dat je de messias op aarde bent. Ik denk van niet. Zullen we afspreken dat jij het niet met mijn mening eens bent, en ik het niet met jouw mening, maar dat we evengoed wel verder moeten?"*[275]

> ("Agree to not agree, that's what the psychosis world is very often about. Okay, you say you are the messiah on earth. I don't think so. Shall we agree that you don't agree with my opinion, and I don't agree with your opinion, but that we still have to move on?")

In 2003, fifteen organisations formed a committee representing a cross-section of the movement. Towards the end of 2005 eight of them decided to officially set up the Landelijk Platform Geestelijke Gezondheidszorg (LPGGZ, National Platform Mental Health Care). When the platform became an association on 1 July 2006, thirteen of them had joined, and over the next months and years more would follow. The LSOVD, Labyrint~In Perspektief and Ypsilon were part of the LPGGZ from the start, and most of the clients' organisations that we have met over the course of this book joined sooner or later. Together, they started laying the foundations for a platform that would enable them to grow into the position they had aspired to all along, representing the voices of Dutch clients and relations at the mental health care table.[276]

Conclusion

It was not surprising that the family organisations met resistance when they arrived on the mental health care scene of the 1980s. The issues that instigated their establishment,

---

[274] De Wilde, 'De prehistorie van MIND', 2-3.

[275] Interview Bert Stavenuiter, 27 January 2022.

[276] De Wilde, 'De prehistorie van MIND', 4-5.

were also those where they could expect disinterest and opposition. Ignorance and stigma were at the top of the list of what they wanted to change, but both public stigma and stigma by association were obstacles to their activities. Anti-psychiatry had fed a countermovement among clients, professionals and other sympathisers that was strongly opposed to relations, who were portrayed as meddlers or even as the source of all mental health problems. In addition, patients' rights were only just being implemented in law, and relations were seen as a threat to that achievement. In their build-up years, the family organisations needed all the strength they could muster to fight ignorance, stigma, family-blaming and other forms of exclusion, in particular in the general public, in mental health care and in the clients' movement.

But there were also doors that swung wide open for them. There were individuals in all those fields who saw their potential: relations in desperate need, innovative and rebellious mental health care professionals, and clients' movement activists who were ready to take their movement to the next level. The warmest welcome the organisations received was at the Ministry of Welfare, Health and Culture. To the government, the relations were an important part of the deinstitutionalisation and substitution puzzle, but also to the reform of the health system that it envisioned: their organisations would be an equally indispensable part of the self-regulating market system in which mental health care consumers would negotiate with the providers and the insurers. The way the relations and their organisations figured prominently in the policy memorandum *Onder anderen* of 1993 made clear that the family organisations had successfully claimed their position in mental health care policy-making.

The doors of mental health care were far from wide open, but they were held ajar by professionals looking for new ways to help patients. Pioneers of the returning biomedical model were figuring out how relations could contribute to their efforts, realising that it was more useful to consider them as allies instead of enemies. In the Netherlands, the alliance of Ypsilon with psychiatrist Rigo van Meer is considered a decisive factor in the return of schizophrenia as a diagnosis and the concomitant reprise of biomedical thinking. But the family organisations which rejected that kind of thinking contributed no less to making professionals aware that relations should not be excluded from all matters of mental health care, but involved to the benefit of all three parties in the triad: the patient, the professional and the relations. Just as anti-psychiatry had opened the door for the clients' movement in the early 1970s, 'anti-anti-psychiatry' did the same for the family movement a decade later.

That the family movement was so quickly considered important and representative enough to take part in the new system on a level with the mighty mental health care sector and the health insurers was definitely a success. But like most patients' and relations' organisations, these were small organisations of heavily burdened people. In addition, cultural barriers stood in the way of involving relatives from various immigrant backgrounds. Had more people joined undifferentiated organisations like the Cliëntenbond and Labyrint~In Perspektief instead of diagnosis-oriented ones, the family movement could have found more strength in numbers. But with the return of the biomedical model, the number of diagnosis-oriented organisations rose sharply and so did the fragmentation in the movement.

As a result, participation in the mental health care system came with enormous challenges for the organisations. The government tried to nudge the three main family organisations towards joining forces, so that they would be stronger, but also easier and cheaper for the Ministry to handle. That might have been a reasonable expectation considering their common cause: empowering relations and giving them a say in mental health care. But the mutual frictions between the organisations were still fresh and only contributed to the development of their distinct identities and opinions. As a result, it took many years for the religiously inspired In Perspektief to agree to merge with the secular Labyrint. As organisations that both privileged the social perspective, in turn, Labyrint and In Perspektief did not see eye to eye with the biomedically oriented Ypsilon. And in the 1990s, admitting that they all had a lot in common with the LSOVD was certainly a bridge too far.

Within any social movement, people butt heads over how to realise their ideals, as the example of the women's movement has shown. For the family organisations, however, it became even more complicated when they came under pressure not only to work together as a family movement, but also to work with the clients' movement from which they had split off in the early 1980s. By developing their own ways to collaborate in a platform, however, the organisations managed to join forces without having to give up their independence, and to work together while respecting their differences. United in diversity, with each other and with the clients' movement, the family movement entered the twenty-first century.

Conclusion

It was remarkable what happened in the early 1980s: all of a sudden, four different organisations of relations of people with severe mental health issues entered the mental health care arena. Although family members and friends had been active in the clients' movement – as the Dutch consumer movement in mental health care called itself – of the 1970s, and some had even taken initiatives in the field before that, what was new was that they organised separately from the clients and explicitly demanded a say in mental health care *for themselves*. In the LSOVD (Landelijke Stichting Ouders van Drugsverslaafden, National Foundation Parents of Drug Addicts, 1980), parents of adolescents with a heroin addiction found each other in their protests against the drug policies and addiction care that were failing them and their children. In Ypsilon (1984) parents of people with chronic psychosis or schizophrenia confronted professionals who had demonised them for causing their loved ones' mental health problems and demanded a say in new care policies that they feared would be inadequate. In Perspektief (In Perspective, 1981) brought together and empowered Christian relations, while Labyrint (1985) did the same thing without a religious slant. Like the LSOVD and Ypsilon, these organisations demanded that the burden of care that rested on the shoulders of the relations of people with severe mental health issues should be acknowledged, that these family members and friends should be treated with understanding and respect, and that they should be taken seriously as partners in mental health care, both in policy and in practice.

What was equally remarkable was that the new family organisations all came from different worlds – or, to be more precise, from widely different belief systems. Labyrint was the brainchild of the Stichting Pandora (Pandora Foundation, 1964), one of the most vocal organisations in the clients' movement which was strongly inspired by anti-psychiatry's social explanatory model – the then-current dominant epidemiological paradigm, in the terminology of experienced health movements theory. Inspired by this belief system, early Labyrint rejected the idea that mental health problems were (biomedical) illnesses, rejected medical diagnoses for such problems (in particular the term schizophrenia) and had the utmost respect for clients' rights. In Perspektief originated from the particular needs of Christian relations. Their religious convictions and fellow believers could be a source of comfort and support, but often their problems were understood neither within their church communities, nor in the rapidly secularising Dutch society as a whole. Through their intense collaborations with Labyrint, the relations gathered in In Perspektief extended their religious explanatory model with insights from the social perspective.

Ypsilon was in the opposite corner, blossoming together with the biomedical explanatory model that, through the 1980s, slowly started to make a comeback in psychiatry. In the 1990s, the biomedical perspective, which had been the dominant epidemiological paradigm in the 1950s and 60s, would return in a new guise as the preeminent perspective. For the relations in Ypsilon, that perspective was essential to explaining their point that people suffering from severe chronic psychosis were unable to exercise their free will and that respecting their autonomy in such a state put them at greater risk, rather than protecting them. Based on the reasoning that 'their patients' suffered from an illness of the brain and needed care more than anything, early Ypsilon protested passionately against the dismantling of psychiatric institutions that was the aim of the government's deinstitutionalisation policy.

The LSOVD, diagnosis-oriented just like Ypsilon, was on the sidelines of the playing field of the family organisations, concentrating on parents' struggles with their children's drug addiction. Stigma, which is even stronger in regard to addiction than to any other severe mental health issue, must have been an important factor in why the LSOVD would not be recognised as a family organisation that the others could ally with until the turn of the century. This obscured the fact that they shared the common cause of making the family's voice heard in mental health care. Considering the fact that addiction care was increasingly developing into a separate branch of mental health care, the separation may have been logical, but it was to be regretted for the many patients and families dealing with a 'double diagnosis' – the far from uncommon combination of addiction and other mental health problems. In addition, the organisations might have been able to join forces in other regards. For example, for both Ypsilon and the LSOVD, it was important to change public perceptions of schizophrenia and addiction, respectively: they wanted everybody to know that their children were patients, suffering from an illness. In particular, the fundamental battle these relations fought in their organisation's early years was to erase the idea that mothers, parents or entire families were to blame for the mental health issues of a loved one.

It was new in the early 1980s that family members developed a politicised collective experience identity of their own, instead of (primarily) backing the clients' movement in the interests of people with severe mental health problems. The relations were prompted to do so because several developments had backed them into a corner. In the mental health care system of the 1950s and 60s, in which the doctor, the head nurse and the social worker made the rules and lay people did not talk back, the position of relations largely depended on the goodwill of the professionals. The case of Mies Osterholt, who spent her entire adult life – spanning the second half of the twentieth century – in institutions, showed that in the worst case, a lack of such goodwill could even result in traumatising neglect and abuse. The increasing popularity of mother-blaming and family-blaming theories in Dutch psychiatry that accompanied the rise of anti-psychiatry through the 1970s, not only put the relations at risk of losing what little agency they had, but also of being accused of having caused their loved one's mental health problems in the first place. Focusing exclusively on the patient, many mental health care professionals paid no attention to the burdened family.

Meanwhile, in the 1970s, new mental health care policies and laws were being prepared. With its deinstitutionalisation policy, the government aimed to destigmatise and empower psychiatric patients, but in the end its primary concern was cutting back the rising costs of mental health care. As a consequence, the policy was implicitly dependent on relations taking more unpaid care responsibilities on their shoulders. That created additional concerns in relations who foresaw a lack of care for their loved one, a tipping of the balance between their burden of care and their coping capacity, while existing malfunctions and blind spots in the care system were still insufficiently addressed. Moreover, with the strengthening of the patients' legal position, for which the clients' movement had fought hard, the exclusion of relations from matters of mental health care also became anchored in legislation.

The relations who stood up in the 1980s did not resemble the young protestors the Netherlands had gotten accustomed to since the rise of the student, feminist, gay and peace movements of the 1960s and 70s – liberation movements that have coloured the dominant historiography of these decades. Most of these organising relations were family men and women, middle-aged or in their thirties at least. The history of the early Dutch family movement shows that they could be outspoken activists, too, out to confront far more powerful players in arenas where they had no previous place at all. The protest movements of the 1960s and 70s were important role models, however, and providers of important tools for the family organisations. And they used that spillover well, for example in developing their mutual support groups and obtaining government subsidies. But at least as important was that a new, self-assured attitude had spread beyond the young and rebellious. The liberatory wave of the 1960s and 70s had introduced *mondigheid* and *bespreekbaarheid* in the Netherlands: the idea that every citizen had a right and a duty to self-advocacy, and that every taboo should be open for discussion. The new family movement took all of that on board and put it into practice.

By 1980, *mondigheid* and *bespreekbaarheid* had developed in an unforeseen direction: they resulted in rising individualism, making personal self-realisation take priority in many people's lives. Whereas before, the clients' movement had not made a distinction between the interests of people with severe mental health problems and loyal relations, the family organisations that arose in the early 1980s were based on the realisation that the interests of patients and relations did not always align. Activist relations of the early

1980s did not intend to cut their ties with their loved one with mental health issues, or to refuse their fair share of care, but they did claim the right to be supported in their difficult position and live lives of their own despite the circumstances. That assertiveness was what set the family organisations of the 1980s so clearly apart from activist relations in mental health care during the previous decades.

In hindsight, it is puzzling that Ypsilon became the figurehead of the family movement of the 1980s, since of the four organisations that I consider part of this early movement, it seemed the least focused on distinguishing the interests of clients and relations. In that respect, Ypsilon was actually more similar to the diagnosis-oriented predecessors of the family movement: Al-Anon (the family branch of AA, Alcoholics Anonymous), the NVA (Nederlandse Vereniging voor Autisme, Dutch Association for Autism, 1978) and the Stichting Anorexia Nervosa (Anorexia Nervosa Foundation, 1978). That Ypsilon nevertheless became synonymous with the Dutch family movement may have had to do with the way psychiatry placed psychosis and its chronic manifestation schizophrenia at the centre of the field, as opposed to autism and anorexia. In addition, the founders of Ypsilon protested against what they saw as the dangers of patients' rights and autonomy without reservations, directly confronting the Cliëntenbond in de Welzijnszorg (Clients' League in Welfare Care), Stichting Pandora (Pandora Foundation) and other organisations in the mainstream of the clients' movement, and questioning everything they had fought for in years prior.

Contrary to the widespread view in the historiography of psychiatry that diagnosis-oriented clients' organisations in mental health care in the Netherlands only arose from the late 1980s onwards, this history has shown that this type of organisation originated not after, but parallel to or even before the undifferentiated activism of the Cliëntenbond, which was founded in 1971. In addition to the earliest self-help organisations in the addiction field (AA, set up in 1948, and Al-Anon, following in 1961), the Fobieclub (Phobia Club) was a patient initiative set up in 1969, while relations founded the Stichting Anorexia Nervosa as well as the NVA in 1978, and the organisations that merged into the latter dated back to 1973 and 1974.

Even if their actions were much less eye-catching than those of the Cliëntenbond and the rest of the clients' movement, the relations who founded these diagnosis-oriented organisations were no less activist, challenging the government and mental health care professionals and researchers openly on forms of mental health care that were lacking, failing or offensive. That was what set them apart from the family movement's predecessors of the 1960s, Al-Anon and Pandora, organisations that, in their early years, built on and promoted modern mental health care and the promise of its innovative therapies and medications. In addition, Al-Anon and early Pandora operated anonymously, safeguarding the identity of patients and relations alike. The primary target of the criticism of these predecessors was the public: the prejudiced, discriminating attitudes that were responsible for stigmatising and excluding mental health care patients, ex-patients and their relations from society.

The space for all these widely diverging organisations to bud was opened up by the rising and retreating waves in the explanatory models for mental health issues. These waves resulted in repeated shifts in the dominant paradigms and belief systems that ruled mental health care. The 1960s optimism about the biomedical approach that came with new forms of therapy, medication and other innovations in psychiatric hospitals was a fine breeding ground for Al-Anon and Pandora. When that optimism deteriorated around 1970 and the social perspective gained dominance – blaming society and the mini-society of the family for individuals' mental health problems and demanding radical changes in psychiatric care, as well as in society at large – that made room for the eye-catching activism of the Cliëntenbond and pushed Pandora into the arms of the social model. Family organisations dealing with diagnoses outside of the mainstream of psychiatry – like autism or anorexia nervosa – called in contrast for more focus on those diagnoses so that appropriate forms of treatment and care for which they were desperate could be developed. In doing so, they in fact stayed true to the biomedical model, although it had then lost its dominance, a factor which may have added to the limited extent to which they have been noticed in historiography. In the late 1980s, however, the dominant epidemiological paradigm began to shift their way, and did so further in the 1990s, when the biomedical perspective reconquered Dutch mental health care. This saw new diagnosis-oriented organisations emerge one after the other.

Neither the undifferentiated nor the diagnosis-oriented organisations, however, were able to bridge the gap with people who looked at mental health issues from other explanation models than the biomedical, the psychological and the social. In Perspektief's fight for the appreciation of the difficulties and merits that christian people could find in their religious explanation model went under in the merger with Labyrint in the end. And all family organisations turned out to be unable to respond to the religious, spiritual and otherwise cultural explanation models and the intersectional factors (such as discrimination) that determined the experience of relations with an immigrant background. From all this, it is clear that the way we deal with mental health issues is culturally determined and that varying explanatory models can add to or relieve some of the burden on the family.

That the family organisations of the early 1980s each related to the shifting paradigms and explanatory models in mental health care in a different way severely limited their options to ally with each other from the start. Since each organisation primarily adhered to one of the explanatory models, consequently, their analyses, priorities and solutions were widely divergent and often even contrary, especially with regard to the hotly debated issue of deinstitutionalisation. Such disagreements are considered common in social movements by sociologists and no reason to refrain from viewing them as movements, or to dismiss or downplay their significance. However, the frictions obscured the fact that the organisations did share a fundamental common cause: to have relations acknowledged as a party of interest in mental health care, a party that deserved a say as well as support. Still, there were also occasions where they managed to work together on that common cause, for example on developing guidelines for professionals and enshrining them in agreements. Such collaborations foreshadowed a slow but sure process of rapprochement between the family organisations and with the clients' movement that would take shape in the early twenty-first century.

In this book, we have also studied late twentieth-century developments in the mental health care arena from the perspective of the family movement that forced its way into that arena in the 1980s. In that process, the family organisations were shaped by each other as well as by the interplay of their actions with those of other major players in that arena: the media and the public, the mental health care sector, the government and the clients' movement. The first priority of the family organisations was mutual support, so that burdened relations could find understanding and solace with each other and could learn from each other how to cope better with their difficult situations. But inextricably linked to that was advocacy: protests and actions aimed at getting a say in mental health care policy and practice.

Reaching new relations and the public at large with what they had on offer was quite a challenge because the same ignorance, false assumptions and stigma that the organisations wanted to remedy placed obstacles in the way of communicating their message – which may be part of the reason why patients' and family organisations in health care in general tended to stay small. Towards the end of the 1990s, however, the family organisations also noticed that relations faced mental health care professionals with an assertiveness that was unheard of fifteen years earlier. The empowerment they promoted and supported was working.

Just how the mental health care sector received the family organisations in the 1980s varied widely. They were embraced immediately by a few early adopters among researchers and practitioners, especially by pioneers of the resurgent biomedical orientation. To the majority of psychiatrists, psychiatric nurses, social workers and other mental health care professionals, however, relations played no part at all in their daily work. To them, paying attention to the family was an extra task they had no desire to add to their already overflowing plates – and under the new law on clients' privacy, that seemed impossible anyway. To those whose professional opinions continued to be shaped by anti-psychiatry and its family-blaming theories, the rise of the family organisations was even a cause for suspicion. Taking Ypsilon as standing for the entire family movement, the movement was often framed as a conservative, even reactionary force, as 'anti-anti-psychiatry'. That there were also family organisations inspired by or directly originating from the anti-psychiatry-inspired clients' movement – Pandora staff members not only founded Labyrint, but also greatly influenced In Perspektief in this regard – was a nuance that eluded many. The energy Labyrint and In Perspektief were able to spend on spreading their message to the outside world, however, was severely limited by the time and effort they had to spend on their ongoing mutual conflicts.

The mutual support activities of the family organisations often got the thumbs up from mental health care workers, even though they did not always do much to actively support the groups or refer people to them. But advocacy and activism aimed at influencing mental health care policies and practices were not something they welcomed. Psychiatry professionals had always been the unchallenged masters of their field, and it took time for them to start opening up: first to the government (in the 1960s and 70s), then to the clients and their movement (in the 1980s and 90s), and lastly to the relations and their organisations. In response to the chilly reception the family organisations received in the 1980s, in the 1990s, they intensified their educational activities for mental health care workers, boosted the creation of family councils in institutions and became increasingly politically active. Ypsilon, in addition, embarked on a charm offensive in order to create a closer relationship to the psychiatric nurses at the coalface, whom they considered the most important professionals in the lives of their loved ones. The more family-blaming faded away over the 1990s, the more the organisations were able to ally with professionals.

The reception of the family organisations of the 1980s by the clients' movement varied too. Just like the situation in mental health care, those who were ideologically shaped by anti-psychiatry would at first respond to them with suspicion. With the rise of the family movement, they foresaw, the clock would be turned back. The relations were seen as the new meddlers, jeopardising the progress that had been made over the previous decade with regard to patients' rights, the autonomy of clients and replacing biomedical thinking in psychiatry with (psycho)social thinking. That perception reflected the agenda of Ypsilon in its early years. To those in the know, it was clear that Labyrint came from different stock: that of Pandora, that of the clients' movement. As a result, Pandora and Labyrint collaborated as natural allies, but any collaboration between the Clientenbond and Ypsilon initially had to go underground.

From the late 1980s onwards, the wave of new, almost exclusively diagnosis-oriented organisations (like the NSMD, the Nederlandse Stichting voor Manisch Depressieven, Dutch Foundation for the Manically Depressed of 1987) indicated that the returning biomedical model was making headway. It created a much more fragmented clients' movement in comparison to the almost entirely undifferentiated activism of the 1970s. The socially inspired Pandora and Cliëntenbond remained the most vocal organisations in the field until after the turn of the century, but increasingly, clients and relations seemed to prefer a diagnosis-oriented organisation, echoing the shifted mental health care paradigm. On the one hand, that divided the family movement. On the other hand, it was easier for these organisations to get along, as they shared a similar biomedical view.

The government was not interested in such dividing lines, however. It welcomed all four family organisations that arrived in the early 1980s with open arms. But the subsidies the organisations were granted, indispensable for their work, came with the expectation of conforming to agendas that were not necessarily their own. In the 1980s, that agenda was largely set in the negotiation between the government, the mental health care sector and the clients' movement, and there were many points about which the family organisations had concerns. The dismantling of institutional care without enough care in the community to replace it, for example; the severe limitation of the possibilities for involuntary commitment of a person in crisis; the shift towards harm reduction policies in addiction care, which left some parents feeling that care workers gave up on their children; and the absence of the relations in the new policies except as implicit, self-evident informal caregivers. Despite the differences of opinion, all four family organisations quickly managed to develop and maintain close relationships with those in charge at the highest levels. Of course, that did not mean they could sway the policies in the direction they preferred overnight, but it was the first step, gaining access to the debate from which they were previously excluded.

Over the course of the 1990s, the government increasingly started using its financial leverage to push the family organisations towards collaborating with each other and with the clients' organisations. In the eyes of policy makers, together the organisations would be better equipped to take on their demanding role as the 'third market player' in the health care system of the future, negotiating mental health care arrangements with the mighty mental health care providers and the insurers. This pressure, however, only made the organisations insist on their own identities and priorities, and if anything, it strengthened their individual identities instead of any collective identity. It was not until the government stepped back a little around the turn of the century and gave pioneers in the organisations the room and means to develop new ways to collaborate that the family and clients' organisations developed a model in which each of them could retain their own position while working together towards common goals. Laying the groundwork for their national platform, they accepted their daunting role as a multifaceted, but cohesive, clients' and family movement.

With this development, the family organisations that in the early 1980s had branched off from the solidarity movement of the 1970s – in which relatives had stood shoulder to shoulder with clients without declaring their own particular interests as relations – were, within twenty years of their rise, in many ways, back to where they started from. That did not mean, however, that those years had been wasted – on the contrary. In an age marked by individualism, it had been necessary to break the unspoken bond between clients and their relations for a while to make clear that they were not one and the same and that their interests did not automatically align. However, for a family movement that strongly protested the ways mental health care practices and policies had driven a wedge between people with severe mental health issues and their loved ones, it would have made no sense to keep that distance and not to profit from the strength that was to be gained by working together. And by honouring their diversity while making the most of their unity, they were able to join forces and be better equipped to face their mighty counterparts in the arena when they entered the twenty-first century.

§

In this book, I have presented the rise of the Dutch family organisations in mental health care in the 1980s and 90s, as well as their predecessors from the 1950s, 60s and 70s. That rise ended once the organisations were established, and that is where this history stops therefore. In the eyes of many who were part of the family movement, at that point in time, they had only just begun. And as the epilogue will show, it was indeed after the turn of the century that they would really start to reap the fruits of their labours. What I have aimed to capture here is the quickly fading history of the family movement's origins. The struggles, successes and failures that followed deserve more attention than I am able to pay to them – they will provide interesting topics for future research.

In addition, it is important to realise that this study is biased in a number of ways. Considering the sources that were available to me – publications more so than internal documents, national sources more so than regional or local ones – this book naturally tends to examine the way in which the organisations presented themselves to the outside world, and the accent is generally on the national level, even though the organisations did much of their most important work at the local level.

Moreover, this book deals predominantly with the organisations in what I call the family movement, rather than individuals and actions outside these organisations. This focus on organised activism also obscures the fact that mental health issues touch everyone and that some groups are largely underrepresented in this story: minor children, people of colour and with non-Dutch backgrounds, and people from modest socioeconomic origins, who were all underrepresented in the early family movement. The focus on the activism of well-intended relations also obscures the historical role of those who abandoned or mistreated those close to them. Doing justice to the perspectives of all these groups in the history of psychiatry requires other approaches. Finally, we should also realise that behind the relations who organised out of frustration over how badly mental health care treated them, there have always been others who felt well supported. Most relatives of people with severe, chronic mental health issues, however, will have had long 'careers' in mental health care, and experienced it in all its shapes and sizes.

The value of this study lies, first, in its contribution of the family perspective to the history of psychiatry, both for the Netherlands and internationally. Despite the family turn taken by the history of psychiatry over the past twenty-five years, this perspective is still quite rare, in particular compared to the vast historiography of psychiatry from a professional point of view. It also negates the claim of a lack of sources on the direct voices of patients and relations, at least for the second half of the twentieth century, when activists in the field have documented their experiences, criticism and insights in their personal writings and presentations as well as those of the organisations they formed. Looking for the protesting voice of patients and relations leads us to new sources for the history of psychiatry 'from below'. That may even prove true for the period prior to 1950.

Second, using the concept of experienced health movements, this history has revealed how deeply personal experiences led relations to develop a politicised collective experience identity from which family activism could grow, which examples and other forms of spillover were available for them to use, and which belief systems, explanatory models and paradigms were in play, both for them and for the main players in the mental health care arena. The concept of experienced health movements provides a tool to historians interested in studying the rise of both consumer and family movements in (mental) health care. Indeed, this study as a whole offers a building block for comparative research into the rise of consumer and family movements in a variety of countries. Combining the experienced health movements approach with the players-and-arenas concept from the strategic interaction perspective offers insights into the interplay of a budding experienced health movement with the powers in the health care field and with society at large, and into how specific national, regional or local circumstances and priorities lead to particular outcomes.

A third aspect of the value of this book lies in its contribution to the historiography of the Netherlands after the Second World War. The existing historiography is strongly focused on the rising and falling liberatory and activist spirit of the period 1960-1990, which makes it puzzling that historians have paid so little attention to the clients' and family movement in mental health care, especially in the 1970s when the clients' movement played an important part in Dutch public debates. In addition, this study shows that not all activists are marked by an unconventional appearance or playful forms of public protest. Average family men and women can be just as provocative in their words and deeds in their efforts to make their voices heard in an arena where they are marginalised, and even conservative voices can be activist if they have no position in an arena where progressive belief systems rule.

These activists may not have been representative of all relations and their experiences in Dutch mental health care, but by examining key fictional sources, we have been able to see that the issues raised by the clients' and family movements were reflected in sentiments that were more widely felt in the society of the time. In *Terug naar Oegstgeest*

(1964), Jan Wolkers confronted us with the unfiltered stigma that was common in the 1960s, and the long-lasting success of his novel means that the book may also very well have reinforced that harmful way of looking at people with severe mental health issues for many years. Although our societies still have a long way to go when it comes to destigmatisation, the way these passages leave today's reader feeling uneasy suggests that we have made some progress.

The direct voice of such a stigmatised patient in Jan Arends's 'Keefman' (1972) marks an important step in that progress: the start of the empowerment of the patient. At the same time, this short story shows the timeless dilemma of navigating between the autonomy of people with severe, chronic mental health problems and their vulnerability. It makes the reader aware of the ways psychiatry could restrain those in their care – a realisation that was of acute importance at the time, as the experiences of patients like Mies Osterholt and Willy Brill's daughter Josephine highlighted – but also shows the indispensability of mental health care, in some shape or form, an uneasy truth for radical supporters of anti-psychiatry.

Hersenschimmen (1984) by J. Bernlef illustrated the immense need for education and support felt by the relations of people with severe mental health issues in the early 1980s, in this case the informal caretakers of people with dementia. The story took on a life of its own, however, when it was embraced as the truthful rendering of the experience of people suffering from the condition, despite its author's efforts to argue that was impossible by definition. Hence to this day, *Hersenschimmen* has come to shape our understanding of an experience that is essentially inaccessible to bystanders, doctors as well as lay persons.

That other 'true' story, *De moeder van David S.* (1980) by Yvonne Keuls, had a similar impact educating the Dutch public about the dangers of heroin. Its core message, however, was that heroin use was a matter of individual choice and that the consequences were therefore the responsibility of the user. They were not something the parents or the family should have to take on their shoulders: their responsibility was to save themselves. Although that position reflected the ways individualism had also reached the family unit by 1980, it turned out a difficult one for the public to grasp. Perhaps this was where individualism reached a limit, in the sense that most people hold on to family ties as long as they can – something that the relations who united in the family movement had already shown when it came to caring for a loved one with severe mental health troubles.

Around 2000, when this history ends, the last founders of the family organisations of the 1980s were stepping down, and today, many of them are no longer with us. Since then, the clients' and family movement has continued to work hard to improve the lives of people with mental health issues and their relations, both inside and outside their platform. This continues to be a challenge in an arena where they are a David facing

Goliaths. I hope that getting to know more about the earliest history of the client's and family movement provides those active in it today with inspiration, and provides new insights to those who are involved in mental health care policy and practice professionally as well.

Ultimately, this story speaks to all of us as relations and as citizens. Seeing how history repeats itself may be disheartening, but this can also give a clearer picture of what to fight for and how. To see where family activism came from and how it all began is to see that even though we may feel powerless, it is possible to provoke change. May that help to keep the fire burning every time the going gets tough.

Epilogue

In 2008, the Ministry of Health, Welfare and Sport followed up on its threats to cut subsidies to the clients' and family movement in mental health care. Only the clients' organisations that represented the largest number of actual, not potential, constituents kept (some of) their funding. Pandora, the Cliëntenbond and the LSOVD (Landelijke Stichting Ouders van Drugsverslaafden, National Foundation Parents of Drug Addicts) did not survive, but Ypsilon and Labyrint~In Perspektief are still very much alive. They are active members of MIND Landelijk Platform Psychische Gezondheid (MIND National Mental Health Platform), as their platform, formerly known as LPGGZ, has been called since 2016. Labyrint~In Perspektief changed its name to MIND Naasten Centraal (Relations Central) in 2022. Ypsilon wears MIND as a prefix to their name since 2019. In doing so, the organisations highlight that they have a common cause more than ever before.[1]

Today, the MIND platform brings together two dozen member organisations and a hundred associated initiatives in the clients', family and recovery movement, each with its own experience-based identity. Among them are many organisations we have met – extensively or only briefly – in the previous chapters: in addition to Naasten Centraal and Ypsilon, there is the former Fobieclub (Phobia Club), now called Angst Dwang Fobie Stichting (Anxiety Compulsion Phobia Foundation), the NVA (Nederlandse Vereniging voor Autisme, Dutch Association for Autism), PlusMinus (the former NSMD, Nederlandse Stichting voor Manisch Depressieven, Dutch Foundation for the Manically Depressed), WEET (the former Stichting Anorexia Boulimia Nervosa) and Anoiksis.[2]

The constituencies of Ypsilon and Labyrint~In Perspektief have declined somewhat since the turn of the century, which may still be considered puzzling in light of how many people are dealing with mental health problems.[3] In addition to the vicious circle

---

[1] Interview Cisca Goedhart, 18 November 2022; 'Organisatie', https://naastencentraal.nl/wie-zijn-wij/organisatie/organisatie/ and 'Ypsilon heet vanaf nu MIND Ypsilon', https://www.ypsilon.org/actueel-ypsilon/nieuws/ypsilon-heet-vanaf-nu-mind-ypsilon/ both accessed 10 March 2023.

[2] 'Leden', https://mindplatform.nl/over-mind-platform/organisatie/landelijke-lidorganisaties; 'Al-Anon Familiegroepen', http://www.al-anon.nl/; homepage Alzheimer Nederland, https://www.alzheimer-nederland.nl/ all accessed 12 May 2023.

[3] Ron de Graaf et al., 'Prevalence of mental disorders, and trends from 1996 to 2009. Results from the Netherlands Mental Health Survey and Incidence Study-2', *Social Psychiatry and Psychiatric Epidemiology* 47 (2012) 2, 203-213; Margreet ten Have et al., 'Prevalence and trends of common mental disorders from 2007-2009 to 2019-2022: Results from the Netherlands Mental Health Survey and Incidence Studies (NEMESIS), including comparison of prevalence rates before vs. during the COVID-19 pandemic', *World Psychiatry* 22 (2023) 2, 275-285.

of being small and limited in their ability to attract the attention of a burdened and stigmatised target group, over the past twenty-five years, the internet has become a factor, diverting potential participants to online initiatives without formal organisations. People's needs have changed, and interest in more traditional forms of organisation has declined. The organisations are, however, moving with the times and catering to the needs of relations today by using the possibilities of the internet and social media too.[4] And over the past fifteen years they have developed their role as the 'third market player' in mental health care representing the voices of patients and relations.

Ypsilon director Bert Stavenuiter and chairwoman Cisca Goedhart of Naasten Centraal, both active in their organisations since 1993, have long enough hindsight to be able to pinpoint how the organisations have changed. When the family organisations emerged in the early 1980s, Stavenuiter says, the situation was so bad that there was enough low-hanging fruit to be picked to show quick improvements. But to be able to move beyond that and take their activism to the next level, the only way was to join forces. This was difficult until well into the twenty-first century, Goedhart explains, because their interests clashed and high-running emotions did not make things easier. Eventually, however, Stavenuiter saw the fear of vanishing in a merged organisation being replaced by the fear of vanishing as a consequence of diminishing constituencies, making it even more urgent to look for strength in numbers. On the plus side, Goedhart points out, the Dutch government has continued, despite the budget cuts it implemented in this period, to support individual organisations as well as their platforms financially, making it possible for all of them to retain their independence.[5]

But there is also a historical aspect to why it became possible for family and clients' organisations to join forces, after having demonised each other for twenty years. Around the turn of the century, the first generation of activists had gone, the generation whose experiences had been so bad that they had sparked their movement, the generation that had opened the door to family and clients' activism, and the generation that had cherished such firm convictions that they denounced the initiatives of others. The new generation that followed developed the art of working together. Goedhart explains the difference between them:

“… *het grote verschil tussen die twee* [generaties] *is dat de eerste boven op de barricades staat en zegt: ik wil dat jullie*	(“… The big difference between those two [generations] is that the first one stands on top of the barricades and says:

---

[4] Interview Bert Stavenuiter, 27 January 2022; interview Cisca Goedhart, 18 November 2022.

[5] Interview Cisca Goedhart, 18 November 2022; interview Bert Stavenuiter, 27 January 2022.

naar mij luisteren. En dat dan de andere partij ondertussen zegt van fijn, ik wil graag horen wat je te zeggen hebt [...]. *En dat die ander dan niet weet wat-ie moet zeggen, want die is altijd aan het vechten geweest dat er naar hem geluisterd moet worden, maar die heeft z'n boodschap eigenlijk nog niet goed geformuleerd. Dus dan blijf je in zo'n clash-stand staan. Die nieuwere ervaringsdeskundigen, dat zijn mensen die natuurlijk meer de ervaring hebben dat er wél naar je geluisterd wordt. Die staan dus ook veel meer in de stand van: hoe kan ik goed verwoorden waar het nog niet goed gaat, zodat we met elkaar kunnen kijken hoe we eruit komen.* [...] *En dat is echt in de hele breedte van de patiëntenbeweging te zien, volgens mij, deze ontwikkeling."*[6]

I want you to listen to me. And that the other party now says fine, I would like to hear what you have to say [...]. And that the first person then doesn't know what to say, because they have always been fighting to make themselves heard, but they haven't actually formulated a proper message yet. So then you remain fixed in some kind of clash mode. Those newer experts-by-experience are people who, of course, have found more that you are listened to. So, their attitude is like: how can I properly articulate where things are not going well yet, so that we can see together how we can solve them. [...] And that can really be seen across the patient movement, I think, this development.")

The new attitude enables the organisations to work together today in MIND, and find common ground even when the interests of relations and clients collide; even when the large apparatus the movement has come to be sometimes raises eyebrows, former board member Titia Feldmann says:

"Je kan wel schelden tegen de koepel, van dat wij groot en dik en [...] *weet ik wat zijn, maar het is wel het enige gezicht dat we hebben met z'n allen, hè. Ik bedoel: als je al die organisaties los laat freewheelen, dan is er echt niemand bereid om te luisteren. Niemand gaat met 36 of 45 verschillende cliëntenorganisaties in gesprek."*[7]

("Surely you can swear at the umbrella organisation, that we are big and fat and [...] whatever, but it's the only face we all share, isn't it? I mean, if you let all these organisations freewheel, then absolutely no one is willing to listen. Nobody talks to 36 or 45 different clients' organisations.")

---

[6] Interview Cisca Goedhart, 18 November 2022.

[7] Interview Titia Feldmann, 20 February 2020.

A lot has changed since the early 1980s. Mother-blaming and family-blaming, perhaps the most fundamental trigger of the family movement, has subsided, although some in the movement say they can still feel it, especially in judgements from their social environment. On the other hand, psychiatrist Floortje Scheepers says that the extreme form taken by family-blaming in the 1970s and 80s makes it difficult for mental health care professionals today to address the influence of parents in cases where they should.[8] The circumstances in mental health care have improved beyond recognition compared to the days of Mies Osterholt, but staff shortages and budget cuts as well as a rising number of people in need of help have continued to create a feeling of crisis, especially since the COVID-19 pandemic, and appeals to make more money available to the sector continue. Likewise, the stigma associated with mental health issues continues to be a problem.[9]

Meanwhile, the clients' movement has changed, too. After the undifferentiated organisations that emerged in the 1960s and 70s were joined by an exploding number of diagnosis-oriented colleagues in the 1980s and 90s, around the turn of the century a whole new line of clients' initiatives surfaced: the recovery movement. Since then, this movement has developed new forms of peer support in its own centres and academies, from a perspective of recovery, not illness. With the recovery movement, clients have really taken matters into their own hands, inviting relations in when they see fit.[10]

The presence of the relations in the mental health care arena is no longer questioned today, although following up that recognition in institutional policies and practices remains a concern. Over the past twenty years, the family organisations have achieved important successes. The *familievertrouwenspersoon* (family advocate) has come to be an asset in the support system for relations, as has the national organisation that employs them to work in the mental health care organisations. They are an unequivocal achievement of the family and clients' movement. The *Kwaliteitsstandaard Naasten* (Quality Standard Relations), developed in close collaboration with the mental health care providers and insurers, has, since 2016, set the official standard in mental health care for collaborating with and supporting relations, and is considered a milestone of the family movement. A more disputed development is that relations have been given a legal position in situations where involuntary commitment is considered. Under the *Wet*

---

[8] Floortje Scheepers, *Mensen zijn ingewikkeld. Een pleidooi voor acceptatie van de werkelijkheid en het loslaten van modeldenken* (Amsterdam 2021) 118.

[9] M. ten Have et al., 'Houding van de algemene bevolking ten opzichte van (ex-)psychiatrische patiënten: resultaten van NEMESIS-2', *Tijdschrift voor Psychiatrie* 57 (2014) 11, 785-794; J. van Weeghel et al., 'Proloog: een onderschat probleem op de agenda', in: J. van Weeghel et al., *Handboek destigmatisering bij psychische aandoeningen. Principes, perspectieven en praktijken* (Bussum 2016) 21-41, 21-23.

[10] Petra Hunsche, *Herstel in beweging. De cliëntenbeweging in de 21^{e} eeuw* (Amsterdam 2022).

verplichte geestelijke gezondheidszorg (WVGGZ, Law Compulsory Mental Health Care), that replaced the *Wet BOPZ (Wet Bijzondere Opnemingen in Psychiatrische Ziekenhuizen,* Law on Special Admissions to Psychiatric Hospitals) in 2020, relations can ask for involuntary commitment of a loved one, and are involved in the decision making that follows, as is the patient. In these cases, the mental health care organisation is also obliged by law to have a family advocate in its institution to support the family.[11]

This shift in mental health care law and policy happened against the background of a swing in public and professional opinion on how to deal with the dilemma between respecting the autonomy of the patient on the one hand, and interfering when the fundamental well-being of the person or their environment is under threat, on the other. The debate on *'verwarde personen'* ('confused persons') became increasingly repressive, Karlijn Roex has concluded.[12] To some, the result feels like turning back the clock on patients' rights in favour of relations' rights, while to others the essence is that better care can be taken of those in extreme need. Meanwhile, the quality of that care has only come under more stress in a sector that is expected to cope with an ever-increasing demand despite continued budget cuts and rising staff shortages.[13]

The discussion on what mental health problems are, what causes them, and what we should do about them, goes on. While the biomedical model is still dominant, especially in the way Dutch mental health care is organised, it is continuously challenged by critical thinkers, experts-by-experience and experts-by-training, who promote new approaches combining and integrating biomedical, social, psychological and religious or spiritual points of view, or letting go of model thinking altogether.[14]

In the clients' and family movement, something similar is becoming discernible in the ways the two principal adversaries of the early family movement are changing their positions. In 2008, Labyrint~In Perspektief stood to lose its entire government subsidy in the reshuffle that dropped the curtain on Pandora, the Cliëntenbond and the LSOVD. To be able to hold on to some subsidy at least, Labyrint~In Perspektief presented

---

[11] 'Goed familiebeleid vanaf nu verplicht in GGZ-instellingen', https://www.ypsilon.org/actueel-ypsilon/nieuws/goed-familiebeleid-vanaf-nu-verplicht-in-ggz-instellingen/ accessed 12 May 2023; interview Titia Feldmann, 20 February 2020; interview Annelies Faber, Els Borgesius & Paul Baart, 13 January 2022; interview Bert Stavenuiter, 27 January 2022; interview Cisca Goedhart, 18 November 2022.

[12] Karlijn Roex, *In verwarde staat. Kritiek op een politiek van normaliteit* (Amsterdam 2019) 100-102.

[13] 'Vacaturegraad ggz blijft onverminderd hoog, uitstroom neemt toe', https://www.cbs.nl/nl-nl/nieuws/2023/08/vacaturegraad-ggz-blijft-onverminderd-hoog-uitstroom-neemt-toe accessed 10 April 2024.

[14] See for example Scheepers, *Mensen zijn ingewikkeld;* Myrrhe van Spronsen & Jim van Os, *We zijn God niet. Pleidooi voor een nieuwe psychiatrie van samenwerking* (Amsterdam, Leuven 2021); Sanneke de Haan, *Enactive Psychiatry* (Cambridge 2022).

its constituency to the Ministry as clients of mental health care, based on evidence that 85% of the family members in the organisation were so heavily burdened that they received some form of mental health care. In doing so, Labyrint~In Perspektief's constituents were effectively redefined as patients, one of those terms their founding mothers abhorred, but that now – barely – saved them from oblivion. That decision may also have contributed to further eroding the dividing lines between clients and relations that were drawn with the creation of the family organisations in the early 1980s. In that sense, the social movement in mental health care has circled back to resemble its beginnings in the solidarity movement around 1970. To Labyrint~In Perspektief chairwoman Goedhart, this was a logical development, as every process of empowerment comes with temporal separation.[15]

Ypsilon made a move that is symbolic too. In 2022, the organisation that had always revolved around family members of people who suffered from chronic psychosis announced that from then on, it would welcome relations no matter what the diagnosis of their loved one. In addition, the news post that announced this shift on their website read, they were going to target their focus more to the relations than in the past, from the view that the person with a mental vulnerability and the family member each have to live their own life. The terms patient, illness or schizophrenia were nowhere to be found.[16] Although each still has its own focus, Naasten Centraal and Ypsilon seem to have bridged the deepest rifts between what once were the two fiercest adversaries in the family movement.

Despite the advances that are made in mental health care and research every day, understanding what causes mental health issues as well as what to do about them is as elusive as ever, and those who struggle with them continue to suffer from the consequences. This history of the origins of the Dutch family movement illustrates how historical shifts in the dominant explanatory models for mental health issues have produced a wide variety of insights, but also how a narrow focus on one type of model can have serious consequences for the people who suffer from mental health problems and their relations. Although all models have their merits, over the past seventy-five years, only one has tended to be dominant at any time, obscuring the merits of the others. The social model that reigned from the late 1960s to the late 1980s turned family members into scapegoats, for example, while the biomedical model that has ruled since then has obscured how detrimental social injustice can be for people's mental health.

---

[15] Interview Cisca Goedhart, 18 November 2022.

[16] Interview Bert Stavenuiter, 27 January 2022; 'MIND Ypsilon laat focus op psychosegevoeligheid los', https://www.ypsilon.org/algemeen/mind-ypsilon-laat-focus-op-psychosegevoeligheid-los/ accessed 19 May 2023.

Over the past forty years, this biomedical model has been so dominant that to many, lay people and professionals alike, it is a given – when you don't feel mentally well, you have an illness, and medication is the solution. History shows us, however, that the way we look at the troubles of the mind is a cultural construction that shifts through time with the tide of the moods and ideas in our society. The merit of such historical knowledge is that it instils an awareness of the wide variety of factors that can cause mental health problems and opens up a wide variety of options for what can and should be done about them – by mental health care professionals and researchers, by government policy makers and advisors, by (potential) clients and relations, by all of us in our society.

Samenvatting

Tot de jaren tachtig van de vorige eeuw was er in de Nederlandse geestelijke gezondheidszorg nauwelijks oog voor naasten van mensen met ernstige psychiatrische problemen en bestonden er ook geen organisaties waarin zij voor hun belangen opkwamen. En dat terwijl vaak een groot deel van de zorg op de schouders van deze naasten terecht kwam. In hoeverre zij in staat waren die zorg te dragen, hing niet zozeer af van het soort problemen waar het om ging – angst, depressie, autisme, een eetstoornis, verslaving, dementie, chronische psychose of schizofrenie of wat dan ook – maar van de balans tussen hun draaglast en hun draagkracht: de zwaarte van de problematiek versus het vermogen van de naasten om daar mee om te gaan.

Veel mensen kregen en krijgen vroeg of laat met zo'n situatie te maken. Statistieken laten immers zien dat vandaag de dag meer dan de helft van de Nederlanders ooit psychische problemen krijgt, en ook destijds liepen die cijfers al hard op. Desondanks werden de problemen van naasten tot circa 1980 niet gezien en ook door henzelf niet openlijk benoemd en aangekaart. En toen ineens, begin jaren tachtig, kwamen er bijna tegelijk verschillende organisaties op van en voor naasten van mensen met ernstige psychiatrische problemen. Hoe kwam dat?

Om de wortels van de Nederlandse naastenbeweging in de geestelijke gezondheidszorg bloot te leggen, is het nodig om te beginnen bij de vroegste actieve of activistische naasten op dit gebied. Al sinds de jaren zestig namen partners en ouders, en later ook broers, zussen, volwassen kinderen en goede vrienden van (voormalige) psychiatrische patiënten initiatieven om het lot van hun geliefden te verbeteren. In die organisaties trokken mensen met psychische problemen en naasten in grote solidariteit met elkaar op. Dat de belangen van patiënten en naasten niet altijd parallel liepen, was in die organisaties niet aan de orde, en dat is wat deze voorlopers onderscheidt van de naastenorganisaties van de jaren tachtig, waar die verschillen – in meerdere of mindere mate – wel werden benoemd. De sociale beweging die al deze organisaties samen vormen noemen we tegenwoordig de cliënten- en naastenbeweging. Die beweging heeft deels een gezamenlijke geschiedenis, en deels een aparte geschiedenis. Dit proefschrift draait om de geschiedenis van het ontstaan van de aparte naastenbeweging in de geestelijke gezondheidszorg in Nederland, maar brengt ook dus ook in kaart hoe naasten daarvoor al deelnamen aan activisme en zelfhulporganisaties op het gebied van geestelijke gezondheid.

In 1961 startten vrouwen van alcoholisten Al-Anon, de familietak van de Anonieme Alcoholisten, en in 1964 richtte een Nederlander die zijn fortuin had gemaakt in Amerika de Stichting Pandora op, een stichting die zich inzette om het stigma rond psychiatrische problemen te bestrijden. Op het eerste gezicht hadden die twee initiatieven misschien niet zoveel gemeen. Maar wat opvalt is dat stigma en een daaruit voortkomende behoefte aan anonimiteit sterk bepalend waren voor hoe de initiatiefnemers opereerden. In Al-Anon werden oprichters en deelnemers beschermd tegen vooroordelen en discriminatie door hun anonimiteit strikt te bewaken. De oprichter van Pandora stond als weldoener geportretteerd in alle kranten, maar hij vertelde er niet bij dat hij zelf 'echtgenoot-van' en 'vader-van' was. Het taboe, de schaamte en het stigma waren ook voor hem kennelijk te groot om zijn ware motivatie bloot te geven.

Tegelijkertijd waren de jaren zestig een tijd van optimisme in de psychiatrie. Er was een groot geloof in de nieuwe medicijnen en behandelmethoden die geïntroduceerd werden. Aan dat geloof lag het biomedisch verklaringsmodel voor psychische problemen ten grondslag en de manier van denken die daarbij hoorde: dat psychische problemen ziektes zijn, dat mensen die eraan lijden ziek zijn en dat ze door dokters in ziekenhuizen beter gemaakt kunnen worden. Dit was ook het perspectief vanwaaruit Al-Anon en het vroege Pandora opereerden. Zij promootten met hun werk in feite de moderne psychiatrie.

Omstreeks 1970 doorbraken de eerste (voormalige) patiënten en naasten het stigma dat in de jaren zestig nog zo allesverstikkend was geweest door openlijk hun verhaal te vertellen in boeken en in de media. Een aantal van deze mensen vond elkaar en besloot in 1971 de Cliëntenbond in de Welzijnszorg op te richten. Niet alleen werd met 'cliënten' zowel (ex-)patiënten als naasten bedoeld, naasten waren bovendien belangrijke drijvende krachten in de eerste tien jaar van de organisatie. Zij werden niet alleen geïnspireerd door hun slechte ervaringen in de ggz, waar hun geliefden werden behandeld, maar ook door een nieuwe wind die in de psychiatrie was opgestoken: de kritische psychiatrie of anti-psychiatrie. In reactie op het biomedisch model, dat zijn optimistische beloftes niet had kunnen waarmaken, ging deze stroming uit van het sociale verklaringsmodel voor psychische problemen: dat waren geen ziektes, maar een gezonde reactie op een ziekmakende maatschappij. Net als andere organisaties in deze kritische tegenbeweging in de psychiatrie stelde de Cliëntenbond de slechte omstandigheden in veel psychiatrische ziekenhuizen aan de kaak, en zette ze zich in voor een betere rechtspositie van cliënten en voor het uitbreiden en verbeteren van ambulante zorg in plaats van zorg in klinieken waar mensen in hun ogen alleen maar slechter van werden.

Deze turbulentie in de psychiatrie was sterk verbonden met de maatschappijkritische en emancipatoire sfeer van de jaren zeventig. Als een van de belangrijkste organisaties in de kritische tegenbeweging stond de Cliëntenbond in het brandpunt van de belangstelling. Na een ingrijpende heroriëntatie voegde in de tweede helft van de jaren zeventig ook Pandora zich bij de beweging. Tegelijkertijd werden er echter, meer in de luwte, ook een paar voorlopers van de naastenbeweging opgericht die niet zo anti-psychiatrisch waren ingesteld. Ouders van zwaar autistische kinderen zetten midden jaren zeventig organisaties op die in 1978 samengingen in de Nederlandse Vereniging voor Autisme, en datzelfde jaar nam een vader van een tienerdochter het initiatief tot de oprichting van de Stichting Anorexia Nervosa. In tegenstelling tot de ongedifferentieerde, sociaal georiënteerde Cliëntenbond, focusten zij juist op een specifieke diagnose.

Er was in die tijd nog weinig kennis van autisme en anorexia nervosa en aan de kennis die er was, hadden naasten geen steun. Erger nog: de experts van het inmiddels dominante sociale verklaringsmodel gingen ervan uit dat iemands psychische problemen werden veroorzaakt door zijn naasten – door de moeder vooral, maar ook door de vader, door de partner, en door de dynamiek in het hele gezin. Het gezin was een minimaatschappij en de gevoelige mens die daarin ‘ziek’ werd, was de kanarie in de kolenmijn. Het was dus zaak die mens te helpen los te breken van dat ‘ziekmakende’ systeem. Met als gevolg dat naasten werden buitengehouden door hulpverleners, ook als zij het leeuwendeel van de zorg droegen. Omdat Nederland een eigen traditie had van autismeonderzoek bleef deze manier van denken hier grotendeels weg uit de autismezorg. Maar daarbuiten verspreidde dit gedachtegoed zich door de hele psychiatrie.

Jarenlang werden veel naasten door de schuldgevoelens die hen werden toegedicht gemuilkorfd. Maar ook als ze hulpverleners troffen die niet zo sterk beïnvloed waren door het sociale verklaringsmodel, werden ze veelal genegeerd, ongeïnformeerd gelaten en buitengesloten. In de vroege jaren tachtig werd daar nog een schepje bovenop gedaan doordat het recht op privacy in de Nederlandse grondwet werden vastgelegd. Dit was een belangrijk succes van de cliëntenbeweging, maar het versterkte het isolement van de naasten doordat hulpverleners dit recht opvatten als een verbod op contact met naasten.

Zoals het biomedische verklaringsmodel in de psychiatrie tien jaar eerder op een zijspoor was gekomen, raakte in de loop van de jaren tachtig het sociale model door teleurstellende resultaten op zijn beurt op zijn retour. Doordat het zoeken naar de oorzaak van psychische problemen in de familiekring een beetje werd losgelaten, kwamen in het hernieuwde biomedische model – dat naar die oorzaak zocht in het brein en de genen – naasten langzaamaan in beeld als bondgenoten van de zorg in plaats van tegenstanders. Het idee dat psychische problemen hersenziekten waren ontsloeg naasten van het schuldgevoel dat zij in hun gezinsleven iets misdaan zouden hebben waardoor ze hun geliefden zouden hebben ziek gemaakt en verminderde het schuldgevoel. Dat gaf naasten de moed om zich te gaan organiseren voor hun eigen belangen. De wig die het anti-psychiatrisch denken had gedreven tussen hen en hun geliefden had duidelijk gemaakt dat hun belangen niet altijd hetzelfde waren, en in een maatschappij waarin individualisme steeds sterker leidend werd, eisten zij bovendien het recht op iets van een eigen leven op. Maar ook mensen in de kritische tegenbeweging in de psychiatrie, die nog altijd redeneerden vanuit het sociale model, ontdekten hoe moeilijk de positie van naaste was wanneer zij probeerden te zorgen voor hun vrienden in tijden van crisis.

In het veranderende klimaat van de jaren tachtig, waarin het biomedische en het sociale verklaringsmodel zich beide lieten gelden, begonnen ineens verschillende groepen naasten zich te organiseren. Binnen vijf jaar zagen vier organisaties het licht: de Landelijke Stichting Ouders van Drugsverslaafden (1980), In Perspektief (1981, voor christelijke naasten), Ypsilon (1984, voor naasten van mensen met schizofrenie) en Labyrint (1985, voor alle naasten). Alle vier hadden ze hetzelfde hoofddoel – erkenning krijgen voor de problemen die naasten ervoeren en voor hun positie als belanghebbende in het overleg over de zorg, zowel op individueel niveau als op het niveau van zorginstellingen en het overheidsbeleid.

Dat gezamenlijke hoofddoel werd echter overschaduwd door onderlinge conflicten tussen de organisaties. Labyrint was een directe afstammeling van Pandora en daarmee een aanhanger van het sociale verklaringsmodel. De initiatiefnemers verzetten zich tegen het ziektedenken, vooral bij 'schizofrenie', en pleitten vooral voor uitbreiding en verbetering van de ambulante zorg. De autonomie van cliënten was voor hen leidend, en zij propageerden dan ook manieren om de positie van naasten te verbeteren die daar op geen enkele manier inbreuk op maakten. In Perspektief kreeg van dat gedachtegoed een heleboel mee doordat het al van meet af aan samenwerkte met Labyrint. Toch duurde het meer dan tien jaar voor de twee organisaties fuseerden, omdat In Perspektief – naar later bleek terecht – vreesde dat de aandacht voor de specifieke problematiek van gelovige naasten dan zou sneuvelen. De opkomst van Ypsilon hing direct samen met de terugkeer van het biomedische model: de leden van deze organisatie beschouwden het ziektedenken als bevrijdend voor naasten en omarmden de terugkeer van de diagnose schizofrenie. Ypsilon en Labyrint verkeerden daardoor jarenlang op zeer gespannen voet met elkaar. De LSOVD had een gedachtegoed rond verslaving dat meer gemeen had met het biomedische dan met het sociale verklaringsmodel. Maar deze organisatie stond de eerste twintig jaar buiten de rest van de naastenbeweging omdat verslaving als een ander probleem werd gezien, ondanks het gedeelde probleem dat ouders beschuldigd werden van het veroorzaken ervan en het veelvuldig samen voorkomen van verslaving en andere psychische problemen.

In een arena waarin zorgprofessionals en overheid de dienst uitmaakten en de cliëntenbeweging zich pas net een positie aan het veroveren was, moesten de naastenorganisaties zich als nieuwe speler zien in te vechten. Door de ongedifferentieerde cliëntenbeweging werd dat met argusogen bekeken: zij zaten niet te wachten op de bemoeienis van de familie die voor hun pas verworven rechten als een bedreiging werd gezien. Ook de meeste hulpverleners stonden niet snel open voor de naastenorganisaties: met de familie hadden zij niets te maken, naasten waren waarschijnlijk zelfs schuldig aan het veroorzaken van de problemen van hun cliënten, en de nieuwe wetgeving maakte het hen onmogelijk om een relatie met de familie aan te gaan, zo werd vaak geredeneerd. En ondanks de enorme omvang van het potentieel bleven de organisaties toch klein. Hoewel patiëntenorganisaties in andere hoeken van de zorg in die tijd relatief even kleine achterbannen hadden, en dat niet noodzakelijk betekende dat mensen geen belangstelling hadden voor hun werk of dat niet steunden, zorgde het ervoor dat ze beperkt werden in hun naamsbekendheid, groei en slagkracht.

De overheid ontving de naastenorganisaties in de jaren tachtig wel direct enthousiast. In de geestelijke gezondheidszorg van de toekomst waren inrichtingen waar patiënten levenslang verbleven verleden tijd, en zouden mensen zoveel mogelijk zorg in hun eigen omgeving krijgen. Vanwege de alsmaar hoger oplopende zorgkosten was daarin een belangrijke rol weggelegd voor mantelzorgers. Op de langere termijn wilde de overheid zich nog verder terugtrekken: in een systeem van marktwerking in de zorg zou alles geregeld worden tussen de zorgaanbieders, de zorgverzekeraars en de zorgconsumenten – cliënten en naasten. Dit was natuurlijk een zeer ongelijk speelveld dat heel moeilijk te betreden was voor deze veelal kleine organisaties van zwaar belaste mensen. Dat verschillende cliënten- en naastenorganisaties ook in de jaren negentig nog met elkaar overhoop lagen over hoe je precies moest kijken naar de problemen en de oplossingen hielp ook niet.

Door de jarenlang steeds verder opgevoerde druk van de overheid begon een aantal organisaties vlak na de eeuwwisseling toch samen te werken. Tegen die tijd was het sociale verklaringsmodel voor psychische problemen echt uit de tijd en nam het aantal diagnosegebonden clienten- en naastenorganisiaties onder invloed van het opnieuw dominante biomedische model snel toe. In het Landelijk Platform Geestelijke Gezondheidszorg (LPGGZ) dat ze toen vormden (het tegenwoordige MIND) gingen ze de uitdaging aan om op te treden als derde partij in de zorg en daarmee de stem van alle cliënten en naasten van Nederland te vertegenwoordigen. Dat de weg naar samenwerking toen toch kon worden ingeslagen, had niet alleen te maken met dat het gros van de cliënten- en naastenorganisaties tegen die tijd het biomedische perspectief deelde, maar ook met wat de naastenbeweging toen al had bereikt: aan de misstanden in de geestelijke gezondheidszorg waartegen naasten in de jaren tachtig oorspronkelijk in opstand waren gekomen, hadden ze toen grotendeels een eind gemaakt.

De twintig jaar waarin de naastenbeweging zich apart had gemanifesteerd waren een noodzakelijke periode in de emancipatie van naasten. Niet gezien, buitengesloten en beschuldigd door hulpverleners en tot op zekere hoogte door de cliëntenbeweging, kwam er in de jaren tachtig door de verschuiving van het dominante verklaringsmodel van sociaal naar biomedisch een klein beetje ruimte waarin naasten andere ervaringen en denkbeelden ontdekten en zich wisten te organiseren. Toen die ontwikkeling in de jaren negentig doorzette werden zij daar zelf ook een aanjagende factor in. Eind jaren negentig waren alle organisaties gesetteld en gaven de oprichters het stokje door aan de volgende generatie. Dankzij het werk van de naastenorganisaties had die de ernstigste misstanden niet meer meegemaakt en was die al meer gewend om gehoord te worden en in overleg te treden met de andere spelers in de arena. Daardoor kon de onderlinge polarisatie langzaamaan wegebben en werd het mogelijk om ondanks onderlinge verschillen met elkaar samen op te trekken voor het gezamenlijke hoofddoel.

Summary

Until the 1980s, Dutch mental health care paid little attention to relations of people with severe mental health problems, and there were no organisations in which they stood up for their interests. And that was despite a large part of the care for their loved ones often ending up on the shoulders of these relatives. The extent to which they were able to provide care depended not so much on the type of problem in question – anxiety, depression, autism, an eating disorder, addiction, dementia, chronic psychosis or schizophrenia or whatever – but on the balance between their burden of care and their coping capacity: the severity of the problem versus their ability to deal with it.

Many people had and will have to deal with such a situation sooner or later. After all, statistics show that today more than half of the Dutch population will experience mental health issues at some point, and even back then those figures were rising rapidly. Nevertheless, until about 1980 the problems of relatives were not seen and they were also not openly named and addressed by themselves. And then suddenly, in the early 1980s, several organisations by and for relatives of people with severe mental health problems sprang up almost simultaneously. How did that happen?

To uncover the roots of the Dutch family movement in mental health care, it is necessary to start with the earliest active or activist relations in this field. Since the 1960s, partners and parents, and later also brothers, sisters, adult children and close friends of (former) psychiatric patients have taken initiatives to improve the fate of their loved ones. In those organisations, people with mental health problems and relatives worked together in solidarity. The fact that their interests did not always coincide was not an issue, and that is what distinguishes such predecessors from the family organisations of the 1980s, where – to a greater or lesser extent – the differences were identified. The social movement that all these organisations form together is now called the clients' and family movement in mental health care. That movement has partly a common history, and partly distinct histories. This dissertation revolves around the history of the emergence of a separate family movement in mental health care in the Netherlands, but also maps out how relations were already involved in mental health activism and self-help organisations before that.

In 1961, the wives of alcoholics started Al-Anon, the family branch of Alcoholics Anonymous, and in 1964 a Dutchman who had made his fortune in America founded the Pandora Foundation, a foundation dedicated to combating the stigma surrounding mental health problems. At first glance, these two initiatives may not have had much in common. But what is striking is that stigma and a resulting need for anonymity strongly determined how these initiators operated. In Al-Anon, founders and participants were protected from prejudice and discrimination by strictly guarding their anonymity. The founder of Pandora was portrayed as a benefactor in all the newspapers, but he did not mention that he himself was a 'husband-of' and a 'father-of'. The taboo, the shame and the stigma were apparently too strong for him to reveal his true motivations.

At the same time, the 1960s were a time of optimism in mental health care. There was great faith in new medicines and treatment methods that were being introduced. Underlying that belief was a biomedically based explanatory model for mental health problems and the way of thinking that went with it: that mental health problems are illnesses, that people who suffer from them are sick and that they can be made better by doctors in hospitals. This was also the perspective that drove Al-Anon and early Pandora. They were, in effect, promoting modern psychiatry with their work.

Around 1970, the first (former) patients and relations broke through the stigma that had been so suffocating in the 1960s by openly telling their stories in books and in the media. A number of these people found each other and decided in 1971 to set up the Cliëntenbond in de Welzijnszorg (Client's League in Welfare Care). Not only did 'clients' refer to both (former) patients and relations, but relatives were also an important driving force in the first ten years of the organisation. They were not only inspired by their bad experiences with mental health care, where their loved ones were treated, but also by a new wind that had sprung up in mental health care: critical psychiatry or anti-psychiatry. In response to the biomedical model, which had failed to live up to its optimistic promises, this new movement was grounded in a social explanatory model for mental health problems: these were not illnesses, but a healthy response to a sickening society. Like other organisations in this critical countermovement in psychiatry, the Cliëntenbond denounced the poor conditions in many psychiatric hospitals, and committed to bettering the legal position of clients and to expanding and improving outpatient care, instead of care in clinics that, in its eyes, only made people worse.

This turbulence in psychiatry was strongly linked to the socially critical and liberatory atmosphere of the 1970s. As one of the most important organisations in the critical countermovement, the Cliëntenbond was the focus of attention. After a radical reorientation, Pandora joined the movement in the second half of the 1970s. At the same time, however, another few predecessors of the family movement were founded, more in the margins - predecessors which were not so much inclined to anti-psychiatry. In the mid-1970s, parents of severely autistic children set up organisations that merged into the Nederlandse Vereniging voor Autisme (Dutch Association for Autism) in 1978, and that same year a father of a teenage daughter took the initiative to establish the Stichting

Anorexia Nervosa (Anorexia Nervosa Foundation). In contrast to the undifferentiated, socially oriented Cliëntenbond, they focused on one specific diagnosis.

At that time, there was little knowledge of autism or anorexia nervosa and the knowledge that was available did not support relations. Worse still, experts who used the now-dominant social explanatory model assumed that a person's mental health problems were caused by their relatives – by the mother especially, but also by the father, by the partner, and by the dynamics in the whole family. The family was a mini-society and the sensitive person who became 'sick' in it was the canary in the coal mine. Therefore, it was important to help that person break free from the 'sickening' system. As a result, relatives were kept out by mental health care professionals, even if they took on the lion's share of the care. Because the Netherlands had its own tradition of autism research, this way of thinking was largely kept out of Dutch autism care. But beyond that, this body of thought spread throughout psychiatry.

For years, many loved ones were muzzled by the feelings of guilt attributed to them. But even when they met mental health care workers who were not so strongly influenced by the social explanatory model, they were often ignored, kept uninformed and excluded. In the early 1980s, such exclusion was taken a step further when the right to privacy became enshrined in the Dutch Constitution. This was an important success of the clients' movement, but it reinforced the relations' isolation because professionals interpreted this right as a prohibition on contact with relatives.

Just as the biomedical explanatory model in psychiatry had been set aside ten years earlier, in the course of the 1980s, the social model in turn declined due to disappointing results. Because the search for the cause of psychological problems inside the family was somewhat abandoned under the renewed biomedical model – that looked for that cause in the brain and the genes instead – relatives slowly came into the picture as allies of care instead of opponents. The idea that mental health problems were brain diseases relieved relatives of the blame that they had done something wrong in their family life to have made their loved ones sick and reduced the feeling of guilt. This gave relations the courage to organise in their own interest. The wedge that anti-psychiatric thinking had driven between them and their loved ones had made it clear that the two groups' interests were not always the same, and in a society in which individualism was increasingly dominant, relations also claimed the right to have something of a life of their own. But even adherents of the critical countermovement in psychiatry, who still reasoned from the social model, discovered how difficult the position of relations was when trying to take care of their friends in times of crisis.

In the changing climate of the 1980s, in which the biomedical and social explanatory models both asserted themselves, various groups of relations suddenly began to organise. Within five years, four organisations emerged: the Landelijke Stichting Ouders van

Drugsverslaafden (LSOVD, National Foundation for Parents of Drug Addicts, 1980), In Perspektief (In Perspective, 1981, for Christian relations), Ypsilon (1984, for relatives of people with schizophrenia) and Labyrint (1985, for all relations). All four had the same main goal – to gain recognition for the problems experienced by relations and for their position as stakeholders in consultations about care, both at the individual level and at the level of care institutions and government policy.

However, that common main goal was overshadowed by various conflicts between the organisations. Labyrint was a direct descendant of Pandora and therefore a supporter of the social explanatory model. Its initiators opposed the idea of mental illness, especially in the case of 'schizophrenia', and argued particularly for the expansion and improvement of outpatient care. The autonomy of clients was their priority, and they therefore proposed ways to improve the position of relations that did not infringe on this autonomy in any way. In Perspektief absorbed a lot of that philosophy because it collaborated with Labyrint from the start. Yet it took more than ten years for the two organisations to merge, because In Perspektief feared – as it turned out rightly – that its attention to the specific problems of religious relations would then be lost. The emergence of Ypsilon was directly related to the return of the biomedical model: its members considered the interpretation of mental health problems as illnesses liberating, and they wholeheartedly embraced the return of schizophrenia as a diagnosis. As a result, Ypsilon and Labyrint were at odds with each other for years. The LSOVD had a perspective on addiction that had more in common with the biomedical than with the social explanatory model. But for the first twenty years, this organisation stood outside the rest of the family movement because addiction was seen as a separate problem, despite the shared issue that parents were accused of causing it, and despite the frequent co-occurrence of addiction and other mental health problems.

In an arena in which mental health care professionals and the government called the shots and the clients' movement was gaining a position, the family organisations had to fight their way in as a new player. This was viewed with suspicion by the undifferentiated clients' movement that was led by the Cliëntenbond and Pandora: it resented the interference of the family, which was seen as a threat to clients' newly acquired rights. Additionally, few mental health care workers were readily open to the family organisations: in their eyes, as professionals they had nothing to do with the family, relatives were probably even guilty of causing their clients' problems, and the new legislation made it impossible for them to enter into a relationship with the relations anyway. And despite the sheer size of their potential constituencies, the family organisations remained small. Although patient organisations in other corners of healthcare also had relatively small constituencies at the time, and this did not necessarily mean that people were not interested in or did not support their work, it meant that they were limited in their name-recognition, growth and strength.

The government, however, welcomed the family organisations immediately and enthusiastically in the 1980s. In the mental health care system proposed for the future, asylums where patients stayed for life would be a thing of the past, and individuals would receive care in their own community as much as possible. Due to ever-increasing healthcare costs, informal caregivers had an important role to play in this vision. In the longer term, the government wanted to withdraw even further: in a regulated market system in healthcare, everything would be arranged between the healthcare providers, the health insurers and the healthcare consumers – clients and relatives. This, of course, was a very uneven playing field that was very difficult for these mostly small organisations of heavily burdened people to enter. The fact that the various clients' and family organisations were still at odds with each other in the 1990s about exactly how to approach the issues they addressed and the solutions they proposed did not help either.

Due to years of increasing pressure from the government, a dozen organisations started to work together just after the turn of the century. By that time, the social explanatory model for mental health problems was definitely outdated and the number of diagnosis-oriented clients' and family organisations had increased rapidly under the influence of the returned biomedical model. In the Landelijk Platform Geestelijke Gezondheidszorg (LPGGZ, National Platform for Mental Health Care) that they formed at that time (the present MIND) these organisations took on the challenge of acting as a third party in healthcare and thus representing the voice of all clients and relations in the Netherlands. The fact that the path to cooperation could be taken at this time was not only due to the fact that the majority of the clients' and family organisations now shared the biomedical perspective, but also to what the family movement had already achieved: by then, they had largely brought an end to the mistreatment of relations in mental health care against which they originally rebelled in the 1980s.

The twenty years during which the family movement existed separately was a necessary period in the empowerment of relations. Unseen, excluded and accused by mental health professionals and to a certain extent by the clients' movement, relations found a small amount of space in the 1980s shift in the dominant explanatory model from social to biomedical in which they could discover other experiences and ideas and determine how to organise themselves. As this development continued into the 1990s, they themselves became a driving factor. By the end of the 1990s, all organisations had settled down and the founders passed the baton to the next generation. Thanks to the work of the family organisations, these new actors had not experienced the most serious forms of mistreatment and were already more accustomed to being heard by and consulting with the other players in the arena. As a result, the polarisation between organisations could slowly fade away and it became possible to work together for their common goals despite their particular differences.

Dankwoord

Bij een kopieerapparaat op een Amsterdamse universiteit werd ik voor het eerst geconfronteerd met een nieuw toekomstperspectief: promoveren. Het was in de zomer van 2017; ik had net mijn deeltijdstudie geschiedenis aan de Vrije Universiteit afgerond. Die zomer stond voor mij in het teken van weemoed, omdat ik (dacht ik) afscheid moest nemen van de academische wereld die mij acht jaar lang zoveel had gegeven, ondanks dat ik mijzelf tot die tijd nooit had gezien als iemand die daar thuis zou kunnen horen. Samen met een handjevol andere deeltijders van zekere leeftijd had ik aan de VU een stimulerend, uitdagend en warm nest gevonden. Het was niet makkelijk geweest om studie en werk te combineren, maar met hun persoonlijke aandacht en begrip voor mijn situatie hadden de hoogleraren, docenten en studieadviseurs het voor mij mogelijk gemaakt om mijn studie te voltooien, zonder de lat daarvoor echter lager te leggen. Liever legden ze die lat nog wat omhoog, zoals Susan Legêne toen ze mij het cruciale zetje gaf om na mijn bachelor te kiezen voor de researchmaster, en zoals Anneke Ribberink toen ze mij begeleidde bij het schrijven van zowel mijn bachelor- als mijn masterscriptie.

Dat kopieerapparaat dat ik me zo goed herinner, stond echter een paar kilometer verderop, in een gebouw van de Universiteit van Amsterdam. Ik stond daar die zomer met Gemma Blok, die ondanks dat ik helemaal niet aan haar universiteit studeerde, bereid was geweest om zich in te zetten als tweede begeleider van mijn masterscriptie, omdat mijn afstudeeronderwerp zich bij uitstek op haar onderzoeksterrein bevond. Terwijl we stonden te wachten tot het kopieerapparaat nog een exemplaar van mijn scriptie had geproduceerd, vertelde Gemma mij dat ze hoogleraar was geworden aan de Open Universiteit en nodigde ze me uit te solliciteren op een promotieplaats die daar openstond. Ondanks dat ik de researchmaster had gedaan, had ik promoveren nooit als een serieuze optie overwogen: ik zag dat mezelf niet doen naast mijn werk. En een betaalde promotieplaats, dat was toch alleen weggelegd voor jonge toptalenten die zonder jarenlange omwegen direct doorstoomden naar een academische carrière? Maar in plaats van dat we die dag afscheid namen van elkaar, betekende de uitnodiging die Gemma me toen deed een nieuw begin. Het begin van een nieuw werkend leven aan de Open Universiteit, waarin we nog steeds dagelijks mogen samenwerken en delen in het plezier en de frustraties van het academisch bestaan.

Omdat mijn onderzoeksplan ook een haakje had naar de letterkunde, werd Erica van Boven mijn tweede promotor. Dat was wederzijds – denk ik – aanvankelijk even wennen. Ondanks mijn oorspronkelijke ambities draaide het er toch op uit dat de literatuur niet meer dan een bijrol ging spelen in mijn proefschrift. Daarop vond Erica haar rol vooral door te kiezen voor de positie van scherpe meelezer die niet alleen mijn schrijfproces becommentarieerde, maar ook ingreep wanneer Gemma en ik te hard doordenderden in onze medisch-historische beroepsdeformatie. In de zes jaar dat we zo met z'n drieën optrokken deelden we ook steeds meer persoonlijk lief en leed; achteraf gezien ook vaak dingen die ons raakten als naasten. De steun die ik in moeilijke tijden van jullie kreeg zal ik nooit vergeten. En de dag dat we besloten dat mijn proefschrift af was, was niet alleen een dag van vreugde, maar ook een dag van spijt dat dit ons aller, allerlaatste begeleidingsgesprek was geweest.

De keuze voor mijn onderwerp was mij ingegeven door een combinatie van factoren uit mijn privé- en werkend leven. Enerzijds kwam het doordat ik al jaren van zeer nabij meemaakte hoe hard het leven kan zijn voor een dierbare die moet dealen met een chronische psychische kwetsbaarheid, en wat daarvan de weerslag is op de mensen om die persoon heen. Maar ook doordat mijn ouders – in het bijzonder mijn moeder – mij vertelden over hoe zulke dingen hadden huisgehouden in onze familie, in de generaties voor mij, en wat de impact daarvan op hen was geweest. Misschien had het daar mee te maken dat ik in mijn werk als freelance tekstschrijver – naar mijn eigen idee bij toeval – gespecialiseerd was geraakt in schrijven voor organisaties in en om de geestelijke gezondheidszorg. Via Netty van Ham van Mentrum en Hannie Boumans van Ypsilon kwam ik voor het eerst in aanraking met de naastenbeweging in de geestelijke gezondheidszorg. Door Hannie ving ik een eerste glimp op van het activisme van naasten en hoe mensen zoals zij zich inzetten voor een betere zorg, niet alleen voor hun eigen geliefden, maar voor ons allemaal.

Tijdens mijn zoektocht naar de wortels van dit activisme, leerde ik nog veel meer 'Hannies' kennen. Vrijwel zonder uitzondering waren activisten van het eerste uur en hun opvolgers – hun namen vindt u op bladzijde 313 en 314 – bereid om mij te vertellen over deze geschiedenis en hun rol daarin, ook al triggerde dat soms heel pijnlijke herinneringen. Anderen waren al overleden of op gevorderde leeftijd zo kwetsbaar geworden dat een gesprek er niet meer in zat. Hen leerde ik kennen door hun eigen publicaties en de publicaties en verhalen van anderen. Daarnaast sprak ik met een steeds groter wordende kring aan mensen die op uiteenlopende manieren verbonden zijn of waren aan de cliënten- en naastenbeweging, en die mij hielpen met tips, contacten en documenten die niet in archieven te vinden zijn. Ik ben ze allen dankbaar voor hun bevlogen activisme, de onvoorstelbare bergen werk die zij hebben verzet en soms nog steeds verzetten, en voor wat ze voor ons allemaal hebben bevochten. Ik hoop met dit proefschrift iets daarvan te hebben vastgelegd, zodat de geschiedenis van deze beweging activisten en belangenbehartigers van vandaag en morgen kunnen blijven inspireren.

Hoewel het er aanvankelijk naar uitzag dat archieven en bibliotheken weinig te bieden zouden hebben voor mijn onderzoek, deed ik daar toch een paar belangrijke vondsten. Medewerkers van die instellingen hielpen mij soms op buitengewone manieren, met name in coronatijd. Marian Hofman en haar collega's van universiteitsbibliotheek van de VU vonden wegen voor onderzoekers zoals ik, zodat ik hun buitengewone historische ggz-collectie weer kon raadplegen. Archivaris Mirjam Hofman van het Archief- en Documentatiecentrum van de Gereformeerde Kerken in Nederland te Kampen ontdubbelde ter plekke voor mij het archief van De Wegwijzer, waarna ze me het overschot meegaf. Gabriëlle Beentjes van het Nationaal Archief in Emmen maakte niet alleen medewerkers vrij zodat ik daar een week lang onderzoek kon doen in het archief van het Algemeen Diakonaal Bureau, zij nodigde mij bovendien uit om bij haar thuis te komen eten op anderhalve meter afstand zodat ik die week niet eenzaam hoefde te verpieteren onder de coronaregels in een B&B.

Van meet af aan ontmoette ik ook enthousiasme voor mijn onderzoek bij de – zeldzame – mensen die al delen van de geschiedenis van de Nederlandse cliënten- en naastenbeweging hadden vastgelegd. Journalist Petra Hunsche, de belangrijkste geschiedschrijver van de cliëntenbeweging, was niet alleen van grote betekenis voor mij door haar publicaties, maar ook door haar groeiende betrokkenheid bij wat ik aan die geschiedschrijving wilde toevoegen vanuit naastenperspectief. Ook Arend Jan Heerma van Voss, die als journalist vanaf de jaren zestig zelf bovenop deze ontwikkelingen had gezeten, hielp me met verhalen, adviezen en verwijzingen. Het spijt me zeer dat hij de voltooiing van dit proefschrift niet meer heeft kunnen meemaken. Ook de generositeit van collega-onderzoekers in de academische wereld heeft me zeer getroffen, met name die van Cecile aan de Stegge en Niels Springveld, die mij uit eigen beweging bronnen en inzichten aanreikten uit hun eigen onderzoek. Van de spreekwoordelijke krabbenmand die de academische wereld heet te zijn heb ik nooit iets gemerkt – eerder het tegendeel.

Dat geldt ook voor alle grote en kleine verbanden waar ik tijdens mijn promotieperiode deel van heb mogen uitmaken. Allereerst dat van de Open Universiteit, waar ik zowel in de faculteit Cultuurwetenschappen als in het studiecentrum Amsterdam de leukste collega's ooit heb getroffen. Onze lunchgesprekken hebben mij voor altijd verpest voor andere werkkringen, en de vriendschappen die ik hier heb gevonden betekenen veel voor mij. Dankbaar ben ik ook voor de inspirerende mensen met wie ik buiten de faculteit en de universiteit heb kunnen leren en werken: bij het Huizinga Instituut, de leesgroep Mad Studies van de Stichting Perceval, de organisatie van het stigmasymposium De Hokjes Voorbij en het bestuur van History Health & Healing, het academisch netwerk van medisch historici in Nederland.

Mijn lieve vrienden en familieleden, dank jullie wel voor jullie niet aflatende steun tijdens mijn promotiejaren. Ook al was het voor jullie soms moeilijk voor te stellen waar ik mee bezig was en kwam het er vooral op neer dat ik weinig tijd voor jullie had, jullie bleven altijd geïnteresseerd en juichten mij toe bij elke stap. Onno van den Muysenberg, jij hebt wat dit betreft wel het meeste moeten incasseren, en toch bleef je altijd mijn belangrijkste supporter, mijn thuisbasis en tegelijk mijn meest uitdagende klankbord. Aan jullie allemaal, mijn dierbare naasten, draag ik met veel liefde dit proefschrift op.

Acknowledgements

At a photocopier at an Amsterdam university, I was confronted for the first time with a new perspective for the future: obtaining a PhD. It was in the summer of 2017; I had just finished my part-time history studies at VU University. That summer was all about melancholy for me, because (I thought) I had to say goodbye to the academic world that had given me so much for eight years, despite the fact that before, I had never seen myself as someone who could belong there. Together with a handful of other part-timers of a certain age, I had found a stimulating, challenging and warm nest at the VU. It had not been easy to combine study and work, but with their personal attention and understanding of my situation, the professors, lecturers and study advisors had made it possible for me to complete my studies, without lowering the bar. In fact, they preferred to raise that bar a bit, like Susan Legêne when she gave me the crucial push to opt for the research master after my bachelor's, and like Anneke Ribberink when she supervised me in writing both my bachelor's and master's thesis.

That photocopier that I remember so well, however, was a few kilometers away, in a building of the University of Amsterdam. I was there that summer with Gemma Blok, who, despite the fact that I was not studying at her university at all, had been willing to act as a second supervisor of my master's thesis, because my topic was in her field of research. While we were waiting for the machine to produce another copy of my thesis, Gemma told me that she had become a professor at the Open University and invited me to apply for a PhD position that was open there. Despite the fact that I had done the research master's, I had never considered doing a PhD as a serious option: I didn't see myself combining that with my work. And a paid PhD position, that was surely only reserved for young top talents who followed the straight path to an academic career without years of making detours? But instead of saying goodbye to each other that day, Gemma's invitation resulted in a new beginning for me. The beginning of a new working life at the Open University, in which we still work together on a daily basis and share in the pleasures and frustrations of academic life.

Because my research plan also had a link to literature, Erica van Boven became my second supervisor. That took some getting used to at first for both of us, I think. Despite my initial ambitions, it turned out that literature would play no more than a supporting role in my dissertation. Erica then found her role mainly by opting for the position of sharp reader who not only commented on my writing process, but also intervened when Gemma and I allowed our medical-historical professional deformation to get the better of us. In the six years that the three of us worked together, we increasingly shared personal joys and sorrows too; in hindsight, often things that touched us as family members or friends. I will never forget the support I received from both of you in difficult times. And the day we decided that my dissertation was finished, it was not only a day of joy, but also a day of regret that this had been our very, very last session.

The choice of my subject was inspired by a combination of factors from my private and working life. On the one hand, it was because for years, I had witnessed from up close how hard life can be for a loved one who has to deal with a chronic mental vulnerability, and what the impact of this is on the people around that person. But also because my parents – especially my mother – told me about how such things had impacted our family, in the generations before me, and what toll that had taken on them. Perhaps that had something to do with the fact that in my work as a freelance copywriter I had become specialised in writing for organisations in and around mental health care. Through Netty van Ham of Mentrum and Hannie Boumans of Ypsilon, I first came into contact with the family movement in mental health care. Through Hannie, I caught a first glimpse of the activism of relations and how people like her are committed to fighting for better care, not only for their own loved ones, but for all of us.

In my search of the roots of this activism, I got to know many more 'Hannies'. Almost without exception, activists from the very beginning and their successors – their names can be found at page 313 and 314 – were willing to tell me about this history and their role in it, even if it sometimes triggered very painful memories. Others had already passed away or had become so vulnerable at an advanced age that a conversation was no longer possible. These people I got to know through their own publications and the publications and stories of others. In addition, I spoke to an ever-growing circle of people who are or were connected to the clients' and family movement in various ways, and who helped me with tips, contacts and documents that cannot be found in archives. I am grateful to all of them for their passionate activism, the unimaginable mountains of work they have done and sometimes still do, and for what they have fought for in the interest of all of us. I hope to have captured some of that with this dissertation, so that the history of this movement can continue to inspire activists and advocates of today and tomorrow.

Although it initially seemed that archives and libraries would have little to offer for my research, I did make a few important discoveries there. Employees of those institutions have sometimes gone out of their way to help me, especially in the COVID-19 period. Marian Hofman and her colleagues at the VU University Library found a way for researchers like me, so that I could access their extraordinary historical mental health collection even when the universities were still closed. Archivist Mirjam Hofman of the Archive and Documentation Centre of the Reformed Churches in the Netherlands in Kampen selected duplicates from the archive of De Wegwijzer for me on the spot, and

allowed me to take the remains with me. Gabriëlle Beentjes of the National Archive in Emmen not only freed up staff so that I could do research in the archives of the Algemeen Diakonaal Bureau for a week, she also invited me to dinner at her home – respecting the 1.5 meters distance rule – so that I did not have to waste away that week in loneliness under the COVID rules in a B&B.

From the outset, I also met enthusiasm for my research among the – very few – people who had already recorded parts of the history of the Dutch clients' and family movement. Journalist Petra Hunsche, the most important historian of the clients' movement, was of great importance to me not only through her publications, but also through her growing involvement in what I wanted to add to that historiography from the perspective of the relations. Arend Jan Heerma van Voss, who as a journalist had been on top of these developments since the 1960s, also helped me with stories, advice and references. I am very sorry that he did not live to see the completion of this dissertation. I was also struck by the generosity of fellow researchers in the academic world, especially that of Cecile aan de Stegge and Niels Springveld, who of their own accord provided me with sources and insights from their own research. I have never experienced the proverbial bucket of crabs that academia is supposed to be – quite the opposite.

This also applies to all the large and small academic and semi-academic communities that I have had the opportunity to be part of during my PhD period. First of all, that of the Open University, where I met the nicest colleagues ever in both the Faculty of Humanities and the Amsterdam study centre. Our lunch conversations have ruined me for other working environments, and the friendships I have found here mean a lot to me. I am also grateful for the inspiring people with whom I have been able to learn and work outside the faculty and the university: at the Huizinga Institute, the Mad Studies Reading Group of the Stichting Perceval, the organisation of the stigma symposium De Hokjes Voorbij and the board of History Health & Healing, the Dutch academic network for medical history.

My dear friends and family members, thank you for your unwavering support during my PhD years. Even though it was sometimes difficult for you to grasp what I was doing and it mainly came down to the fact that I had little time for you, you always remained interested and cheered me on every step of the way. Onno van den Muysenberg, you have had to endure the most in this respect, and yet you always remained my most important supporter, my home base and at the same time my most challenging critic. To all of you, my dear relations, I lovingly dedicate this dissertation.

Sources

Archives

Archief- en Documentatiecentrum van de Gereformeerde Kerken (ADC), Kampen
Archive De Wegwijzer

International Institute of Social History (IISH), Amsterdam
ARCH01540 Archive MDHG Amsterdam, box 20 Stukken betreffende: kinderen van verslaafde ouders/ouders van verslaafde kinderen (E/1)

Museum of the Mind, Haarlem
Pandora Library
Audiovisual Collection

National Archive, The Hague
2.19.130 Archives of the Cliëntenbond, (1970) 1971-1990 (1991) [referred to in this book as NL-HaNA-CB]
2.21.334 Archives of Mrs. C. van Eijk-Osterholt, with regard to her sister Mies Osterholt, (1920) 1959-1998 (2002)

Netherlands Institute for Sound & Vision (NISV), Hilversum
Sound & Vision Television Archive [referred to in this book as NISV-SVTA]

The Utrecht Archives, Utrecht
1492 Deputaten Gemeenteopbouw van de Gereformeerde Kerken in Nederland (aanvulling) (1859) 1962-1999, Familie en vrienden van psychisch zieke mensen [referred to in this book as UA-GKN-F]

Rotterdam City Archive, Rotterdam
230-04 Psychiatrische Inrichting Maasoord, sinds 1958 Delta ziekenhuis te Poortugaal (1900) 1941-1994 (1995), box 250 Familieraad: contactgroep voor familieleden en vrienden van psychiatrische patiënten, (Ypsilon)

Personal archives

Ria van den Abeele
Treeske Blase
Wouter van de Graaf
Karin Groen
Jan Heijmans
Linda Horn
Margriet Mannak
Ronald May
Willem Momma
Inge van Ooijen
Juanita Slengard
Daisy Smith
Paul van Trigt
Erik Vleeschdraager
Hans van der Wilk
Joke Zwanikken-Leenders

Newsletters of organisations

Consulted in the following archives and libraries:
ADC = Archief- en Documentatiecentrum van de Gereformeerde Kerken, Kampen
IISH = International Institute of Social History, Amsterdam
RL-H = Royal Library, The Hague
UA-GKN-F = The Utrecht Archives, Utrecht, 1492 Deputaten Gemeenteopbouw van de Gereformeerde Kerken in Nederland (aanvulling) (1859) 1962-1999, Familie en vrienden van psychisch zieke mensen

ANtenne (Stichting Anorexia Nervosa) – *RL-H*
Alzheimer Nieuwsbrief (Alzheimerstichting) – *RL-H*
De Boei (Anonieme Alcoholisten) – *IISH*
De Wegwijzer – *ADC*
Bulletin van de Clientenbond – *RL-H*
Eigendruk (Labyrint) – *UA-GKN-F*
Engagement (Landelijke Stichting ter Behartiging van de Belangen van Autistische Kinderen en hun Ouders, Nederlandse Vereniging voor Autisme) – *RL-H*
Fobie Vizier, Vizier (Fobieclub, Angst Dwang en Fobiestichting) – *RL-H*
FZA Kwartaalberichten (Federatie van Instellingen voor Alkohol en Drugs) – *IISH*
Info (Landelijke Stichting Ouders van Drugsverslaafden) – *RL-H*
Knipselkrant Pandora – *RL-H*
'n Bijzondere Krant (In Perspektief) – *RL-H, UA-GKN-F*
Nieuwsbrief Ypsilon, Ypsilon Nieuwsbrief (Ypsilon) – *RL-H, UA-GKN-F*
Relatief (Labyrint~In Perspektief) – *RL-H*

Newspapers and popular magazines

Online newspaper archives

Delpher.nl (up to circa 1995)
Nexis Uni (1995-present)

Newspapers

Algemeen Dagblad
Algemeen Handelsblad
Dagblad voor Noord-Limburg
De Stem
De Telegraaf
De Tijd
de Volkskrant
Het Parool
Het Vaderland
Het Vrije Volk
Leeuwarder Courant
Leidsch Dagblad
Nederlands Dagblad
Nieuwsblad van het Noorden
NRC Handelsblad
Provinciaal Zeeuwse Courant
Trouw

Magazines

De Engelbewaarder
Gekkenkrant
Margriet
Libelle
Vrij Nederland
Haagse Post

Interviews

Treeske Blase, 28 September 2018
Annelies Faber, Els Borgesius & Paul Baart, 13 January 2022
Titia Feldmann, 20 February 2020
Cisca Goedhart, 18 November 2022
Karin Groen & Rita van Mourik, 1 February 2019
Linda Horn & Lineke Marseille, 28 May 2021
Alphons Katan, 4 December 2018
Wil van der Laak, 11 January 2023
Margriet Mannak, 21 September 2021
Ronald May & Rob van Dijk, 12 March 2019
Willem Momma, 29 November 2018

Reina van Mourik, 12 May 2021
Inge van Ooijen, 12 January 2021
Jos van der Poel, 11 August 2022
Bas van Raaij, 21 June 2018
Juanita Slengard, 22 October 2021
Bert Stavenuiter, 27 January 2022
Paul van Trigt, 30 November 2021
Erik Vleeschdraager, 7 October 2020

Informants

Huub Beijers
Hannie Boumans
Ellen Ebbenn
Wouter van de Graaf
Mennie Groenevelt
Freek Heerema
Arend Jan Heerma van Voss
Petra Hunsche
Yvonne Keuls
Harm Luth
Willem Oosterbaan
Grieteke Pool
Eugène Poppe
Evelien Quelle
Tom Rusting
Grietje Santing
Daisy Smith
Cecile aan de Stegge
Wim Trinks
Ties van de Ven
Ria van den Abeele
Hans van der Wilk
Netty van Ham
Josine van Hamersveld
Irma van Milt
Arijan van Winkoop
Guus Verhoef
Gee de Wilde
Joke Zwanikken-Leenders
Janny Zwerver

Literature

Author's last names starting with De, Le or Van are alphabetised according to those prefixes and thus found under D, L and V.

10 jaar dr. Leo Kannerhuis ([Oosterbeek] [1984]).

Aan de Kerk, Martje, *Madness and the city: Interactions between the mad, their families and urban society in Amsterdam, Rotterdam and Utrecht, 1600-1795* (PhD thesis University of Amsterdam 2019).

Abma, Ruud, 'De patiënt. De opkomst van de therapeutische samenleving', in: Jeroen Jansz & Peter van Drunen, *Met zachte hand. Opkomst en verbreiding van het psychologisch perspectief* (Maarssen 1997) 115-131.

Alcoholics Anonymous Comes of Age (New York 1957).

Alcoholics Anonymous: The Story Of How One Hundred Men Recovered From Alcoholism (New York 1939).

Angermeyer, Matthias C. & Asmus Finzen (eds.), *Die Angehörigengruppen. Familien mit psychisch Kranken auf dem Weg zur Selbsthilfe* (Stuttgart 1984).

Anstadt, Sera, *Al mijn vrienden zijn gek. De dagen van een schizofrene jongen* ('s-Gravenhage 1983).

Arends, Jan, 'Keefman', in: Jan Arends, *Keefman* (Amsterdam 1991 [1972]) 7-39.

Arends, Jan, *Keefman* (Amsterdam 1991 [1972]).

Baart, P.C., 'Familieorganisaties moeten erkenning krijgen', *Maandblad Patiëntenbeweging* (1993) 4, 19.

Bacopoulos-Viau, Alexandra & Aude Fauvel, 'The Patient's Turn: Roy Porter and Psychiatry's Tales, Thirty Years on', *Medical History* 60 (2016) 1, 1-16.

Badinter, Elisabeth, *L'amour en plus: histoire de l'amour maternel (XVIIe-XXe siècle)* (Paris 1980).

Bakker, Catharina Th., Gemma Blok & Joost Vijselaar, *Delta. Negentig jaar psychiatrie aan de Oude Maas* (Utrecht 1999).

Bakker, Nelleke, Jan Noordman & Marjoke Rietveld-van Wingerden, *Vijf eeuwen opvoeden in Nederland. Idee en praktijk 1500-2000* (second revised edition; Assen 2010).

Bartlett, Peter & David Wright (eds.), *Outside the Walls of the Asylum: The History of Care in the Community 1750-2000* (London, New Brunswick 1999).

Bartstra, D.S.J., 'The peculiar relations between professionals and victims', in: Charles D. Kaplan & Martien Kooyman, *Proceedings of the 15th International Institute on the Prevention and Treatment of Drug Dependence, April 6-11 1986 Amsterdam/Noordwijkerhout (The Netherlands)* (Rotterdam 1987) 332-334.

Basisberaad GGZ, *Thuis is waar de ander is. Allochtone cliënten in de geestelijke gezondheidszorg en de cliëntenbeweging* (Rotterdam 2000).

Beltman, Henk, *Buigen of barsten. Hoofdstukken uit de geschiedenis van de zorg aan mensen met een verstandelijke handicap in Nederland 1945-2000* (PhD thesis Rijksuniversiteit Groningen 2001).

Benner, Arend G., *Streven naar limonade. De NVA als partner in een vertoogcoalitie rond autisme, 1973-2003* (Master's thesis Universiteit van Amsterdam 2003).

Bergers, Albert & Daniël de Lange, *Zij zijn van ons geslacht* (Hilversum 1960).

Bernlef, J., 'Herinneringen van een vergeetachtige', in: *Hersenschimmen* (fiftieth edition; Amsterdam 2010 [1984]) 5-9.

Bernlef, J., *Hersenschimmen* (fiftieth edition; Amsterdam 2010 [1984]).

Bierenbroodspot, P., *De therapeutische gemeenschap en het traditionele psychiatrisch ziekenhuis* (Meppel 1969).

Bijl, R.V., A. Ravelli & G. van Zessen, 'Prevalence of psychiatric disorder in the general population: results of the Netherlands Mental Health Survey and Incidence Study (NEMESIS)', *Social Psychiatry and Psychiatric Epidemiology* 33 (1998) 12, 587-595.

Binneveld, Hans, *Filantropie, repressie en medische zorg. Geschiedenis van de inrichtingspsychiatrie* (Deventer 1985).

Blaauwbroek, Hans, *Betrokken omgeving. Modelregeling ggz-instelling-naastbetrokkenen* (Utrecht, Rotterdam 2004).

Blok, G. ' "Onze eigen kleine wereld". De provinciale ziekenhuizen in het tijdvak 1945-1965', in: Joost Vijselaar (ed.), *Gesticht in de duinen. De geschiedenis van de provinciale ziekenhuizen van Noord-Holland van 1849 tot 1994* (Hilversum 1997) 166-192.

Blok, G. & T.C. Bolt, 'Geschiedenis van de zorg voor mensen met EPA; wederzijdse aanpassing als ideaal', in: Ad Kaasenbrood & Lex Wunderink (eds.), *Ernstige psychiatrische aandoeningen* (Houten 2021) 19-34.

Blok, Gemma, 'Enkele reis op z'n retour. Santpoort en het Amsterdamse Model', in: Joost Vijselaar (ed.), *Gesticht in de duinen. De geschiedenis van de provinciale psychiatrische ziekenhuizen van Noord-Holland van 1849 tot 1994* (Hilversum 1997) 238-267.

Blok, Gemma, ' "Tall, Spanking People": The Idealisation of Adolescents in a Dutch Therapeutic Community', in: Marijke Gijswijt-Hofstra & Hilary Marland, *Cultures of Child Health in Britain and the Netherlands in the Twentieth Century* (Amsterdam 2003) 265-285.

Blok, Gemma, *Baas in eigen brein. 'Antipsychiatrie' in Nederland 1965-1985* (Amsterdam 2004).

Blok, Gemma, 'Van "zedelijke verheffing" tot "harm reduction". Verslavingszorg in Arnhem en Nijmegen, 1900-2000', in: J. Vijselaar et al., *Van streek. 100 jaar geestelijke gezondheidszorg in Zuid-West Gelderland* (Utrecht 2007) 152-191.

Blok, Gemma, *Ziek of zwak. Geschiedenis van de verslavingszorg in Nederland* (Amsterdam 2011).

Blok, Gemma, 'The politics of intoxication. Dutch junkie unions fight against the ideal of a drug-free society, 1975-1990', in: Martin Dinges & Robert Jütte (eds.), *The transmission of health practices (c. 1500 to 2000)* (Stuttgart 2011) 69-88.

Blok, Gemma, ' "We the Avant-Garde": A History from Below of Dutch Heroin Use in the 1970s', *BMGN – Low Countries Historical Review* 132 (2017) 1, 104-125.

Blok, Gemma & Joost Vijselaar, *Terug naar Endegeest. Patiënten en hun behandeling in het psychiatrisch ziekenhuis Endegeest 1897-1997* (Nijmegen 1998).

Blom, Onno, *Het litteken van de dood. De biografie van Jan Wolkers* (Amsterdam 2017).

Blum, Linda M., 'Mother-blame in the Prozac Nation: Raising Kids with Invisible Disabilities', *Gender & Society* 21 (2007) 2, 206-226.

Boerdam, S., 'Oudergroepenwerk drugteam Haarlem', in: *Ouders en verslaving. Verslag van een tweede themadag op 8 oktober 1983* (Bilthoven 1983) 40-45.

Bolderhey, Patricia, 'Behandelde, familie, behandelaar (5)', *Maandblad Geestelijke Volksgezondheid* 35 (1980) 2, 152-154.

Bolt, Timo & Leonie de Goei, *Kinderen van hun tijd. Zestig jaar kinder- en jeugdpsychiatrie in Nederland 1948-2008* (Assen 2008).

Bongers, Jasper, 'Harm Reduction as a Citizenship Movement: The Case of Hoog Catharijne, Utrecht (1973-2001)', *The Social History of Alcohol and Drugs* 37 (2023) 1, https://doi.org/10.1086/723361.

Borgesius, Els, *Hulpverleners en familie: partners in de zorg. Een handleiding voor hulpverleners in de ggz* (Assen 1994).

Borsboom, Denny et al., 'Network analysis of multivariate data in psychological science', *Nature Reviews Methods Primers* 58 (2021) 1, doi.org/10.1038/s43586-021-00055-w.

Boss, Eelco, *Buikhuisen in KRI-minologisch perspectief. Het onderzoek van prof. dr. W. Buikhuisen door de ogen van een reclasseringstijdschrift* (Master's thesis Universiteit Utrecht 2012).

Bosscher, Doeko, 'Toward a Community of Interests: the Netherlands and the United States between the World Wars', in: Hans Krabbendam, Cornelis A. van Minnen & Giles Scott-Smith, *Four Centuries of Dutch-American Relations 1609-2009* (Amsterdam 2009) 401-419.

Bosscher, Lies & Bert Stavenuiter, *Bescherming voor psychotische mensen. Problemen en aanbevelingen rond de wet BOPZ* (Rotterdam, Den Haag 1996).

Bowlby, John, *Maternal Care and Mental Health: A Report Prepared on Behalf of the World Health Organization as a Contribution to the United States Programme for the Welfare of Homeless Children* (New York 1967 [1951]).

Brabers, Anne, Wouter van der Schors & Judith de Jong, *Zorggebruikers zien patiëntenorganisatie als belangrijke bron voor lotgenotencontact* (Utrecht 2017), https://www.nivel.nl/sites/default/files/bestanden/Factsheet_Zorggebruikers_zien_patientenorganisatie_als_belangrijke_bron_voor_lotgenotencontact.pdf accessed 25 February 2024.

Braslow, Joel T. & Stephen R. Marder, 'History of Psychopharmacology', *Annual Review of Clinical Psychology* 15 (2019) 25-50.

Brill, Willy, 'Mijn dochter en de psychiatrie', *Maandblad Geestelijke Volksgezondheid* 34 (1979) 11, 738-744.

Brinkgreve, C. & M. Korzec, *'Margriet weet raad'. Gevoel, gedrag, moraal in Nederland 1938-1978* (Utrecht 1978).

Broekaar, Lise, *Wie dit leest is gek. Een boekje voor jongeren over gekke normalen en normale gekken* (Amsterdam [2003]).

Brouwers, Ton, 'Jan Arends. Keefman', in: Ton Anbeek, Jaap Goedegebuure & Bart Vervaeck, *Lexicon van literaire werken* (Groningen 1989-2014; 1998) 1-14.

Brown, Phil et al., 'Embodied Health Movements: New Approaches to Social Movements in Health', *Sociology of Health and Fitness* 26 (2004) 1, 50-80.

Brown, Phil et al., 'Field Analysis and Policy Ethnography in the Study of Health Social Movements', in: Jane C. Banaszak-Holl et al., *Social Movements and the Transformation of American Health Care* (New York 2010) 101-116.

Brown, Phil et al., 'Health Social Movements. History, Current Work, and Future Directions', in: Chloe E. Bird et al. (eds.), *Handbook of Medical Sociology* (sixth edition; Nashville 2010) 380-394.

Brown, Phil et al., 'Embodied health movements', in: Phil Brown, Rachel Morello-Frosch & Stephen Zavestoski (eds.), *Contested illnesses: Citizens, science, and health social movements* (Berkeley 2012) 15-32.

Brown, Phil, Rachel Morello-Frosch & Stephen Zavestoski, *Contested illnesses: Citizens, science, and health social movements* (Berkeley 2012).

Carp, E.A.D.E., 'Vooroordelen tegen geesteszieken', *R.K. Artsenblad* 39 (December 1960) 273-280.

Coleborne, Catherine, *Madness in the Family: Insanity and Institutions in the Australasian Colonial World, 1860-1914* (Basingstoke, New York 2010).

Colijn, Margo, *De droom van Mary. Ouders over hun drugsverslaafde kind* (Zutphen 1996).

Contratto, Susan, 'Psychology Views Mothers and Mothering: 1897-1980', in: Vivian Patraka & Louise A. Tilly, *Feminist Re-Visions: What Has Been and Might Be* (Ann Arbor 1983) 149-178.

Corrigan, Patrick W., Benjamin G. Druss & Deborah A. Perlick, 'The Impact of Mental Illness Stigma on Seeking and Participating in Mental Health Care', *Psychological Science in the Public Interest* 15 (2014) 2, 37-70.

Corrigan, Patrick W. & Frederick E. Miller, 'Shame, blame, and contamination: A review of the impact of mental illness stigma on family members', *Journal of Mental Health* 13 (2004) 6, 537-548.

Corrigan, Patrick W., Amy C. Watson & Frederick E. Miller, 'Blame, Shame, and Contamination: The Impact of Mental Illness and Drug Dependence Stigma on Family Members, *Journal of Family Psychology* 20 (2006) 2, 239-246.

Crossley, Nick, *Contesting Psychiatry: Social Movements in Mental Health* (London, New York 2006).

Crowley, P., 'Family therapy approach to addiction', *Bulletin on Narcotics* 40 (1988) 1, 57-62.

De Boer, Nico, ' "Riaggs moeten stoppen met ouwehoerdingetjes" ', *De Gazet* 22 (1995) 6, 6-8.

De Goei, Leonie, *In de kinderschoenen. Ontstaan en ontwikkeling van de universitaire kinderpsychiatrie in Nederland, 1936-1978* (Utrecht 1992).

De Goei, Leonie, *De psychohygiënisten. Psychiatrie, cultuurkritiek en de beweging voor geestelijke volksgezondheid in Nederland, 1924-1970* (Nijmegen 2001).

De Goei, Leonie, Sonja van 't Hof & Giel Hutschemaekers (eds.), *Curium 1955-1995. Bladzijden uit de geschiedenis van de Nederlandse kinder- en jeugdpsychiatrie* (Utrecht 1995).

De Graaf, Ron et al., 'Prevalence of mental disorders, and trends from 1996 to 2009. Results from the Netherlands Mental Health Survey and Incidence Study-2', *Social Psychiatry and Psychiatric Epidemiology* 47 (2012) 2, 203-213.

De Haan, Sanneke, *Enactive Psychiatry* (Cambridge 2022).

De Jonge, Marlieke, 'Antwoord', *Maandblad Geestelijke Volksgezondheid* (1990) 2, 184-185.

De Kort, Marcel, *Tussen patiënt en delinquent. Geschiedenis van het Nederlandse drugsbeleid* (Hilversum 1995).

De mantel een zorg. De plaats en de rol van de naaste van de patiënt in de ggz (Lochem, Gent 1987).

De Reus, Tjerk, *God, religie en ons brein. In gesprek met psychiater Herman van Praag* (Kampen 2011).

De Rooy, Piet, *Alles! En wel nu! Een geschiedenis van de jaren zestig* (Amsterdam 2022).

De Wilde, Gee, 'De prehistorie van MIND' (s.l. 2017), https://www.canonsociaalwerk.eu/1998_clientsturing/2017-01-Gee-de-Wilde-De%20prehistorie%20van%20MIND.pdf accessed 18 May 2023.

Dell'Osso, Liliana et al., 'Historical Evolution of the Concept of Anorexia Nervosa and Relationships with Orthorexia Nervosa, Autism, and Obsessive-Compulsive Spectrum', *Neuropsychiatric Disease and Treatment* (2016) 12, 1651-1660.

Den Boef, August-Hans, 'Jan Wolkers, Terug naar Oegstgeest,' in: Ton Anbeek, Jaap Goedegebuure & Marcel Janssens, *Lexicon van literaire werken. Besprekingen van Nederlandstalige literaire werken 1900-heden* (Groningen 1990) 12-13.

Den Ouden, Marjon, *Een psychiatrische tegenbeweging in Nederland. Een inventarisatie van tien jaar organisatievormen, akties en tegenpraktijken (1970-1980)* (Amsterdam 1981).

Dercksen, Adrianne & Sonja van 't Hof, *Erkenning gevraagd. Organisaties van patiënten, cliënten en hun familie in de geestelijke volksgezondheid* (Utrecht 1996).

Dolnick, Edward, *Madness on the Couch: Blaming the Victim in the Heyday of Psychoanalysis* (New York 1998).

Duyvendak, Jan Willem & Olivier Fillieule, 'Patterned Fluidity: An Interactionist Perspective as a Tool for Exploring Contentious Politics', in: James M. Jasper & Jan Willem Duyvendak, *Players and Arenas: The Interactive Dynamics of Protest* (Amsterdam 2015) 295-318.

Duyvendak, Jan Willem & Ruud Koopmans, 'Protest in een pacificatiedemocratie. Nieuwe sociale bewegingen en het Nederlandse politieke systeem', in: Jan Willem Duyvendak et al. (eds.), *Tussen verbeelding en macht. 25 jaar nieuwe sociale bewegingen in Nederland* (Amsterdam 1992) 39-57.

Duyvendak, Jan Willem, Conny Roggeband & Jacquelien van Stekelenburg, 'Politics and People. Understanding Dutch Research on Social Movements', in: Olivier Fillieule & Guya Accornero, *Social Movement Studies in Europe: The State of the Art* (New York, Oxford 2016) 232-249.

Ehrenreich, Barbara & Deirdre English, *For Her Own Good: 150 Years of Experts' Advice to Women* (New York 1978).

Elias, J. & W. van Santen, *Drie familie-organisaties GGZ. Rapport uitgebracht aan: De Staatssecretaris van het ministerie van Welzijn, Volksgezondheid en Cultuur* (Diemen etc. 1994).

Engelsman, E., 'Het drugbeleid, de hulpverlening en de ouders van drugverslaafden', in: *Verslag tweede themadag LSOVD 8 oktober 1983* (Bilthoven 1983) 21-29.

Esselink, Rozemarijn, Projektgroep Psychiatrische Tegenbeweging & Stichting Pandora, *Tien jaar psychiatrische tegenbeweging in Nederland. Een samenvattend verslag van een inventarisatie van organisatievormen, akties en tegenpraktijken in de periode 1970-1980* (Amsterdam 1982).

Esser, P.H., *Alcoholisme* (Kampen 1960).

Fabrega, Horacio, 'Psychiatric Stigma in the Classical and Medieval Period: A Review of Literature', *Comprehensive Psychiatry* 31 (1990) 4, 289-306.

Fabrega, Horacio, 'The Culture and History of Psychiatric Stigma in Early Modern and Modern Western Societies: A Review of Recent Literature', *Comprehensive Psychiatry* 32 (1991) 2, 97-119.

Flora, Katerina, Antonis Raftopoulos & Theodote Pontikes, 'A Look at the Evolution of the Self-Help Movement', *Journal of Groups in Addiction and Recovery* 5 (2010) 3, 214-225.

Foucault, Michel, *Histoire de la folie* (Paris 1961).

Foudraine, Jan, *Wie is van hout… Een gang door de psychiatrie* (Baarn 1971).

Foudraine, Jan, *Bunkerbouwers. Ontmoetingen met afgeslotenen* (Amsterdam 1997).

Foudraine, Jan, *Wie is van hout… Een gang door de psychiatrie* (thirty-second edition; Amsterdam 2021).

Fox, Becky et al., *Psychiatrische tegenbeweging in Nederland* (Amsterdam 1983).

Friedan, Betty, *The Feminine Mystique* (Harmondsworth 1963).

Fris, M. & J.E. de Leeuw den Bouter, *Ouders Van Drugverslaafden en de hulpverlening. Evaluatie van het convenant* (Utrecht 1994).

Geerts, Irene, *The image of a generation: (Gender) images of heroin addicts and their parents in the Netherlands, 1980-1985* (Master's thesis VU University Amsterdam 2017).

Geestelijke volksgezondheid. Nota (Tweede Kamer, vergaderjaar 1983-1984, 18463, nrs. 1-2).

George, Bill, 'What's in a name? Client participation, diagnosis and the DSM-5', *Journal of Mental Health* 19 (2010) 6, 479-482.

Gibbels, Mario, 'De GGZ-patiëntenbeweging als derde partij', *Maandblad Geestelijke Volksgezondheid* 49 (1994) 9, 976-981.

Gijswijt-Hofstra, Marijke & Harry Oosterhuis, 'Psychiatrische geschiedenissen', *BMGN – Low Countries Historical Review* 116 (2001) 2, 162-197.

Glas, Gerrit, *Person-Centred Care in Psychiatry: Self-relational, Contextual and Normative Practices* (London 2019).

Goffman, Erving, *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* (New York 1961).

Goffman, Erving, *Stigma: Notes on the Management of Spoiled Identity* (New York 1963).

Goudsblom-Oestreicher, M.E.I. & W.M. Hirs, 'Oranje kongresenquête. Verantwoording en resultaten', *Maandblad Geestelijke Volksgezondheid* 26 (1971) 1, 26-40.

Goudsblom-Oestreicher, M.E.I., 'De kongres-themagroepen. Verslag van de diskussies', *Maandblad Geestelijke Volksgezondheid* 26 (1971) 1, 30-36.

Gravestein, J.H., 'De veranderde houding tegenover de psychiatrie', *Tijdschrift voor Ziekenverpleging* 11 (1958) 14, 406-409.

Hardeman, W.J. & E. de Vries, 'Een familieraad als waakhond voor chronische patiënten', *Maandblad Geestelijke Volksgezondheid* 43 (1988) 12, 1239-1243.

Harrington, Anne, 'Mother Love and Mental Illness: An Emotional History', *Osiris* 31 (2016) 1, 94-115.

Hartwell, Carol Eadie, 'The Schizophrenic Mother Concept in American Psychiatry', *Psychiatry* 59 (1996) 3, 274-297.

Heerma van Voss, A.J., 'De geschiedenis van de gekkenbeweging. Belangenbehartiging en beeldvorming voor en door psychiatrische patiënten (1965-1978)', *Maandblad Geestelijke Volksgezondheid* 33 (1978) 6, 398-428.

[Heerma van Voss, A.J.], untitled foreword to *Maandblad Geestelijke Volksgezondheid* 41 (1986) 7/8, 689-690.

Heerma van Voss, Daan, 'Bloemen van geluk moet je zelf planten', *Vizier* 48 (2018) 3, 24-37.

Hellema, Duco, *Nederland en de jaren zeventig* (Amsterdam 2012).

Henckes, Nicolas, *La politique du handicap psychique. Familles, psychiatres et Etat face à la chronicité des maladies mentales des années 1960 aux années 1970* (s.l. 2011), hal.archives-ouvertes.fr/hal-00769756, 27-40.

Henckes, Nicolas, 'Entre thérapie et oblation. Le discours de l'Unafam sur les familles de malades mentaux (1963-1980)', in: L. Guignard, H. Guillemain & S. Tison (eds.), *Expériences de la folie. Criminels, soldats, patients en psychiatrie, XIXe-XXe siècles* (Rennes 2013) 313-322.

Hoefnagels, G.P., 'Witte-jassen-criminaliteit', *De Gids* 136 (1973) 1, 590-598.

Horn, Linda, 'Een vergeten groep: familieleden van psychiatrische patienten', *Maandblad Geestelijke Volksgezondheid* 41 (1986) 9, 878-889.

Horn, Linda, 'Tussen twee grenzen van het eigen belang', *Welzijnsmaandblad* 40 (1986) 9, 11-16.

Horn, Linda, 'Antwoord', *Maandblad Geestelijke Volksgezondheid* 42 (1987) 1, 63.

Horn, L.M., 'Met recht betrokken', in: L.M. Horn, O.P.F. Oldenburg & J.H. Scholma-Hofdijk, *Met recht betrokken. Verslag van het eerste lustrumcongres van de Stichting* Labyrint*, gehouden in samenwerking met de sectie gezondheidsrecht van de juridische faculteit van de Vrije Universiteit op woensdag 9 mei 1990* (Utrecht 1991) 55-57.

Horn, L.M., O.P.F. Oldenburg & J.H. Scholma-Hofdijk, *Met recht betrokken. Verslag van het eerste lustrumcongres van de Stichting* Labyrint*, gehouden in samenwerking met de sectie gezondheidsrecht van de juridische faculteit van de Vrije Universiteit op woensdag 9 mei 1990* (Utrecht 1991).

Hunsche, Petra, *De strijdbare patiënt. Van gekkenbeweging tot cliëntenbeweging. Portretten 1970-2000* (Haarlem 2008).

Hunsche, Petra, *Herstel in beweging. De cliëntenbeweging in de 21^{e} eeuw* (Amsterdam 2022).

Hurdles, Peregrine & Richard Wright, *The Locus of Care: Families, Communities, Institutions, and the Provision of Welfare since Antiquity* (London, New York 1998).

Ippel, Pieter, 'Rechtspositie van familieleden', *Maandblad Geestelijke Volksgezondheid* 45 (1990) 10, 1087-1090.

Ippel, Pieter & Linda Horn, *Richtlijnen voor een zorgvuldige communicatie tussen hulpverleners en familieleden van psychiatrische patiënten* (Utrecht 1992).

Jacobs Brumberg, Joan, *Fasting Girls: The History of Anorexia Nervosa* (Cambridge 1988).

'Jan Arends en de Bezige Bij', *De Engelbewaarder* 4 (1979) 15, 29-50.

Jan Wolkers: Serpentina's petticoat (Nederlandse keur no. 59, Purmerend 1967).

Jansen van Galen, John, *Het ik-tijdperk* ([Amsterdam] 1980).

Jansen, Q.A., 'Openingswoord', in: *Verslag tweede themadag LSOVD 8 oktober 1983* (Bilthoven 1983) 2-4.

Janssens, Sophie, *Wegloper waarheen? Een sociaal-culturele geschiedenis van het wegloopfenomeen in Nederland, 1950-2000* (Master's thesis Universiteit van Amsterdam 2023).

Jansz, Jeroen, 'Het kind. Deskundige opvoedingsadviezen en -interventies', in: Jeroen Jansz & Peter van Drunen, *Met zachte hand. Opkomst en verbreiding van het psychologisch perspectief* (Maarssen 1997) 37-55.

Jasper, James M., *The Art of Moral Protest: Culture, Biography, and Creativity in Social Movements* (Chicago, London 1997).

Jasper, James M., *Protest: A Cultural Introduction to Social Movements* (Cambridge, Malden 2014).

Jasper, James M., 'Introduction. Playing the Game', in: James M. Jasper & Jan Willem Duyvendak, *Players and Arenas: The Interactive Dynamics of Protest* (Amsterdam 2015) 9-32.

Jasper, James M. & Jan Willem Duyvendak, *Players and Arenas: The Interactive Dynamics of Protest* (Amsterdam 2015).

Kanner, Leo, 'Autistic Disturbances of Affective Contact', *Nervous Child* 2 (1943) 3, 217-250.

Kanner, Leo, 'Problems of Nosology and Psychodynamics of Early Infantile Autism', *The American Journal of Orthopsychiatry* 19 (1949) 3, 416-426.

Katschnig, Heinz, 'Zur Geschichte der Angehörigenbewegung in der Psychiatrie', *Psychiatrische Praxis* 29 (2002) 3, 113-115.

'Keerpunt', *Welzijnsweekblad* (1994) 5, 3.

Kennedy, James, *Nieuw Babylon in aanbouw. Nederland in de jaren zestig* (Amsterdam 1995).

Kennedy, James, *Een weloverwogen dood. Euthanasie in Nederland* (Amsterdam 2002).

Kennedy, James, *Stad op een berg. De publieke rol van protestantse kerken* (Zoetermeer 2010).

Kennedy, James C., 'Cultural Developments in the Dutch-American Relationship since 1945', in: Hans Krabbendam, Cornelis A. van Minnen & Giles Scott-Smith, *Four Centuries of Dutch-American Relations 1609-2009* (Amsterdam 2009) 931-948.

Kersbergen, Corinne, *De psychiatrische tegenbeweging in de jaren 80. Van het inrichtingsbed naar de stoel van de beleidsmaker* (Master's thesis Universiteit van Amsterdam 1989).

Keuls, Yvonne, *Jan Rap en z'n maat* (Baarn 1977).

Keuls, Yvonne, *De moeder van David S., geb. 3 juli 1959* (Baarn 1980).

Keuls, Yvonne, *Het verrotte leven van Floortje Bloem* (Baarn 1982).

Keuls, Yvonne, 'Signaleren en informeren', *Bulkboek* 11 (1982) 126, 32-37.

Keuls, Yvonne, *Madame K. Van Indisch kind tot Haagse dame* (Amsterdam 2001).

Keuls, Yvonne & Tony van Verre, *De arrogantie van de macht* (Baarn 1986).

Keuning, Nico, *Angst voor de winter. Jan Arends: leven en werk* (Amsterdam 2014).

Klein, Alexandre, 'Never far away. Those Close to the Ill: Key Players in the History of Health', *Histoire social/Social History* 54 (2021) 122, 499-506.

Kooyman, Martien, *The Therapeutic Community for Addicts: Intimacy, Parent Involvement, and Treatment Outcome* (PhD thesis Erasmus University Rotterdam 1992).

Kriesi, Hanspeter et al., *New Social Movements in Western Europe: A Comparative Analysis* (London, New York 1995).

Kuiper, P.C., *Hoofdsom der psychiatrie* (Utrecht 1973).

Kuipers, Elizabeth & Estelle Moore, 'Expressed Emotion and Staff-Client Relationships: Implications for Community Care of the Severely Mentally Ill', *International Journal of Mental Health* 24 (1995) 3, 13-26.

Ladd-Taylor, Molly & Lauri Umansky (eds.), *"Bad" Mothers: The Politics of Blame in Twentieth-Century America* (New York 1998).

Lakeman, Jan, *Toevlucht en thuisbasis. 15 jaar Alzheimerstichting* ([Bunnik] 1999).

Last, Oksana & Rex Last (eds.), *10 years Eufami: 1992-2002* [Brussels 2002].

Laurs, P., *Recht voor psychiatrische patiënten. Een onderzoek naar de rechtsbescherming voor in psychiatrische ziekenhuizen opgenomen patiënten* (PhD thesis Rijksuniversiteit Utrecht 1988).

Le Clerq, Christien & Daisy Smith, 'Over In Perspektief', in: Christien le Clerq, Daisy Smith & Olda van den Burg-Wigboldus (eds.), *Verdriet zoekt onderdak, Over pastoraat aan familieleden van (ex-)psychisch zieke mensen* (Zoetermeer 1994) 59-66.

Le Grange, Daniel et al., 'Academy for Eating Disorders Position Paper: The Role of the Family in Eating Disorders', *International Journal of Eating Disorders* 43 (2010) 1, 1-5.

Legemaate, J., *De rechtspositie van vrijwillig opgenomen psychiatrische patiënten* (PhD thesis Universiteit van Amsterdam 1990).

Leven met een alkoholist met de hulp van Al-Anon (New York 1978).

Link, Bruce G. & Heather Stuart, 'On Revisiting Some Origins of the Stigma Concept as it Applies to Mental Illnesses', in: Wolfgang Gaebel, Wulf Rössler & Norman Sartorius (eds.), *The Stigma of Mental Illness – End of the Story?* (Cham etc. 2017) 3-28.

Louter, Michiel, *Uit de inrichting. Vertelde verhalen over tachtig jaar inrichtingspsychiatrie in Nederland (1925-2005)* (Amsterdam 2005).

Mans, Inge, *Zin der zotheid. Vijf eeuwen cultuurgeschiedenis van zotten, onnozelen en zwakzinnigen* (Amsterdam 2004).

Meijer, Ischa, 'J. Bernlef', in: Ischa Meijer, *De interviewer en de schrijvers. 50 literaire interviewers van 1966 tot 1993* (Amsterdam 2003) 277-282.

Methorst, G.J., *Mannen en vrouwen van psychiatrisch patiënten, Een onderzoek naar verschillen in ervaringen, huwelijksbeleving en psychisch welbevinden* (PhD thesis Landbouwhogeschool Wageningen 1985).

Meynen, Maria, *Cirkel van verslaving. Brieven aan mijn zoon die stierf aan een overdosis* (Amsterdam 1985).

Morello-Frosch, Rachel, Phil Brown & Stephen Zavestoski, 'Introduction: Environmental Justice and Contested Illnesses', in: Phil Brown, Rachel Morello-Frosch & Stephen Zavestoski (eds.), *Contested illnesses: Citizens, science, and health social movements* (Berkeley 2012) 3-14, 5.

Nederland, Trudi & Jan Willem Duyvendak, *De kunst van effectieve belangenbehartiging door de patiënten- en cliëntenbeweging* (Utrecht 2004).

Nederland, Trudi, Jan Willem Duyvendak & Margaret Brugman, *Belangenbehartiging door de patiënten- en cliëntenbeweging. De theorie* (Utrecht 2003).

Neill, John, 'Whatever Became of the Schizophrenogenic Mother?', *American Journal of Psychotherapy* 44 (1990) 4, 499-505.

Neuvel, Koos, *Alzheimer. Biografie van een ziekte* (Amsterdam [2014]).

Nieweg, Edo, 'De mythe van de koele moeder herzien. Over vooruitgang en vooroordeel in de psychiatrie', *Maandblad Geestelijke Volksgezondheid* 57 (2002) 9, 854-860.

Nuijten, Arjan, *Regulating Paradise: The Local Origins of Harm Reduction in the Netherlands* (PhD thesis University of Amsterdam 2024).

Onder anderen. Geestelijke gezondheid en geestelijke gezondheidszorg in maatschappelijk perspectief (['s-Gravenhage] 1993).

Onderzoeksgroep Demokratisering in de Hulpverlening, *De positie van de psychiatrische patiënt in Nederland. Een onderzoeksverslag naar aanleiding van de enquête "De positie van de psychiatrische patiënt", Deel 1 Van aanpassing tot zelfmoord, een alfabetische samenvatting en keuze uit antwoorden en opmerkingen bij de open vragen* (Amsterdam 1977).

Onderzoeksgroep Demokratisering in de Hulpverlening, *De positie van de psychiatrische patiënt in Nederland. Een onderzoeksverslag naar aanleiding van de enquête "De positie van de psychiatrische patiënt", Deel 2 Cijfermatige inzichten en overzichten* (Amsterdam 1977).

Oosterbaan, Henny, *Omgaan met gekte. Hoe familieleden de zorg voor psychiatrische patiënten volhouden* (Utrecht 1990).

Oosterholt, Doke, 'Genezen van jezelf (2)', *Maandblad Geestelijke Volksgezondheid* (1990) 2, 183-184.

Oosterhuis, Harry & Marijke Gijswijt-Hofstra, *Verward van geest en ander ongerief. Psychiatrie en geestelijke gezondheidszorg in Nederland (1870-2005), Band II* (Houten 2008).

Otte, John, *Getekend Lenny. Kind van alcoholisten* (Amsterdam 1987).

Oudenampsen, Dick & Majone Steketee, 'De patiëntenbeweging: van afhankelijkheid naar eigen regie', in: Thijl Sunier et al. (eds.), *Emancipatie en subcultuur. Sociale bewegingen in België en Nederland* (Amsterdam 2000) 76-97.

Oudshoorn, Joyce, 'Half werk. Vrouwenbeweging, emancipatie en politiek, 1950-1990', *Leidschrift* 17 (2002) 9, 35-52.

Paull, Evelien, *In het land der blinden. Een martelgang door de psychiatrie* (Bilthoven 1973).

Petri, Meta, 'Er is een kliënt in de zaal: enkele gevoelens en gedachten rondom een incident', *Maandblad Geestelijke Volksgezondheid* 26 (1971) 1, 12-15.

Pirson, O. et al., ‘Schizofrenie en de familie’, supplement to *Neuron* 17 (2012) 6, 4.

Porter, Roy, ‘The Patient’s View: Doing Medical History from Below’, *Theory and Society* 14 (1985) 2, 175-198.

Porter, Roy, ‘Anti-Psychiatry and the Family: Taking the Long View’ in: Marijke Gijswijt-Hofstra & Roy Porter, *Cultures of Psychiatry and Mental Health Care in Postwar Britain and the Netherlands* (Clio Medica volume 49; Amsterdam, Atlanta 1998) 257-281.

Querido, Arie, *De omgang met geesteszieken in het gezin* (Practische gids voor medische en hygienische vraagstukken no. 2; Amsterdam 1935).

Ribberink, Anneke, *Leidsvrouwen en zaakwaarnemers. Een geschiedenis van de aktiegroep Man Vrouw Maatschappij (MVM) 1968-1973* (Hilversum 1998).

Righart, Hans, *De eindeloze jaren zestig. Geschiedenis van een generatieconflict* (Amsterdam 1995).

Roex, Karlijn, *In verwarde staat. Kritiek op een politiek van normaliteit* (Amsterdam 2019).

Rohlinger, Deana A. & Haley Gentile, ‘Sociological Understandings of Social Movements: A North American Perspective’, in: Conny Roggeband & Bert Klandermans, *Handbook of Social Movements Across Disciplines* (second edition; Cham 2017) 9-32.

Roskam, Eva, *Lezen over Yvonne Keuls* (Den Haag 1987).

Rutten, Alex, *Jan Foudraine. Psychotherapeut, onderzoeker, schrijver* (Amsterdam 2021).

Santing, G., ‘De zorg voor verblijfspatienten. Het gezichtspunt van de familie’, in: C.J. Slooff & W.M.A. Verhoeven, *Opstellen over ontwikkelingen in en rond de verblijfspsychiatrie* (Leiderdorp 1992) 43-47.

Scheepers, Floortje, *Mensen zijn ingewikkeld. Een pleidooi voor acceptatie van de werkelijkheid en het loslaten van modeldenken* (Amsterdam 2021).

Schene, Aart & Bob van Wijngaarden, *Familieleden van mensen met een psychotische stoornis. Een onderzoek onder Ypsilonleden* (Utrecht, Amsterdam 1993).

Schene, Aart, *Thuis bezorgd. Een literatuuronderzoek naar het verschijnsel ‘burden on the family’* (Utrecht 1986).

Schilder, Aleid, *Hulpeloos maar schuldig. Het verband tussen een gereformeerde paradox en depressie* (Kampen 1987).

Schrameijer, Flip (ed.), *Thuis bezorgd: verslag. Een studiedag over de zorg voor psychiatrische patienten in het thuismilieu* (Utrecht 1988) 10-28.

Schrameijer, F., *Springzaad, van kiemen tot verspreiden. Behandeling en beleid van het Dr. Leo Kannerhuis: leren, ervaren en overdragen* (Doorwerth 2003).

Schrameijer, Flip, *De adolescentenkliniek. Onderzoekers en behandelaars over schizofrenie* (Amsterdam, Antwerpen 2005).

Schudel, W.J., *Opgenomen…, opgegeven? Een exploratief onderzoek naar het gebruik van de bedden in psychiatrische ziekenhuizen* (Deventer 1976).

Scull, Andrew, *Museums of the Mad: The Social Organisation of Insanity in Nineteenth-Century England* (London 1979).

Scull, Andrew, *Madness in Civilization: A Cultural History of Insanity from the Bible to Freud, from the Madhouse to Modern Medicine* (London 2010).

Scull, Andrew, *Desperate Remedies: Psychiatry's Turbulent Quest to Cure Mental Illness* (London 2022).

Seeman, Mary V., 'Forty-five years of schizophrenia: personal reflections', *History of Psychiatry* 17 (2006) 3, 363-373.

Seeman, Mary V., 'The Changing Role of the Mother of the Mentally Ill: From Schizophrenogenic Mother to Multigenerational Caregiver', *Psychiatry – Interpersonal and Biological Processes* 72 (2009) 3, 284-294.

Serchuk, Marisa D. et al., 'Vicarious Stigma and Self-Stigma Experienced by Parents of Children with Mental Health and/or Neurodevelopmental Disorders', *Community Mental Health Journal* 57 (2021) 1537-1546.

Sheehan, Lindsay, Katherine Nieweglowski & Patrick W. Corrigan, 'Structures and Types of Stigma', in: Wolfgang Gaebel, Wulf Rössler & Norman Sartorius (eds.), *The Stigma of Mental Illness – End of the Story?* (Cham etc. 2017) 43-66.

Shorter, Edward, *A History of Psychiatry: From the Era of the Asylum to the Age of Prozac* (Chichester 1997).

Smilde, Miek, *Raarhoek* (Amsterdam, Antwerpen 2011).

Smith, Nicholas C., 'How can stigma contribute to our understanding of the formation and mobilization of collective identities in health social movements?', *Sociology Compass* 14 (2020) 1-2.

Snelders, Stephen & Frans J. Meijman, *De mondige patiënt. Historische kijk op een mythe* (Amsterdam 2009).

Snijders-Oomen, A.W.M., 'Autistisch gedrag, een nieuw initiatief in het Noorden van Nederland', *Tijdschrift voor Zwakzinnigheid en Zwakzinnigenzorg* 13 (1976) 4, 61-72.

Sommer, Robert, 'Family Advocacy and The Mental Health System: The Recent Rise of the Alliance for the Mentally Ill', *Psychiatric Quarterly* 61 (1990) 3, 205-221.

Sommerfeld, Denise P., 'The origins of mother blaming: Historical perspectives on childhood and motherhood', *Infant Mental Health Journal* 10 (1989) 1, 14-24.

Spruit, Inge, *Van wie zijn de kinderen? De passie en compassie van Sjef Teuns, strijdbare kinderpsychiater* (Nijmegen 2009).

Stanton, M. Duncan & Thomas C. Todd, *The Family Therapy of Drug Abuse and Addiction* (New York 1982).

Sterwald, Christopher & Jeffrey Baker, 'Frosted Intellectuals: How Dr. Leo Kanner Constructed the Autistic Family', *Perspectives in Biology and Medicine* 62 (2019) 4, 690-709.

Stichting Actiecomité Verontruste Ouders, *Zwartboek alternatieve hulpverlening* ('s-Gravenhage [1975]).

Stichting Kongres Psychiatrie in Werkelijkheid, *De Keefmanlezingen* (Amsterdam 1988).

Stichting Patiëntenvertrouwenspersoon Geestelijke Gezondheidszorg, *Verslag 1981-83* (Utrecht 1983).

Stolk, P.J., *Een soort vuur. Verkenningen in de klinische psychiatrie* (Amsterdam 1975).

Suzuki, Akihito, *Madness at Home: The Psychiatrist, the Patient, and the Family in England, 1820-1860* (Berkeley, Los Angeles, London 2006).

Swierstra, Koert, Otto Janssen & Jan Hendrik Jansen, *Heroïnegebruikers in Nederland. Deel II De reproductie van het heroïnegebruik onder nieuwe lichtingen* (Groningen 1986).

Talley, Ronda C. & John E. Crews, 'Framing the Public Health of Care Giving', *American Journal of Public Health* 97 (2007) 2, 224-228.

Tellegen, Egbert, *Waar was de dood nog meer... Autografie van een psychose* (Bilthoven 1971).

Ten Have, M. et al., 'Houding van de algemene bevolking ten opzichte van (ex-)psychiatrische patiënten; resultaten van NEMESIS-2', *Tijdschrift voor Psychiatrie* 57 (2014) 11, 785-794.

Ten Have, Margreet et al., 'Prevalence and trends of common mental disorders from 2007-2009 to 2019-2022: results from the Netherlands Mental Health Survey and Incidence Studies (NEMESIS), including comparison of prevalence rates before vs. during the COVID-19 pandemic', *World Psychiatry* 22 (2023) 2, 275-285.

Ter Haar, Aartjan, Sander R. Hilberink & Alice Schippers, 'Shifting terminology and confusing representations. An examination of intellectual disability terminology in Dutch newspapers from 1950 to 2020', *Alter* 17 (2023) 4, 31-52.

'Thematic section: The Ill and Those Close to Them', *Histoire Social/Social History* 54 (2021) 112, 491-650.

Thewissen-van Velzen, Mary, *Witboek over de zorg voor mensen met schizofrenie* (Rotterdam 1992).

Toms, Jonathan, 'MIND, Anti-Psychiatry, and the Case of the Mental Hygiene Movement's "Discursive Transformation" ', *Social History of Medicine* 33 (2020) 2, 622-640.

Tonkens, Evelien, *Het zelfontplooiingsregime. De actualiteit van Dennendal en de jaren zestig* (Amsterdam 1999).

Trimbos, Kees, *Antipsychiatrie. Een overzicht* (Deventer 1975).

Trimbos, C.J.B.J., 'Opening', in: Flip Schrameijer (ed.), *Thuis bezorgd: verslag. Een studiedag over de zorg voor psychiatrische patienten in het thuismilieu* (Utrecht 1988) 5-9.

Tromp, Ferry & Maarten Nederhorst, *Ouders kinderen van de rekening* (Baarn 1977).

Turpijn, Jouke, *80's dilemma. Nederland in de jaren tachtig* (Amsterdam 2011).

Van Amerongen, Bob, 'Ouders van drugsverslaafden: van schuld naar verantwoordelijkheid. Een terugblik op tien jaar', *Maandblad Geestelijke Volksgezondheid* 44 (1989) 2, 115-124.

[Van] Belzen, J.A. & J. Vijselaar, 'The historiography of Dutch psychiatry and mental health care', *History of Psychiatry* 2 (1991) 7, 281-288.

Van Berckelaer-Onnes, Ina, 'Ouders van kinderen met ASS door de jaren heen. The hand that rocks the cradle', *Kind en Adolescent* 36 (2015) 4, 229-240.

Van Boekel, Leonieke et al., 'Comparing stigmatising attitudes towards people with substance disorders between the general public, gps, mental health and addiction specialists and clients', *International Journal of Social Psychiatry* 61 (2015) 6, 539-549.

Van Boven, Erica, *Bestsellers in Nederland 1900-2015* (Antwerpen, Apeldoorn 2015).

Van de Loo, Vilan, *De vrouw beslist. De tweede feministische golf in Nederland* (Wormer 2005).

Van de Putte, Eveline, *Het zwijgen voorbij. Portretten van Surinaamse mantelzorgers van familieleden met ggz-problematiek* (Utrecht 2012) 10-18.

Van den Berg, Jan, 'Familieleden en de psychiatrie', *Maandblad Geestelijke Volksgezondheid* 42 (1987) 1, 60-63.

Van den Hoofdakker, R.H., *Het bolwerk van de beterweters. Over de medische ethiek en de status quo* (Amsterdam 1971).

Van der Heijden, Ria, 'De psychiater als God?', *Forum* (1982) 2, 3-7.

Van der Horst, Frank C.P., 'John Bowlby's ontmoeting met de Nederlandse kinder- en jeugdpsychiatrie: verslag van een werkbezoek in 1950', *Kind en Adolescent* 35 (2014) 4, 255-267.

Van der Kroef, Reinhilde, *25 jaar en nog nooit een normaal mens ontmoet. Pandora, psychiatrie en beeldvorming* (Baarn 1990).

Van der List, J.H.A., *Het zich autistisch gedragende kind en zijn ouders. Een onderzoek in opdracht van de Landelijke Stichting ter Behartiging van de Belangen van Autistische Kinderen en hun Ouders (BBAKO)* ([Amsterdam] 1975).

Van der Post, L.F.M., 'Netwerkbenadering in de sociale psychiatrie', in: Flip Schrameijer (ed.), *Thuis bezorgd: verslag. Een studiedag over de zorg voor psychiatrische patiënten in het thuismilieu* (Utrecht 1988) 50-72.

Van der Sanden, Remko L.M. et al., 'Stigma by Association Among Family Members of People with a Mental Illness: A Qualitative Analysis', *Journal of Community & Applied Social Psychology* 25 (2015) 5, 400-417.

Van der Sanden, Remko, *Stigma by association: Among family members of people with mental illness* (PhD thesis Maastricht University 2015).

Van der Stel, J.C., *Drinken, drank en dronkenschap. Vijf eeuwen drankbestrijding en alcoholhulpverlening in Nederland* (Hilversum 1995).

Van Deth, Ron & Walter Vandereycken, *Van vastenwonder tot magerzucht. Anorexia nervosa in historisch perspectief* (Meppel 1988).

Van Dijk, W.K., *Interimrapport van de Werkgroep rechtspositie patiënten in psychiatrische ziekenhuizen* ('s-Gravenhage 1977).

Van Dullemen, Inez, *Vroeger is dood* (Amsterdam 1976).

Van Eck, L.A.J.M. & J.L. van de Lande, 'Behandelde, familie, behandelaar', *Maandblad Geestelijke Volksgezondheid* 34 (1979) 11, 746-751.

Van Eijk-Osterholt, C.A., *Laten ze het maar voelen... Vijfentwintig jaar belangenbehartiging voor een verpleegde* (Amsterdam 1972).

Van Eijk-Osterholt, C.A., *Laten ze het maar voelen... Een verhaal over psychiatrische inrichtingen, belangenbehartiging, acties en de commissie-Van Dijk* (Amsterdam 1981).

Van Eijk-Osterholt, C.A., ' "When we are born, we cry that we are come to this great stage of fools" ', in: L.M. Horn, O.P.F. Oldenburg & J.H. Scholma-Hofdijk, *Met recht betrokken. Verslag van het eerste lustrumcongres van de Stichting* Labyrint*, gehouden in samenwerking met de sectie gezondheidsrecht van de juridische faculteit van de Vrije Universiteit op woensdag 9 mei 1990* (Utrecht 1991) 59-66.

Van Eijk-Osterholt, Corrie, ‘Familieleden en de psychiatrie (2)’, *Maandblad Geestelijke Volksgezondheid* 42 (1987) 2, 172-176.

Van Eijk-Osterholt, Corrie, *Uitbehandeld. Een kroniek* (Rotterdam 2002).

Van Eijk-Osterholt, Corrie & Kurt Bökenkamp, *Wartaal van een gek. Het schokkende verhaal van Johanna Stuten-te Gempt* (Den Haag 1983).

Van Furth, Eric, *Eetstoornissen in context* (Inaugural lecture Universiteit Leiden 2013).

Van Harberden, Pieter, *Zelfhulp bij Anonieme Alcoholisten* (Groningen 1986).

Van Lieshout, Jan, ‘Wie A zegt, wil ook B zeggen, maar waar begint het eigen alfabet?’, *Welzijnsmaandblad* 39 (1985) 2, 26-29.

Van Lieshout, Peter, *Symptomen van de tijd. De dossiers van het Amsterdamse Instituut voor Medische Psychotherapie (IMP), 1968-1977* (Nijmegen 1991).

Van Meer, C.R., ‘De benadering van schizofrene patiënten en hun familie’, in: Flip Schrameijer (ed.), *Thuis bezorgd: verslag. Een studiedag over de zorg voor psychiatrische patienten in het thuismilieu* (Utrecht 1988) 73-82.

Van Meer, Rigo, ‘Steunende gezinsbegeleiding bij schizofrenie’, *Maandblad Geestelijke Volksgezondheid* 41 (1986) 9, 867-877.

Van Meer, Rigo, *Leven met schizofrenie. Een handleiding voor familie, vrienden en andere betrokkenen* (Amsterdam 1987).

Van Meer, Rigo, *Schizofrenie van nabij. Belasting van familieleden van schizofreniepatiënten en effecten van steunende gezinsbegeleiding* (Delft 1991).

Van Mens-Verhulst, Janneke & Berteke Waaldijk (eds.), *Vrouwenhulpverlening 1975-2000. Beweging in en rond de gezondheidszorg* (Houten 2008).

Van Ooijen, Inge, ‘Het eigen belang van ouders in de psychiatrie (2)’, *Maandblad Geestelijke Volksgezondheid* 41 (1986) 12, 1267-1271.

Van Rooijen, Maria, ‘ “Van die kant bekijken wij het eigenlijk nooit” ’, *Maandblad Patiëntenbeweging* (1993) 5, 9.

Van Spronsen, Myrrhe & Jim van Os, *We zijn God niet. Pleidooi voor een nieuwe psychiatrie van samenwerking* (Amsterdam, Leuven 2021).

Van ’t Hof, Sonja & Tamara Verstegen, *Ervaring gebundeld. Organisaties van patiënten, cliënten en hun familie in de geestelijke gezondheidszorg* (Houten, Diegem 2002).

Van Tulder, Jeannette & René Borkus, *Veranderend perspektief. 10 jaar patiënteninvloed in de gezondheidszorg* (Haarlem 2001).

Van Vlodrop, Jan & Mary Thewissen-van Velzen, *Onze schizofreniepatiënten, wat er met hen gebeurt. Noodkreet zwartboek eisenpakket* ([Rotterdam] [1989]).

Van Wamel, Anneke, Christien Muusse & Sonja van Rooijen, *Geïntegreerde behandeling van dubbele diagnose cliënten. Handreiking* (Utrecht 2012).

Van Weeghel, Jaap et al., ‘Proloog: een onderschat probleem op de agenda’, in: Jaap van Weeghel et al., *Handboek destigmatisering bij psychische aandoeningen. Principes, perspectieven en praktijken* (Bussum 2016) 21-41.

Van Weeghel, Jaap et al., *Handboek destigmatisering bij psychische aandoeningen. Principes, perspectieven en praktijken* (Bussum 2016).

Van Weerden-Dijkstra, J.R., *De houding ten opzichte van geestelijk gestoorden. Verslag van een onderzoek* (Groningen 1969).

Vander Ven, Thomas & Marikay Vander Ven, 'Exploring Patterns of Mother-Blaming in Anorexia Scholarship: A Study in the Sociology of Knowledge', *Human Studies* (2003) 26, 97-119.

Vandereycken, Walter, *Tussen mythen en feiten. Diagnose en behandeling van het zogenaamde anorexia nervosa gezin* (PhD thesis Katholieke Universiteit Leuven 1980).

Vijselaar, Joost, ' "Vrijheid, gelijkheid en broederschap". Een revolutie in de psychiatrie', in: Joost Vijselaar (ed.), *Gesticht in de duinen. De geschiedenis van de provinciale ziekenhuizen van Noord-Holland van 1849-1994* (Hilversum 1997) 192-238.

Vijselaar, Joost (ed.), *Gesticht in de duinen. De geschiedenis van de provinciale ziekenhuizen van Noord-Holland van 1849-1994* (Hilversum 1997).

Vijselaar, Joost, 'Zonder Curium: het Medisch Opvoedkundig Bureau als spil van de Leidse kinderpsychiatrie en kinderpsychotherapie, 1962-1969', in: Leonie de Goei, Sonja van 't Hof & Giel Hutschemaekers (eds.), *Curium 1955-1995. Bladzijden uit de geschiedenis van de Nederlandse kinder- en jeugdpsychiatrie* (Utrecht 1995) 101-127.

Vijselaar, Joost, 'Out and In: The Family and the Asylum: Patterns of Admission and Discharge in Three Dutch Psychiatric Hospitals 1890-1950', in: Marijke Gijswijt-Hofstra et al. (eds.), *Psychiatric Cultures Compared: Psychiatry and Mental Health Care in the Twentieth Century: Comparisons and Approaches* (Amsterdam 2005) 277-294.

Vijselaar, Joost, *Het gesticht. Enkele reis of retour* (Amsterdam 2010).

Vijselaar, Joost & Ruud Abma, 'Psychiatrie in meervoud. De wetenschappelijke oriëntaties van de Nederlandse psychiatrie in het interbellum (1918-1940)', *Studium* 3 (2010) 79-81.

Vink, Marian & Daan Stremmelaar, *Krachtige mensen in beweging. Geschiedenis van de patiënten- en cliëntenbeweging in Amsterdam* (Amsterdam 2022).

Vroemen, Jac, 'Affaire medisch opvoedkundig bureau Leiden. De guerilla tegen psychiater Sjef Teuns en zijn staf', in: *Dat wordt me te gek. De psychiatrie kritisch bekeken. Artikelen en interviews* (Amsterdam 1972) 89-96.

Walker Mellyn, Elizabeth, *Mad Tuscans and their Families: A History of Mental Disorder in Early Modern Italy* (Philadelphia 2014).

Weber, Cees, '25 jaar NVA. Enige kanttekeningen en notities', *Wetenschappelijk Tijdschrift Autisme* 2 (2003) 3, 88-95.

Weima, Jan, *Beeldvorming ten opzichte van geestelijk gestoorden* (Leidschendam 1962).

Werkgroep rechtspositie patiënten in psychiatrische ziekenhuizen, *Rapportage resultaten enquête* ('s-Gravenhage 1979).

Werkgroep rechtspositie patiënten in psychiatrische ziekenhuizen, *Rechtspositie patiënten in psychiatrische ziekenhuizen. Eindrapport* (['s-Gravenhage] 1980).

Wester, D.H., *Lusten en lasten van alcohol* (third edition; Den Haag 1961).

Westerhof, Margriet, ‘De boze taal van een eenzaam man. Over waanzin in de romanliteratuur en over de receptie van het verhaal *Keefman* van Jan Arends in het bijzonder’, *Groniek* 23 (1990) 109, 105-117.

Whooley, Owen, *On the Heels of Ignorance: Psychiatry and the Politics of Not Knowing* (Chicago, London 2019).

Willemsen, Cees, *Van God los. Geschiedenis van de psychiatrische inrichting Sint-Antonius* (Breda 1997).

Woelre, Jan, *Mijn zoon is verslaafd. Een lijdensweg door de hulpverlening* (’s-Gravenhage 1985).

Wolkers, Jan, *Terug naar Oegstgeest* (Amsterdam 1965).

Wolkers, Jan, ‘Gezinsverpleging’, in: *Alle verhalen van Jan Wolkers* (Amsterdam 1981) 14-21.

Wolkers, Jan, ‘De geest waait’, in: Gemma Blok & Joost Vijselaar, *Terug naar Endegeest. Patiënten en hun behandeling in het psychiatrisch ziekenhuis Endegeest 1897-1997* (Nijmegen 1998) 139-145.

Wright, David, ‘Getting out of the Asylum: Understanding the Confinement of the Insane in the Nineteenth Century’, *Social History of Medicine* 10 (1997) 1, 137-155.

Zeegers, M., *Moeilijk in de omgang. Leven met zenuwzieken* (Nijkerk, Den Haag 1970).

List of abbreviations

AA	Alcoholics Anonymous
ADB	Algemeen Diakonaal Bureau van de Gereformeerde Kerken (General Diaconal Bureau of the Reformed Churches)
AWBZ	Algemene Wet Bijzondere Ziektekosten (General Law on Exceptional Medical Expenses)
BBAKO	Stichting ter Behartiging van de Belangen van Autistische Kinderen en hun Ouders (Foundation for the Advocacy for Autistic Children and their Parents)
BOPZ, Wet	Wet Bijzondere Opnemingen in Psychiatrische Ziekenhuizen (Law on Special Admissions to Psychiatric Hospitals)
BWA	Bond voor Wetenschappelijke Arbeiders (Scientific Workers' League)
CAD	Consultatiebureau voor Alcohol en Drugs (Clinic for Alcohol and Drugs)
EUFAMI	European Federation of Associations of Families of People with Mental Illness
FVO	Federatie van Oudervereniging (Federation of Parents' Associations)
FZA	Federatie van Instellingen voor Alcohol en Drugs (Federation of Institutions for Alcohol and Drugs)
LPGGZ	Landelijk Platform Geestelijke Gezondheidszorg (National Platform Mental Health Care)
LPR	Stichting Landelijke Patiëntenraden (Foundation National Patient Councils)
LSOVD	Landelijke Stichting Ouders van Drugsverslaafden (National Foundation Parents of Drug Addicts)
MDHG	Medisch-sociale Dienst Heroïne Gebruikers (Medico-social Service Heroin Users)

MGV	Maandblad Geestelijke Volksgezondheid (Mental Health Monthly)
MOB	Medisch Opvoedkundig Bureau (Medical Pedagogical Bureau)
NCMH	(American) National Committee for Mental Hygiene
NFGV	Nationale Federatie voor Geestelijke Volksgezondheid (National Federation for Mental Health)
NOVA	Noordelijke Oudervereniging voor Autisme (Northern Parents' Association for Autism)
NP/CP	Nederlands Patiënten/Consumenten Platform (Dutch Patient/Consumer Platform)
NSA	Noordelijke Stichting Autisme (Northern Autism Foundation)
NSMD	Nederlandse Stichting voor Manisch Depressieven (Dutch Foundation for the Manically Depressed)
NVA	Nederlandse Vereniging voor Autisme (Dutch Association for Autism)
NZR	Nationale Ziekenhuisraad (National Hospital Council)
PVP	Patiënten Vertrouwenspersoon (Patient Advocate)
RIAGG	Regionale Instelling voor Ambulante Geestelijke Gezondheidszorg (Regional Institution for Ambulatory Mental Health Care)
RP/CP	Regionaal Patiënten/Consumenten Platform (Regional Patient/Consumer Platform)
SAVO	Stichting Actie-comité Verontruste Ouders (Foundation Action Committee Alarmed Parents)
SHAKA	Stichting voor Hulp aan Autistische Kinderen en Adolescenten (Foundation for Help for Autistic Children and Adolescents)
SLKF	Stichting Landelijke Kamer Familieraden in de GGZ (Foundation National Chamber Family Councils in Mental Health Care)

SPK	(German) Sozialistisches Patientenkollektiv (Socialist Patient Collective)
SSN	Stichting Schizofrenie Nederland (Schizophrenia Foundation of the Netherlands)
UNAFAM	(French) Union nationale des Familles et Anciens malades mentaux et de leurs associations (National Union of Families and Elders of the Mentally Ill and of Their Organisations)
VABOO	Vereniging Algemene Bond van Ouders en Opvoeders (Association General League of Parents and Educators)
VIDO	Vrouwen In De Overgang (Women Going Through Menopause)
VOCP	Vereniging Ouders van Chronisch Psychotici (Association Parents of the Chronically Psychotic)
WOUW	Wijze Oude Wijven (Wise Old Women)
Wvggz	Wet verplichte geestelijke gezondheidszorg (Compulsory Mental Health Care Act)

FAMILY MATTERS

The rise of the
Dutch family movement
in mental health care
1960 - 2000

Open Universiteit