



PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Administration for Children and Families
Washington, D.C. 20201-0000

The Honorable William Jefferson Clinton
President of the United States
The White House
Washington, D.C.

Dear Mr. President:

When John F. Kennedy launched the President's Panel on Mental Retardation in 1961, neither poverty in America nor the extent and significance of mental retardation were well researched or understood. In 1969, the President's Committee on Mental Retardation produced the landmark publication, *The Six Hour Retarded Child*, linking mild cognitive disabilities in typical-appearing children with conditions associated with poverty. The ensuing years have revealed much about how substandard housing, environmental hazards, lack of access to medical care - particularly pre-natal care - poor nutrition, violence and especially alcohol and other drugs impact on development. Yet so much remains to be done to ameliorate those conditions.

In 1999, the President's Committee on Mental Retardation revisited *The Six Hour Retarded Child*, to assess the lives of adults with mild cognitive disabilities living at the fringes of American society. "The Forgotten Generation Summit" convened 75 national experts, including adults with mental retardation, to examine the consequence of social failure to adequately support these people leading marginal lives. Their deliberations are reflected in this document, with many policy recommendations for your consideration that we believe will address some of their concerns.

The plight of those living in poverty was a key concern to PCMR member John F. Kennedy, Jr. To follow on the experience and recommendations of "The Forgotten Generation," Mr. Kennedy adopted the concept of a PCMR conference on Poverty and Early Onset Disability to be co-sponsored by his Reaching Up Foundation. In his absence, the conference will go forward in New York City in February of the year 2000. We dedicate this Report to the President 1999: The Forgotten Generation, to the memory of John F. Kennedy, Jr., his life, spirit and aspirations.

Please accept this Report, as we continue to work together to meet the needs of our nation's most vulnerable citizens.

Sincerely,

Valerie J. Bradley
Chair

The Forgotten Generation

1999 Report to the President



**President's Committee on Mental Retardation
Administration for Children and Families
U. S. Department of Health and Human Services**

Nancy Sullivan, Editor and Layout Artist
Bev Adcock, Co-Editor

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Acknowledgements

The President's Committee on Mental Retardation takes this opportunity to thank its members Ruth L. Luckasson, J.D., and K. Charlie Lakin, Ph.D., and Professor Alexander Tymchuk, Ph.D. who organized *The Forgotten Generation Conference*. Their stature, hard work, and scholarship made possible the formulation of the excellent recommendations in this Report.

Our thanks to the Social Security Administration Office of Disability for providing the funds to support the conference.

The frame around which the conference was built were discussion papers prepared by a wide variety of professionals and scholars in the field who are listed separately in this Report. Their collected papers will appear soon in a textbook format, edited by Luckasson, Lakin and Tymchuk.

Thanks, too, to Dr. George H. Bouthilet, Program Officer, and Deputy Executive Director John L. Pride, the staff who implemented the conference plan.

My personal thanks to Nancy Sullivan, Founder and Executive Director of Empowerment Network Unlimited, Inc., who translated the proceedings of a complex and often technical conference into the current highly readable Report, and to Bev Adcock who assisted her in the project and Hank Bersani, Ph.D. who served as a reviewer.

The Committee would also like to express its appreciation to Olivia A. Golden, Assistant Secretary for the Administration for Children and Families for her leadership, commitment, and support.

Jane Browning
Executive Director
PCMR

Voices

It is easy to objectify the issues raised and the recommendations offered within these pages. To do so would be to diminish the importance of the pain, frustration, wonder and hope that touch the lives of thousands of individuals with mild cognitive limitations throughout this country. The *Voices* that are threaded throughout this document are snapshots of real people leading real lives as individuals with mild cognitive limitations in communities across the nation. We deeply appreciate these individuals because it is only through their stories that the words contained herein are brought to life. The names of most of these individuals have been altered due to the overwhelming desire of people with mild cognitive limitations to remain anonymous.

PCMR would like to extend its appreciation to the people whose lives grace this publication and to those who shared their stories, including: Bev Adcock, Valerie Bradley, Jane Browning, Sheryl Dicker, Cathy Ficker Terrill, Amy Fisher, Caroline Hoffman, Moe Mahometa, Cathy McLaughlin, James Meadours, Joe Meadours, Mary Nelson, Erin Rager, Nancy Sullivan, Susan Kidd Webster, and the Wisconsin Council on Developmental Disabilities.

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Acknowledgements

Forgotten Generation Summit



The PCMR Forgotten Generation Summit

Thirty years ago, the President's Committee on Mental Retardation published a report called "The Six-Hour Retarded Child." This report brought national attention to a group of children who in school were identified as mentally retarded, but who were abandoned to their own resources after school. These children appeared so "typical" and were generally so street "smart" that neither were they thought to need any types of specialized supports, nor were supports provided.

For nearly three decades, the country has been investing in Americans with substantial cognitive limitations. Expanded funding created a comprehensive network of community services to meet the needs of people with mental retardation and developmental disabilities. New Federal and State laws that defined and fortified the rights of these individuals and underscored new programs also funded advocacy organizations to address civil rights issues.

Recent laws in the United States have often promoted a priority for those with the most severe disabilities. This has been done to address the problem of people with the most severe disabilities being



excluded from services because resources went to serve those who had the greatest potential to succeed with the least amount of support. The new emphasis on serving those with the most severe needs first benefited this group dramatically. However, resources were increasingly limited and those with "cognitive limitation," including a "mild" cognitive limitation who required support were frequently excluded.

As services to people with more severe disabilities were rapidly expanding, new services geared toward providing support to the general population were created. Social welfare programs, cash assistance programs, Food Stamps, housing assistance, medical services and many other types of supports were designed to help those

Americans who were living life on the edge. This included people who were in poverty, unemployed, in poor health, exploited, abused, disheartened and confused.

It was into this changing, confusing world that the "six-hour retarded" children moved as they dropped out or graduated from school. Without support, these individuals were faced with great struggles in making choices, finding adequate housing, getting and keeping jobs, obtaining health care, fitting into community life, maintaining marriages, and meeting other expectations that come with adulthood. Though their need for peri-

"By all accounts, adults with mild cognitive limitations formed a generation that was not only forgotten by the disability community, they were forgotten by society."

-Tymchuk, Lakin & Luckasson

odic support continued, such support was a diminishing priority within the traditional mental retardation service agencies (Tymchuk, Lakin & Luckasson, 1999). By all accounts, adults with mild cognitive limitations formed a generation that was not merely of decreasing importance within the disability community, they were largely overlooked by society.

The fact that access to specialized mental retardation/developmental disabilities services remains so very inadequate for individuals with lifelong disabilities who live in lower socioeconomic households — which includes disproportionately people from racial and ethnic minorities — can be traced to assumptions in the 1960s about conquering the social ills of poverty. The belief at the time was that mental retardation was largely the consequence of economic deprivation and the only enduring solution was to mount a broad-based attack on the root causes of poverty, ignorance and discrimination. According to this theory, people with mild cognitive limitations would benefit from the rising tide of improvements in generic health care, housing, job training, employment, and public assistance programs. Furthermore, by remaining outside the formal mental retardation service system, such individuals would avoid being labeled and could then blend into the mainstream of American society (Gettings, 1999).

How are these people doing? Do they find what they need in the

"generic" service system? How does the increasing complexity of the information age affect them? How are they faring as the generic supports of welfare are being restructured and reduced, or even stopped? These and many other questions led PCMR to sponsor a Summit in February 1999 on the Forgotten Generation.



To stimulate thought on important topics within specific areas, a number of discussion papers were prepared. These papers, listed in the shaded box to the right, will be incorporated into a book entitled *The Forgotten Generation: The Status and Challenges of Adults with Mild Cognitive Impairments in American Society*, to be published. Themes and key quotes from these papers are woven throughout the pages of this report combined with thoughts and recommendations of Summit participants.

To set the atmosphere for this important gathering, experts in the field of disabilities shared their

thoughts about the lives of people with mild cognitive limitations, the challenges they face and how society attempts to address some of those needs.

Valerie Bradley PCMR Chair

PCMR Chair Valerie Bradley welcomed participants to the Summit and thanked them for taking time from their busy lives to address the issues of *The Forgotten Generation*. She expressed her pleasure to see PCMR addressing the needs of people with mild cognitive limitations, people who have been ignored for far too long, living only in the shadows of our thoughts. Bradley urged participants to read the wealth of information provided in the background papers, examine issues, explore alternatives, and develop recommendations for change.

Bradley expressed her hope that this Summit would culminate in powerful prescriptions that could lead to an improved quality of life for individuals with mild cognitive limitations.

Jane Browning PCMR Director

PCMR Director Jane Browning extended her welcome to participants. She also spoke of the important effort that PCMR was making to attend to needs so long ignored. Browning told participants

that, "I lived for a number of years in Little Rock, Arkansas, and had the privilege of becoming well-acquainted with the poet, Miller Williams. An old-fashioned liberal, Miller took the opportunity to admonish his young friend, the new president, to retain the kind of government that could intervene to help those in need. His inaugural poem reminded President Clinton that 'Who dreamed for every child an

**"Who dreamed for every child a chance,
Cannot let luck alone turn door-knobs, or not."**

Miller Williams
Inaugural Poem, 1997

even chance, Cannot let luck alone turn doorknobs or not." She continued, noting that this quote embodies the purpose of the Summit—to share our collective expertise to design creative ways that generic service systems can learn how to "turn those doorknobs" for people with mild cognitive limitations.

K. Charlie Lakin, Ph.D.

Dr. Charlie Lakin recognized the awkwardness of the term "mild cognitive limitations" that was used to define a broader group than "mild mental retardation." This

term was chosen because it carried less stigma than mental retardation and it provided a reference for a group that was far broader than that defined as having mental retardation.

Lakin challenged Summit participants: "We hope that our discussions will address how we can make our common institutions (like places of employment and community organizations) and our common aspirations (like a home of one's own, intimacy and a valued social role) more accessible to all. We'd like to explore whether we can create more universal design in the social aspects of our communities that bring the kinds of access that universal designs have brought to our physical spaces."

Several newspaper articles about individuals with mild cogni-

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-Charles Lakin

tive limitations in difficult, even heart-rending, situations were shared with participants, stories like this one about a woman named Kathy:

"Kathy has lived most of her life in a modest bungalow her parents bought for her 40 years ago. Her family put the house in her name when her father died so that Kathy—who has mild mental retardation—would always have a home. But she is now on the verge of losing that home. Somehow, after living on her own successfully for seven years, she stumbled into a quagmire of debt—about \$77,000 in the past 2 years—by taking out increasingly larger loans to pay off previous loans. In a few months a county judge probably will approve the bank's foreclosure on her \$54,000 home-equity loans and she will have to move. Her older sister feels guilty that she didn't pay closer attention to Kathy's finances. She blames a woman who apparently bilked Kathy out of thousands of dollars, but she blames the bank even more. She is furious that a bank would loan so much money to someone so vulnerable and naive." Lakin noted that stories about people with mild cognitive limitations appeared on the front pages every day—some positive, more often in difficult life circumstances.

Lakin ended his remarks addressing the stigma that people experience. "People must struggle to survive an identity that others have given them, an identity that is often far too limited for their dreams. These people must overcome what

"Part of the challenge of diminishing handicap is that of stigma. Stigma deprives people of strong expectations for themselves and fair opportunity from others."

—Charlie Lakin

we believe them not to be able to do. And often they must overcome what we have tried to teach them not to expect from themselves. . . Part of the challenge of diminishing handicap is that of stigma. Stigma deprives people of strong expectations for themselves and fair opportunity from others."

**Alexander J. Tymchuk,
Ph.D. and Robert
Edgerton, Ph.D.**

Dr. Alexander J. Tymchuk graciously delivered Dr. Edgerton's keynote address, as he could not be present for the Summit due to serious illness. He reminded the audience of Edgerton's many accomplishments, including his early and monumental work— *Cloak of Competence* and praised Edgerton for his tireless efforts in expanding the body of research in the field and in educating tomorrow's professionals.

"I am struck by how far we have come since I entered the field," Edgerton remarked, and then described a very different world when he began his research in 1959. He described people who were among the first to leave the Pacific State Hospital. These individuals with mild mental retardation—early pioneers in community living—were virtually thrust into the community, unprepared and unsupported, challenged to "sink or swim." They did not have the advantage of the comprehensive community service system that now exists; they had nothing in the way of supports then. Impressive advances have been made since then, yet Edgerton cautioned that there is still much work to be done.

According to Edgerton, this "hidden majority" of individuals who were once labeled mentally retarded have disappeared from the view of human service providers. Some have likely made good adaptations and need little or no help from such agencies. "Many of the people I continue to follow are un-

"Many of the people I continue to follow are unknown to the human service system, yet continue to need help of all sorts that they do not receive."

—Robert Edgerton

known to the human service system, yet continue to need help of all sorts that they do not receive."

Edgerton's remarks ended with an introduction to the videotape called "Ted's Story." The story is about a man with mild retardation whom Edgerton met in 1959 when Ted was living in a trailer behind a bar where he did janitorial work. The video chronicles the meaningful life he has led, giving as much to others as they have given to him. "Whatever we say and do in this field in which we have chosen to spend so much of our lives, it is people like Ted, now seventy years old, who must remain at the center of our attention."

Nancy Ward

Ms. Nancy Ward is the founder chairperson of Self Advocates Becoming Empowered, a national self-advocacy group, and the Self-Advocacy Coordinator for Oklahoma People First. Ward congratulated PCMR on taking a big step in working with self-advocates and including them as part of the team in the *Forgotten Generation* Summit. She reminded the group that self-advocacy (people with disabilities advocating for themselves) has a rich history that self-advocates need to share.

"PCMR can teach us," Ward continued, "how to access the political arena. We feel President Clinton has included us in that he has done more for us than any other

recent President. But there are still things that he needs to do. PCMR can help us by paving the way for the President to hear our concerns. We need to have PCMR help us gain the ability to not just be included in the political arena, but be understood." She also advised PCMR of the need to use "user-friendly" language in their meetings and in publications, so that self-advocates can effectively participate in discussions and benefit from information produced.

Ward told Summit participants of a time when she was watching TV in the late 70s when she was just beginning to learn how to advocate for herself. "A commercial came on where they were parading kids with disabilities across the stage. To me, it was saying give us money because you feel sorry for us. The last thing people with disabilities need is for others to feel sorry for us because then society is not going to give us the opportunity to grow. They will never see us as more than little kids. It made me mad and I yelled at the TV. Well you know what happens when you yell at a TV—nothing! So, some friends talked to me about becoming a member of Advocacy First of Lincoln, which was the local People First chapter.

"I suggested that we write a letter to President Carter and [the sponsoring agency] to get rid of the commercial. I don't think that our one letter alone changed this, but they took the commercial off. This taught me a very valuable lesson:

"People with disabilities have the right to be involved in all meetings that affect their health, work, home life, futures and lives. A key recommendation of this Summit should be for all human services to adopt the philosophy,

***Nothing About Us Without Us!*"**

—Nancy Ward

how to direct my feelings in a positive way. I knew real well how to direct my feelings in a negative way."

Concluding, Ward explained that self-advocates had a leadership gathering in February 1999. The audience included people from diverse cultures and cross disabilities. The slogan was "Nothing About Us Without Us!" She closed noting that people with disabilities have the right to be involved in all meetings that affect their health, work, home life, futures and lives. She requested that this philosophy be one of the recommendations that comes from this Summit —***Nothing About Us Without Us!***

Susan Daniels, Ph.D.

Susan M. Daniels, Ph.D., Deputy Commissioner for Disability and Income Security Programs, Social Security Administration, gave the luncheon keynote. Daniels spoke of a "growing number of people with disabilities who can work, and want to work." She noted that due to recent advances like the Americans with Disabilities Act, changing attitudes in society and the rapidly changing world of technology — today, more than ever before, "being disabled does not mean that you can't contribute to our nation's economy." She continued, noting that complex barriers to work still remain and the time is right to "launch new initiatives to help break through these barriers."

Her vision includes four parts:

- (1) Consumer Choice, so that people can pursue meaningful careers.
- (2) Encouraging widespread innovations in both the public and private sectors and collaboration on new and streamlined approaches that minimize bureaucracy and maximize the focus on achieving employment.
- (3) Linking outcomes to financial rewards with an eye toward stable employment.
- (4) Assuring that health care is secure, as this is an essential factor in the choice people make of whether to pursue

gainful employment or not. "No one should lose health care because they desire to move into employment."

"I pledge my effort, and that of my SSA colleagues, to work with you to devise new approaches to getting real jobs for persons with disabilities. Our customers are calling..."

—Susan Daniels

Daniels expressed great enthusiasm about the possibilities for the future because of the collective focus on innovation and increasing opportunities for constructive dialogue. She ended her presentation with a powerful promise: "I pledge my effort, and that of my SSA colleagues, to work with you to devise new approaches to getting real jobs for persons with disabilities. Our customers are calling..."

limitations. She reviewed the purpose of the Summit, which was to generate new ways of thinking about the issues facing people with mild cognitive impairments in American society.

Participants were divided into five groups to address five broad areas: Employment & Economic Security, Housing and Community Living; Criminal Justice, Citizenship and Civil Rights; Psychological, Familial and Spiritual Well-Being and Health and Physical Well-Being. Luckasson explained that authors would present a summary of the papers addressing each issue. Then the group should decide on the major issues to be addressed by the group and discuss a range of possibilities that would improve the situation for people with mild cognitive limitations. Finally, each group should finalize these recommendations and prepare a short report on the outcomes to the full group.

In closing, Luckasson challenged participants to be creative in their vision and recommendations and wished them well in their endeavor.



Ruth Luckasson, J.D.

Professor Ruth Luckasson extended a warm welcome to participants and thanked them for their commitment to examine issues surrounding people with mild cognitive

Resources

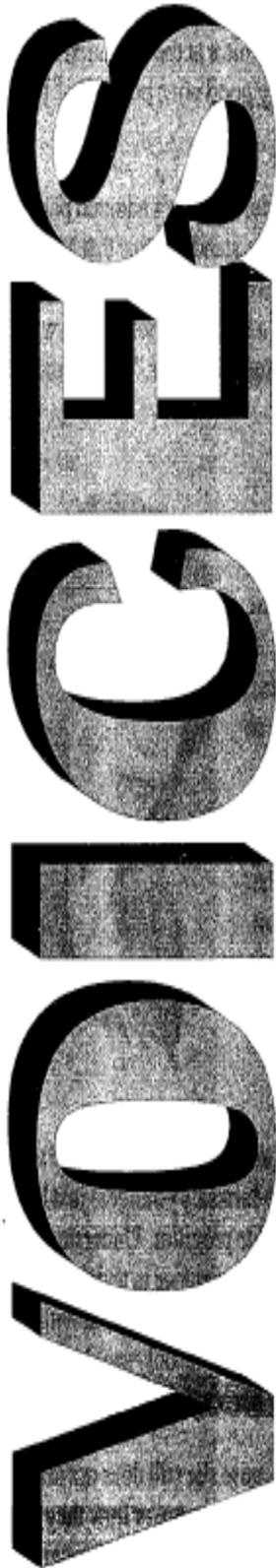
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- Tymchuk, Ph.D., Alexander J., Lakin, Ph.D., K. Charlie, Luckasson, J.D., Ruth. (1999). Life at the Margins: Intellectual, Demographic, Economic and Social Circumstances of Adults with Cognitive Limitations in an Increasingly Complex Society in *The Forgotten Generation: The Status and Challenges of Adults with Mild Cognitive Limitations in America*. To be published.

Who Are People With Mild Cognitive Limitations?



stantly overdrawn. He got credit cards in the mail and soon had many debts

Dan and Don



No explanation of the Forgotten Generation so clearly shows the challenges of people with mild cognitive limitations than the story of twin brothers Dan and Don. These brothers in their 40s are very much alike in many ways. The differences that occur are, for the most part, slight, like the difference in their test scores. When the brothers were tested to see if they were eligible for services, Dan's IQ came out to be 72 and Don's was 68. Although these four test points did not make much difference in Dan's and Don's ability to learn things, they ended up making a huge difference in their lives.

At the time Dan and Don were born, a person with an IQ under 80 was considered to have mental retardation. Later the high score was changed to 70. *Presto!* Dan no longer had mental retardation and he was no longer eligible for mental retardation services.



Still qualified for disability services, Don received special education in school that concentrate on "life skills." After school he qualified for adult services and lived in a group home for a while. Don learned to dress himself neatly, be well groomed, handle money, ride public transportation, shop for groceries, cook, have good manners and pretty much take care of his own needs. He learned work skills and has held the same job for many years. He never learned to read beyond first grade level or to be comfortable speaking to groups.

Dan's life was very different. He had been receiving special education; then the IQ level was raised and that support stopped. He was never eligible for adult services. Dan's parents struggled to teach him all the things Don was learning, but were not as successful. Although usually clean, Dan's hair isn't always combed, his clothes don't always match, and he cannot cook or shop on his own. Money in particular is a huge problem. Dan had his own checking account for a while but was con-

PCMR Report

stantly overdrawn. He got credit cards in the mail and soon had more debts than he could pay. Although Dan has had several jobs, he has difficulty learning all the things he needs to know and never keeps a job for long. He reads at a fifth grade level and is quite good at public speaking.

Dan has had his best success since he and Don started sharing an apartment because they are able to split duties. His parents continue to provide major support although they are in their 70s. However, Don is planning to get married which will leave Dan on his own and once again dependent on his parents for things he cannot do alone. What will happen when his parents are gone?

Who Are People with Mild Cognitive Limitations?



Among the citizens of American society is a group of individuals who are, at once, nearly invisible and highly visible. They are invisible because they look pretty much just like everyone else. They wear many faces, representing all of the cultures, religions, and ethnic backgrounds that blend together to make up our rich national tapestry. They live in every town, every rural area, and every metroplex. They are our friends, neighbors, coworkers, employees, fellow churchgoers and Little League parents. Their existence is so much a part of mainstream U.S.A. that we often fail to notice that these individuals have mild cognitive limitations and may need extra supports to accomplish daily tasks or, at times, even to survive.

Do not be confused by the term "mild cognitive limitations." This term is not meant to describe a new category of mental disability. It is not part of the accepted definition of mental retardation nor is it a term that is approved or preferred by PCMR. The phrase "mild cog-

nitive limitations" was used at the *Forgotten Generation Summit* and appears in this publication to facilitate discussion about people who have relatively mild

cognitive limitations in their day-to-day functioning and who may require interventions and supports (Tymchuk, Lakin & Luckasson, 1999). In his remarks to Summit participants, Dr. Charlie Lakin explained that the term "mild cognitive limitations" was chosen in an effort to avoid the restrictions of the term "mild mental retardation" and expand the group being identified. The label of mental retardation is offensive to many people, particularly self-advocates. "Mild mental retardation" is also more narrow in focus than the population addressed by the Summit, many of whom do not fit into a precise definition due to the mild nature of their challenges.

People with mild cognitive limitations may have been identified in school as having "mild mental

retardation" or "learning disabilities" and in need of special services to benefit from education. If students were able to make passing grades without special help, however, they may never have been identified as needing specialized services, or they may have tested "too high" to be eligible for special education. These students with mild cognitive limitations simply muddled through school and might have been considered "lazy" or "disadvantaged," and many dropped out before graduation. Attention that might have been given to learning needs in school were rarely available to individuals after school ended, though the need for them continued (Edgerton, 1999).

"Depending on the availability of supports, not only have these young people been faced with new

demands of work, relationships, and of behavior, but also they were faced with the realization that they lacked adequate knowledge and skills with which to successfully handle such new demands" (Tymchuk, Lakin & Luckasson, 1999). The "typical" appearance and street "smarts" of individuals with mild cognitive limitations led others to see them as being fully competent and capable and set the same expectations of understanding and behavior that they held for those without cognitive limitations. A desire to be accepted led people with mild cognitive limitations to adopt what Robert Edgerton first called a cloak of competence, in an effort to hide from others hardships in understanding, communicating, making choices, managing budgets, building relationships and working. So by their own design, those within this population often became even more invisible.

In his discussion about this "hidden majority" Edgerton (1999) notes that "everyone needs social supports whether from family, friends or human service agency and research indicates that these individuals need a wide array of Supports." Yet such supports are typically not there for adults with mild cognitive limitations. In the absence of these supports, people are at higher risk (Tymchuk, Lakin & Luckasson, 1999).

Members of this "hidden" population only become highly visible when the challenges of life push them into dire circumstances and

the social networks and supports that they need are not in place. Individuals with mild cognitive limitations are often unemployed or underemployed, working only a few hours a week or from time to time. As a result they frequently live their lives in poverty. Unable to afford adequate housing, these individuals are plentiful in homeless shelters, living from handout to handout, and as tenants of federally subsidized housing, often located in high crime areas. Though members of this population can be wonderful, nurturing parents with support, many end up in family courts and in jeopardy of losing children because of neglect, poverty or abusive marriages. These individuals may have brushes with law enforcement and can easily be led into criminal situations that result in long-term incarceration or even worse conse-

quences. For many, health care comes from emergency room visits, free clinics and other places where prevention and consistency of health care are not emphasized (Tymchuk, Lakin & Luckasson, 1999).

As these adults age, an interesting thing seems to occur. People seem to become more socially competent as they move into their 60s. "With the passage of time, communicative and interpersonal skills improve, and so do the skills necessary for success in the workplace and appropriateness in public places" (Edgerton, 1999). Older adults generally are more accepted as their limitations—slow thought, limited memory, slow responses, lapses in judgment—are more generally expected from people in their senior years. However this older

Shifting public policies, gaps in resources and services, a lack of support have led to these individuals being at a heightened risk of: Victimization; Maltreatment; Acts of violence against them; Incarceration; Lowered life satisfaction; Lowered living standards; Child removal; Family disintegration; Placement of children within foster care; Failures in the criminal justice system; Inadequate physical and mental health & well-being; Limited competence in parenting skills; Dropping out of school; Homelessness; Joblessness; and illiteracy.

—Tymchuk, Lakin & Luckasson

generation remains vulnerable to poverty, often not being able to afford adequate health care just when health needs increase dramatically.

Recent shifts in public policy have made individuals with mild cognitive limitations even more vulnerable. A key concept in disability policy is to serve all individuals with disabilities, including individuals with the most significant disabilities, and to give priority to those with the most severe disabilities when funds are limited. A clear example of this concept is in the Vocational Rehabilitation system that must adopt an order of selection if sufficient funds are not available to serve everyone. Entitlement programs, such as SSI, have always targeted individuals with the most significant disabilities (Silverstein, 1999). People with mild cognitive limitations are often excluded from such specialized services. If more generic supports exist, these individuals may not be aware of them, or how to find help if they need it. With the current anti-welfare mentality, people with mild developmental disabilities are most vulnerable to being abandoned by governmental agencies that search for less inclusive definitions of what constitutes need (Bogdan & Taylor, 1999).

How many people fall into this hidden population? The truth is that we have no idea. How do we identify a population that does not typically appear to be different from the general population? Sometimes limitations are clear; much of the

time they are neither clear nor linked to the concept of any particular disability. It is unlikely that people who often try to hide their learning difficulties from others would willingly be counted among this population. While it has been relatively easy to gather data on how many children receive special education for mental retardation, learning disabilities or mild behavioral problems, identifying dropouts or those on the margin of passing is not so simple. To complicate the situation, today many school districts no longer identify kids as having mild mental retardation. Instead they are "learning disabled," "intellectually handicapped" or "cognitively impaired"—broad titles that can include a variety of disabilities. The 1997 Amendments to IDEA lets schools label children ages 3-9 as "developmentally delayed." This loss of a specific label even while in school will make the challenges of knowing how many people we are talking about and how they are affected even harder.

In defining this Forgotten Generation, the reference has been made that this population includes "six-hour retarded children" from years ago who have reached adulthood. The perception is not meant to be limiting, for this is a population spanning all generations. Children who are only now in special education face the same uncertain futures and lack of supports as they move into adulthood as those who graduated from special education so many years ago. Without action, the situation will continue.

The issues that face adults with mild cognitive limitations are incredibly complex. In the pages that follow, issues that arise in various areas of life—employment, housing, community life, health, and others—are more fully explored. In each section, the recommendations made by *Forgotten Generation Summit* participants are proposed. The recommendations in this report represent mere starting points, as there may be many solutions beyond these. However, if these recommendations are translated into action, they can have a powerful impact on the lives of people with mild cognitive limitations and can go a long way to enabling the adults of today, and those of tomorrow, to lead more satisfying, less challenging lives.



Resources

Bogdan, Ph.D., Robert and Taylor, Ph.D., Stephen J. Building Stronger Communities for All: Thoughts About Community Participation for People with Developmental Disabilities in *The Forgotten Generation: The Status and Challenges of Adults with Mild Cognitive Limitations in America*. To be published.

Edgerton, Ph.D., Robert B. "The Hidden Majority" of Persons with Mental Retardation/Developmental Disabilities in *The Forgotten Generation: The Status and Challenges of Adults with Mild Cognitive Limitations in America*. To be published.

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Employment and Economic Security



Thomas



SEEDS
GROWN

Thomas is 38. He was identified as having mild mental retardation and received special education in school. After leaving school, Thomas was not eligible for adult services but he found a part-time job at a fast food

place and a part-time job as a janitor at a store. He worked hard but neither job provided health care benefits. For a while, Thomas did pretty well. Although only making slightly above minimum wage, he managed to move out into an apartment with a friend.

A few months ago Thomas lost his janitorial job. The business wanted to save money and decided to have their other employees split the janitorial duties. Thomas could no longer afford to pay his share of the apartment expenses and could not find another job. He still had the part-time job at the fast food place, but was forced to move back in with his mom. His father died several years ago and his mom has limited income so Thomas has to use part of his income to buy utilities and groceries.

Thomas deeply resents not having as much money as he used to have when he had both jobs, especially now that he has more free time and wants to go out and do things. He blames his mother for taking his money and often yells at her when she won't give him as much spending money as he wants. Recently Thomas wandered into one of those quickie loan places that don't require collateral. He came out with \$100 and was very happy for a while. When the money ran out, he tried to borrow again, but was turned down. He went to a similar company and borrowed another \$100. When that was gone, he borrowed \$100 from a third place. His mother only discovered this when the companies came to collect because Thomas had not been making payments. Thomas is now thousands of dollars in debt because the papers he signed included an agreement to pay 300% interest per day on the unpaid balance. The companies are threatening to file suit and have even threatened Thomas's mother. He will probably have to file bankruptcy in order to avoid the debt.

Andrew

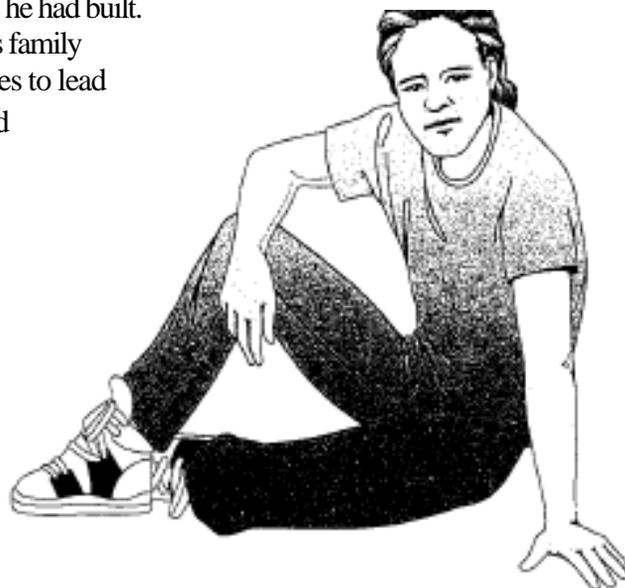
Andrew has had a good life with a loving family. He was in special education in school, but when he got out, he hated being considered disabled. Now, as a young adult, he knew he could make it on his own if he could just get a job. He was right.

Andrew's parents recognized their son's desire to stand on his own and supported it wholeheartedly. Andrew didn't want to go through vocational rehabilitation services so his mother contacted their local chapter of The Arc and asked if they knew about any jobs that might be right for Andrew. Though they had no leads at the time, the director promised to contact her with any prospects. That very afternoon the call came that a new Marriott hotel was opening in their Southern city in several months. Job interviews were to start the next day and they welcomed people with disabilities.

Andrew was hired on the spot and began his career by washing dishes in the restaurant. That was 11 years ago. Since then, he's had numerous raises and promotions. He also has full benefits. Andrew was not just hired as an employee; he quickly became a valued member of the hotel staff. He participated in all of the employee activities, like company picnics and parties, and won "Employee of the Month" several times during his tenure. With a stable income, Andrew was able to move into an apartment—he could make it on his own. In the last few years, Andrew's parents, who continue to provide great support for him, retired and moved to another city.

Andrew chose to stay with his job and his apartment—the life he had built.

While Andrew sees his family frequently, he continues to lead his own life as a valued employee, friend and member of the community.



Employment and Economic Security

Employment & Security

When we meet someone new one of the first things we want to know about them is where they work and what they do for a living. Where a person works is an important part of who they are and how people think of them, and it is the key to whether they will have enough money to live as they wish. Those with prestigious or high paying jobs are more highly valued in American society than those doing menial labor or earning low wages. People with mild cognitive limitations, already forgotten by society, are seen as even less important because many have no job or receive very low pay. Why aren't they working?

Recent studies confirm a continuing and troublesome trend toward high rates of unemployment or underemployment for former recipients of special education services (Rogan, Leucking & Held, 1999). Many of them will be people with mild cognitive limitations.

Obviously success in school affects our ability to find a job. While the Individuals with Disabilities Education Act (IDEA) has greater emphasis on transition services and preparing students with disabilities for life, what about students with mild cognitive limitations who are not far enough behind academically to qualify for special education? They could greatly benefit from school work experience programs but schools have returned to a focus on the education "basics" and this has meant less focus on vocational skills and work experience programs (Kregel, 1999).

Students with mild cognitive limitations usually have schedules and curricula similar to general education but are not always given support services or activities that will help them succeed. They often fall behind. Schools frequently leave students with disabilities out of vocational education. Even when students with mild cognitive limitations are in vocational programs, many of them leave school unemployed or with part-time, entry-level positions. A high percentage of youth with mild disability labels flunk out, get expelled, or drop out of high school (Rogan, Leucking & Held, 1999).

Where a person works is an important part of who they are and how people think of them, and it is the key to whether they will, have enough money to live as they wish.

In 1996 Congress created a block grant program to assist the states in returning able-bodied adults on welfare to work. States have broad authority to determine the most effective way to reduce their welfare caseloads. So far, caseloads have declined at a much faster rate than originally anticipated but it is not clear if this is due to the success of the work programs states have initiated or due mainly

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to the strict time limits for how long people may receive assistance. One fact is clear: the booming national economy and the low unemployment rate and high tax collection it has produced has cushioned the impact of welfare reform. Blessed with huge surpluses, many states have been able to offer welfare recipients intensive job training and placement services, subsidized child-care, and other social supports to help them return to work (Gettings, 1999). What will happen when this stops?

The disability service system has programs such as supported employment or sheltered workshops to help people learn work skills and earn money, but people with mild cognitive limitations usually do not qualify for either program. Without qualifying for disability services, they have no meaningful place to spend their days, and need government benefits or help from their families to survive (Kregel, 1999).

The few students with mild cognitive limitations who do manage to qualify for work programs after leaving school face additional barriers. There are long waiting lists for services and they lose skills and abilities while waiting (Kregel, 1999). Those who get into services often end up in segregated sheltered workshops or activity centers that pay even less than minimum wage and don't prepare them for jobs in the local workforce. The few who do get jobs have low paying entry-level positions with little hope of advancement or raises (Kregel, 1999).

Some people with mild cognitive limitations qualify for disability benefits through Social Security Disability Insur-

ance (SSDI) or Supplemental Security Income (SSI). Less than 1% return to work. One reason for this is that the way the programs are designed actually discourages employment. Working should help people make more money and need less help. However, many times people are actually worse off being employed because the disability programs are set up to take away money or benefits if people attempt to work. (Kregel, 1999). Many times they lose more benefits (health care, housing, childcare) than they earn in work income.

Too many jobs do not offer health benefits especially if the job pays minimum wage or is part-time. Yet these are the jobs people with mild cognitive disabilities are most likely to get. Individuals should not have to choose between having a job and getting health care and the other support services they need, but this is the choice many people with mild disabilities face.

The good news is that the area of employment holds great hope for solving many of the problems faced by people with mild cognitive limitations. If we can remove many of the barriers they face to employment, they will be able to earn enough money to be independent and the current economy is ideal. More jobs have been created in the last eight years than in any other time period this century (Wehman, Targett, Eltzeroth, Green, Brooke, & Barcus, 1999). According to Wehman et. al. (1999) when the Vice Chair of the Federal Reserve (Rivlin, May 12, 1998) is quoted as saying "... at the rate businesses are hiring, the U.S. economy will soon run out of workers..." there is something terribly wrong, or at

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least highly inefficient with a labor market where large numbers of people with disabilities remain

When employers do hire people with mild cognitive limitations the accommodations they need in order to work are free or very low cost. This is because the accommodations needed are for employers to explain things in clear, simple language, make sure they understand what they are to do, allow them a slightly longer time to learn routines or process information, and make sure they feel comfortable enough with co-workers or bosses to ask for more direction when needed. Other accommodations might include a quiet place to work or having a checklist of what they are to do (Wehman, Targett, Eltzeroth, Green, Brooke, & Barcus, 1999).

Employers are in need of workers and people with mild cognitive limitations are in need of jobs. Our challenge is to remove the barriers that prevent these two groups from getting together so that people with mild cognitive limitations can be successfully employed.

Resources

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Recommendations in Employment and Economic Security

School to Work Transition Programs

Public school systems are not doing a good job preparing students—including those with disabilities—to transition into successful employment and community life as adults.

from school to work, for all high school students. Career development and transition plans for all students should be driven by the talents, interests and needs of the individual.

RECOMMENDATIONS:

- ◆ Make schools accountable for their transition efforts based on the outcomes of students with a philosophy of "everyone graduates with a job." Schools and cooperating agencies should receive recognition including financial incentives for individuals who are successfully placed into competitive employment opportunities and sanctions for those whose transition programs wither. For schools that place little emphasis on transition or whose transition efforts consistently meet with little success, stringent measures should be taken to suspend or withhold federal funding until energies are refocused on generating successful outcomes for people.
- ◆ Develop individualized educational plans, including plans for transitioning
- ◆ Urge schools to put primary emphasis on providing training to prepare all students for successful careers. Upon transition, generic and specialized resources should be identified that provide continuing supports needed for the individual to pursue desired career moves.
- ◆ Increase the participation of individuals with mild cognitive limitations in school-related programs funded under the School to Work Opportunities Act, the Department of Labor's Employment and Training Administration programs and the Department of Education's Office of Vocational Education.
- ◆ Encourage individuals, family members, educational personnel, employers, and adult service agency representatives to work together to ensure that people have lifelong access to the community supports they need to pursue careers.

Employment and Economic Security

Building Partnerships

Involving the business community in partnerships to employ people with mild cognitive limitations can work to educate them about the advantages of workforce diversity, encourage staff sensitivity to individual needs, strengthen training and supports for all employees and build the employer's capacity to provide long term supports to employees with specialized needs.

RECOMMENDATIONS:

- ◆ Develop creative partnerships between individuals, schools, service agencies, businesses, industry and others to address the needs of people with mild cognitive limitations.
- ◆ Help employers develop effective strategies to employ individuals with mild cognitive limitations that are responsive to their specific needs. These supports might include, but certainly are not limited to, modified or expanded workplaces, job accommodations, assistive technology,

employee training, mentoring programs, employee orientation, development of interdependent or shared jobs and the development of natural supports.

- ◆ Work with the National Association of Employment Assistance Programs and similar groups to enhance the focus on supports for people with mild cognitive impairments as part of their nurturance of all employees.
- ◆ Expand and enhance school-business partnerships to include all students not just those without disabilities.
- ◆ Identify and replicate model programs that are working to develop long-term partnerships between the business communities and providers of supports. This enhances the capabilities of the workplace to embrace individuals with mild cognitive impairments.
- ◆ Expand the current Work Opportunities Tax Credit so that the economic incentives to employers are equivalent to that provided by the Welfare to Work Tax Credit.



Employment and Economic Security

Support for Employers

Many employers would be willing to employ people with mild cognitive limitations if they had the support and technical assistance in areas such as training, job accommodations, on-the-job training techniques, supervision strategies and other areas that impact successful employment.

RECOMMENDATIONS:

- ◆ Train potential employers, service providers, educators, and the general public to interact effectively, support and assist individuals with mild cognitive limitations.
- ◆ Provide employers convenient access to the information and technical assistance they need for training, supporting and accommodating employees with cognitive limitations.
- ◆ Expose the myths surrounding individuals with cognitive limitations and promote healthy, positive images and accurate information regarding these individuals and their potential to achieve successful employment.

Training and Support

Quality training and support programs for people with mild cognitive limitations can have a powerful impact on successful employment.

RECOMMENDATIONS:

- ◆ Hold all government agencies and service providers accountable for high quality employment outcomes for individuals. Impose financial sanctions when programs consistently fail to improve the employment situation for individuals with mild cognitive limitations.
- ◆ Provide integrated, competitive employment opportunities for individuals with mild cognitive limitations.
- ◆ Assure that necessary training and supports, including life-skills and literacy training, are available in school and throughout life.
- ◆ Adopt the "Nothing about us without us" philosophy and promote the involvement of individuals with mild cognitive limitations in the design, development, implementation and evaluation of employment supports and services.

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- ◆ Promote an array of demonstration projects and the use of their findings to remove the walls between funding streams.
- ◆ Assure that accessible, dependable public transportation systems, including paratransit systems, are readily available to individuals with mild cognitive limitations throughout the country.

for benefits should they lose their jobs and be unable to return to work in the future.

Create employment incentives for individuals who do not require income support, but need long-term health care to meet their medical needs while working.



Work Disincentives

Many people who receive public benefits and attempt to return to work are threatened not only with loss of income if they return to work, but loss of health coverage, subsidized child care and other benefits.

RECOMMENDATIONS:

- ◆ Develop strategies to move individuals from welfare to competitive employment using proven methods.
- ◆ Establish Medicare and Medicaid buy-in programs that will provide consumers long-term access to required health care.
- ◆ Enable individuals whose benefits stop due to employment to remain eligible

Housing



STRESS WELFARE CIVIL IN VOLUNTARY

Althea



Althea works 10-15 hours a week at a minimum wage job. If she didn't work, she'd never be able to make it. She and her son struggle since there's no child support to help. Her son's father is in prison. Althea's wages from work are too high for her to get Food Stamps. Although she is able to work some, she now makes less than what she received through her son's Aid to Families with Dependent Children (AFDC). The more money she makes, the more her SSI goes down, her rent goes up and the cost of childcare increases. Althea works hard despite the challenges she faces but she feels like she is drowning in increasing costs and shrinking income. She worries all the time about her son's future, and her own.

Matthew

A Vietnamese orphan, Matthew was adopted as a baby by an American military couple. Later, he was removed from their home because his adoptive family abused him. At 18, Matthew was on his own; he was all alone. He received special education services in school in his Western state but because his cognitive limitations are mild and he is very well spoken and can take care of himself, he never qualified for adult disability services or for SSI. When Matthew left school, he got a job working for a roofing company. He was sharing a house with some friends and getting by fairly well. One day there was a bad accident at work and a bucket of hot tar was spilled on Matthew. He received 3rd degree burns on the right half of his face, his right arm and chest and a few other places where the tar splattered.

Matthew had no health insurance. The company not only fired him but also refused to let him file a claim under worker's compensation. The company later filed bankruptcy. Matthew's "friends" threw him out of the house when he got behind on the rent and he ended up on the street. He needed skin grafts and physical therapy to avoid losing the use of his hand.



Someone gave Matthew the phone number of a local advocacy group. Homeless, he called to ask for help finding a place to live. After a lot of advocacy on his behalf over a three-year period, Matthew began to draw worker's compensation. After one more year he will be eligible for lifetime benefits. He is also now on Social Security Disability Insurance (SSDI).

Matthew's situation is a good example of the frustration that often occurs when people are applying for assistance. Worker's compensation wanted to use Matthew's Social Security eligibility as the way to qualify him for benefits and Social Security wanted to use his worker's

comp eligibility to qualify him for disability. It took some very fast "tap dancing" by advocates to convince worker's compensation to give Matthew coverage for medical care related to the burns so he was able to get physical therapy and many skin grafts.

Though Matthew now has enough income to survive, most of it goes for housing. To afford the apartment, he must have roommates. His present roommates are taking advantage of him by talking him out of money, running up his phone bills and stealing his belongings. Advocates have urged Matthew to move into a situation in which he is not exploited, but Matthew prefers living with these people to being alone. He is currently in debt because one of the housemates convinced him to borrow money for her from a loan company at a huge interest rate. Whether he will be able to continue to afford this place to live, no one knows.

Matthew's medical problems have gotten worse. He began having chest pains, which were diagnosed as panic attacks. At the insistence of his advocate, Matthew had a stress test to rule out heart problems. He had a heart attack during the test and had to have open-heart surgery. Medicare did not cover all the costs and he now has large hospital bills on top of a soaring loan amount. Matthew also has high cholesterol and is supposed to be watching his diet. That is not going well as all the foods he loves best are on the forbidden list. The only thing certain in Matthew's future is that he continues to need strong, powerful advocacy.

Housing

HOUSING

Where and how we will live is something to which all of us give a great deal of thought, time and the major part of our income. Long before we move out of our parents' homes, we dreamed of where we would live, how many closets we would have, how big the yard would be, and how close we wanted to live to school, work, shopping malls and grocery stores. As our income increases (from getting a raise in salary or winning the lottery), most of us will spend at least part of the income on furniture, paint, wallpaper, or even moving to a more expensive place. Our homes are a very important part of who we are. But what is it like for people whose housing choices are limited or don't exist at all?

For people with low incomes housing is not a matter of choice but a matter of what you can afford. Most people with mild cognitive limitations live with aging parents, in poor quality housing, or in crowded homeless shelters. The few who are lucky enough to have housing may pay 75% or more of their monthly income for rent. The most serious housing problems are in households with the lowest incomes, which include many people with mild cognitive limitations (Galbraith, 1999).

The major barrier faced by individuals with mild cognitive limitations in housing is low income. Supplemental Security Income (SSI) is by far the primary source of income for millions of people with disabilities. If a person is on SSI, his/her maximum SSI income is \$494 a month. This is equal to an hourly wage of \$3.09 — more than \$2 below

minimum wage. HUD considers a person to have a very low income if his/her income is half of the average income. But even this is more than twice as much money as the average SSI recipient gets. Using HUD Fair Market Rents as the standard for modest rental housing, nowhere in the U.S. can a person living on SSI rent a one-bedroom apartment for less than 50% of his or her income. This is a crucial problem because landlords and housing management companies usually

Using HUD Fair Market Rents as the standard for modest rental housing, NOWHERE in the U.S. can a person living on SSI rent a one-bedroom apartment for less than 50% of his or her income.

deny rental applications when the rent would take more than half of the person's income (Galbraith, 1999).

People with mild cognitive limitations face an even greater challenge: unless they have a secondary disability, they cannot even get SSI. If they were able to earn sufficient money working (up to \$700 per month before their SSI is reduced), this would not be a problem. But just as they have difficulty getting on SSI, they are also less likely to be eligible for work programs and so have little chance to learn work skills.

Housing



Many adult vocational and workforce training programs established with federal funding do not serve individuals with mild cognitive limitations. As a result, many of them are unemployed or employed only once in a while. Others may be working for only a few hours a week. If they are employed, it is usually for minimum wage. Although full-time work should give a person enough income to afford a decent place to live, a HUD study found a disturbing trend in the opposite direction. Between 1991 and 1995, when most of the nation was becoming better off financially, more

Between 1991 and 1995, when most of the nation was becoming better off financially, more low-income people who worked found themselves unable to afford housing.

low-income people who worked found themselves unable to afford housing.

Without SSI and without the ability to earn enough money to afford housing, many people with mild cognitive limitations are dependent on the welfare system. Because they often fall through the social service cracks — either by accident or because of the way public policy is determined — people with mild cognitive limitations face the same problems faced by anyone who is poor and not well educated. Temporary Assistance to Needy Families (TANF) has replaced the old welfare system. However, people on TANF must be in a work program and there are lifetime limits on how long a person can receive checks with no exceptions for people who have difficulty learning or chronic problems. Housing subsidies are often tied to TANF eligibility. But even getting a housing subsidy may not help.

Between 1993 and 1995 there was a 9% reduction in housing that was affordable for low-income families. To add to the problem, since 1995 Congress has stopped new funding for programs that help pay the difference between what housing costs and what low-income families can afford (Galbraith, 1999).

At a time when the emphasis is on people with disabilities living in regular housing in the community rather than in costly institutions, changes to federal housing policies mean there is less and less affordable housing available.

Federal law now permits owners of federally subsidized housing to keep people with disabilities out by renting only to elderly people. A recent report

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entitled *Priced Out in 1998: The Housing Crisis for People with Disabilities* published by the Consortium for Citizens with Disabilities Housing Task Force and the Technical Assistance Collaborative, Inc. (1999) underscored the concern about recent federal policies, stating that "*during the last decade, federal housing policies have been driven by a desire to exclude, rather than include, people with disabilities, and have reinforced the stigma and housing discrimination experienced by people with disabilities every day.*" An estimated 1 million or more people with disabilities are on waiting lists for subsidized housing (where the federal government pays part of their rent) and many of them wait for years. It is doubtful that people with mild cognitive impairments are even included in this number since they would have to identify themselves as having a disability and most will go to great lengths to avoid such a label.

It is clear that in order for any true changes to take place in where and how people with mild cognitive limitations live, there must be much more safe, accessible and affordable housing and people must be able to earn enough money to pay for their housing needs.

Resources

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Recommendations in Housing

Leadership

Strong and persistent national leadership is essential to improving the lives of people with mild cognitive

Public Awareness

People have little access to information about housing options or resources that can provide help to people seeking low-income housing.

RECOMMENDATIONS:

- ◆ Take swift and potent action to develop progressive policies regarding housing needs and community supports for individuals with mild cognitive limitations.
- ◆ Assure that the budget and all of the initiatives are in sync. For example, when supporting work incentives and tax credits so that people can become employed, expanding home/community options must include housing resources targeted to people with disabilities to match the employment initiatives, such as providing an additional 20,000 Section 8 vouchers.
- ◆ Convene key players to discuss the housing needs of people with mild cognitive limitations and advocate for more affordable housing options.

RECOMMENDATIONS:

- ◆ Expose the travesty that people with disabilities—even those earning minimum wage—are living in poverty and often cannot afford safe or adequate housing.
- ◆ Introduce information on and planning for housing as part of the high school transition process.
- ◆ Simplify the reading level of housing information papers and documents.
- ◆ Produce a yearly easy-to-read publication on how to access affordable housing and existing funding programs.
- ◆ Train housing program personnel on the needs of people with mild cognitive limitations.

Housing

Research

More information is needed in every aspect of housing and people with mild cognitive limitations.

RECOMMENDATIONS:

- ◆ Conduct a national survey on the housing needs of people including those with disabilities.

Build Coalitions

Working cooperatively through local and state coalitions to address poverty and housing issues can lead to powerful changes.

RECOMMENDATIONS:

- ◆ Identify and promote opportunities for advocates, advocacy agencies, Public Housing Authorities, and local governments to work together to solve housing problems.
- ◆ Form state and local housing coalitions including self-advocacy and disability groups, provider organizations and others to influence how housing money is spent.

- ◆ Build on supports to coalitions to describe the needs of the various populations, teach citizens to access housing, work to influence the allocation of resources for safe, affordable housing and advocate for civil rights protection in housing.
- ◆ Encourage the disability community to actively participate in the Consolidated Plan (ConPlan) that cities and counties receiving Federal housing assistance are required to develop and update annually. The ConPlan is a comprehensive 5 year planning document that describes housing needs, market conditions, housing strategies, and outlines an action plan for investment of federal housing funds.
- ◆ Encourage service providers, disability groups, family, friends, and provider organizations to join low income housing coalitions at national, state, and local levels. Self-advocates should become active in these coalitions underscoring the theme, "Nothing About Us, Without Us." These coalitions embrace other populations, such as people on welfare, immigrants and the homeless, pooling resources and political power to become formidable in their influence.

Transition Planning

Housing issues should be part of every student's public school transition plan.

Housing

RECOMMENDATIONS:

- ◆ Use IDEA and school to adult life transition planning to build in supports, including housing, for life after school and to prepare families and students for change.
- ◆ Develop transition planning specifically for foster care children with cognitive limitations in the areas of community living and housing as this group faces particular challenges in transitioning to adult life.

Federal Housing Issues

Changes in Federal housing and related initiatives could have a profound impact on improving the housing situation for people with cognitive limitations.

RECOMMENDATIONS:

- ◆ Identify and evaluate positive state and federal practices in supports for persons with mild cognitive limitations affected by welfare reform.
- ◆ Encourage state governors to include work and housing initiatives for people with disabilities in their National Governors' Association agenda.
- ◆ Provide State Legislators examples of good models of housing development ideas from other states.

- ◆ Increase the stock of low-income housing. Reverse the trend that has taken money out of housing programs to help people with disabilities.
- ◆ Support a home of your own program that significantly expands the potential for home ownership by individuals with mild cognitive limitations.
- ◆ Link housing (Section 8) vouchers to SSI or to Home and Community Based Waiver Supports so when someone qualifies for one service, they qualify for all.
- ◆ Move beyond HUD to reach whatever federal resources can help to increase funding for affordable housing:
- ◆ Work with corporations and lenders to help them understand the needs of individuals with mild cognitive limitations.
- ◆ Increase the flexibility of eligibility for Fannie Mae loans.
- ◆ Increase participation of private loan institutions in developing loan products for people with disabilities.
- ◆ Assure that the 20% of TANF dollars that can go to family supports is used creatively for housing.

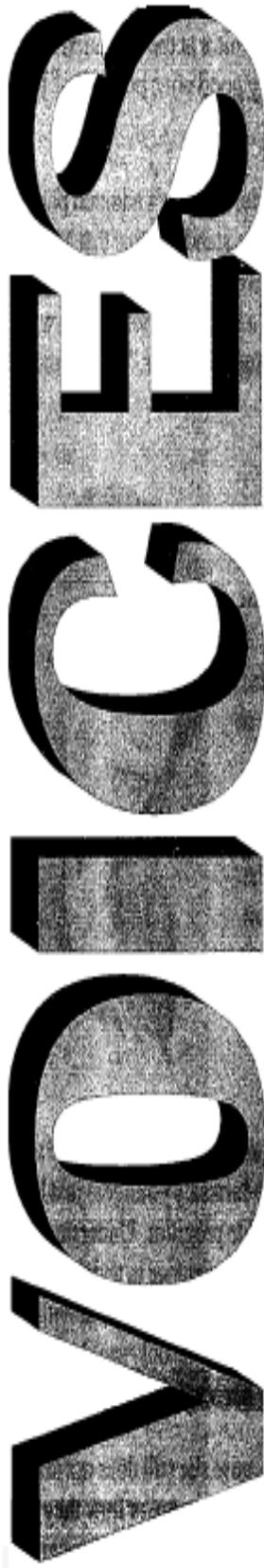
Raise the minimum wage and eliminate barriers to people saving money, so people can work their way out of poverty.



Community Living



Moe



Moe is a character. At 57, he is well spoken and can read and write. Special education wasn't an option at the time Moe was in school; he dropped out before graduating. Since the age of 13, he has worked for a country club in his hometown. He's had several jobs there, but the best job is the one he has now. In his khaki pants and green shirt, he's a golf caddie. What to some teens might be just a fun summer job has become a lifetime career and much more for Moe. He is very good at his job and popular with the guests and with the other staff.

Moe's family had some troubles while he was growing up, troubles that led to strained relationships among his siblings. Several years ago, Moe and the sister with whom he lived went from the Midwest all the way to Alabama to see another sibling. The visit didn't go very well. From there, Moe and his sister went to Memphis. Then, he unexpectedly found himself alone, stranded in a strange town with no money. He spent a few nights at the Salvation Army wondering what he would do. Ever resourceful, Moe called the president of the board of the country club where he worked and told him what had happened.

Soon he was on a Greyhound bus back to his home, but the home he had with his sister was no longer an option. Determined to keep Moe from becoming homeless, his friends at work fixed up the gardener's storage area so that Moe could live there, just until he could get back on his feet. He returned to work but his work is seasonal, April through October, and Moe was having trouble making ends meet. His friends at work were also concerned because living on the property was not a good long-term solution. So they called around and finally found an agency that could provide him a space in Section 8 housing—he didn't fit the criteria for a group home for people with mental retardation. When they had a meeting to make a plan for Moe, his friends and coworkers were there—all supportive and concerned for him.

Despite the hard times, Moe reclaimed security and friendship from a support network that remains broad and cohesive. He has made friends with some of the people in the Section 8 housing program. He also likes cooking his own meals, especially his favorite— spaghetti! Though he's happy with his living arrangements right now, he's planning to move into an apartment with a friend one of these days.

Moe walks to church every Sunday where he sees some of the people he's known from the country club. He even admits to having a pretty girlfriend who is from a "well-to-do" family but he says he has no plans for getting married at his age. In the winter months, Moe supplements his income by doing contract work at the workshop that the provider runs. Moe is very proud of who he is and of the achievement award he recently won.

A friend who works for the parks department gives Moe a ride to work every day. Health-wise, he's doing pretty well right now. Moe's boss—the president of the board of the country club—makes sure he doesn't overdo. He doesn't allow Moe to work in the rain or work too long in the sun. On those days, the president will drive Moe home. It's clear Moe's boss and coworkers want him to be around for a long time. Moe even gets to rub elbows with a lot of sports celebrities, like Michael Jordan and Mike Ditka, when the PGA comes to town.

It is ironic that in the disability arena, we struggle to define the elusive term "inclusion" when all we need to do is just ask Moe. Though he encounters problems from time to time, his life is full and getting better every day.

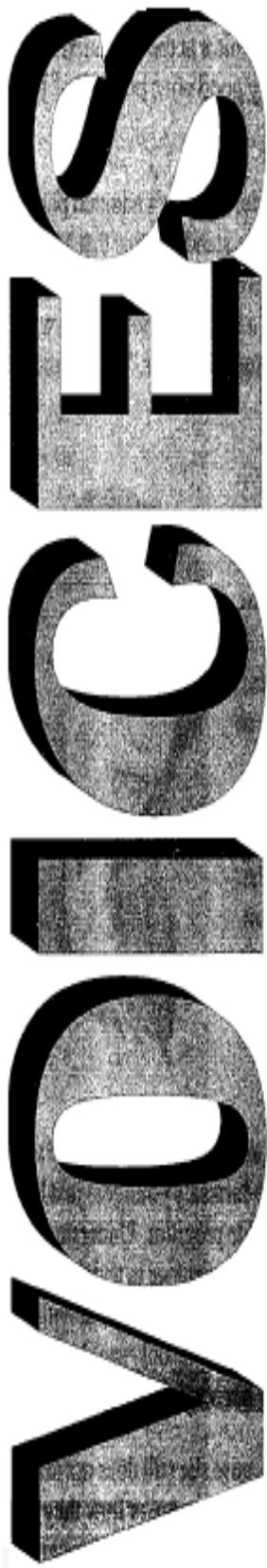


Nakita

Nakita thanks God that spring is finally here because she can turn off the heat and save precious money. To increase income, Nakita rented out a room in her home, but that made her food stamps go down to only \$85 a month. It's barely enough to buy food for her son so she gets her nourishment from "dumpster diving." When no one is around, Nakita gets food out of dumpsters behind restaurants. At least she did, until the car died.

Living below the poverty level hurts her physically and mentally. Nakita wants to work and wishes that she could, though the challenges she faces preclude working. "I honestly don't know what to do," she says. Nakita quit wearing an artificial eye because the ointment she needs costs \$9-10 a month and to clean it costs \$25- 30. Her benefits don't cover this, so her only choice is a patch.

"I'd give up anything for my son, so he can have a few things. I don't want him growing up and hating the USA. We are a proud country — so proud that the 'higher up' people turn their backs on us as if we don't exist." Nakita continues, "I have never had much self- esteem, but now I have none. I worry all the time. I don't want my son to see just how bad off we are. I keep my tears inside 'till he's tucked away in bed for the night. No child should have to worry if he's gonna get a meal today or not. So this is my goal — bring him up the best I know how and pray he too will have a future like other kids."



Community Living

COMMUNITY LIVING

Community is a place where *people live in harmony, have meaningful and satisfying face to face relationships, care about each other and look out for each other* (Bogdan and Taylor, 1999). But people can live in the community and still be isolated, ignored and lonely. How do we help people with mild cognitive limitations become part of their communities and build close relationships that will give them lifelong support?

Most of us feel part of our communities because we have friends there. We feel welcome in the churches, schools and other places. People greet us with a smile when we go to the store and we are known by sight and often by name. We know what the rules are for how we should dress and act and we fit in with how the rest of the people in the neighborhood look and act. We are accepted because we are similar to others in our communities.

People with mild cognitive limitations often struggle to fit into their communities. They do not always understand what the rules are for being like everyone else and they may be just different enough to be noticed. These individuals may have a hard time making friends because they are at a particular disadvantage. Their disability is not easily identified so they may avoid some stigma but this also means that people may see them as "odd" without realizing the differences may come from disability.

Successful life in the community often depends on the availability of supports and services. In most states, eligibility for

Community is a place where "people live in harmony, have meaningful and satisfying face to face relationships, care about each other and look out for each other."

-- Bogdan & Taylor, 1999

publicly funded services and supports is limited to individuals with more severe and profound disabilities and even then there are long waiting lists. Reforms in these systems may not benefit people with mild cognitive disabilities (Bradley, Agosta & Kimmich, 1999). The mental retardation system has an all or nothing approach to support while people with mild disabilities usually need only a few services now-and then. Most people with mild cognitive limitations cannot even qualify for services unless they have additional disabilities and so they have to get help from agencies who serve individuals with low-incomes.

Poverty is widespread among those with mild cognitive limitations. Many people are unemployed or employed only sporadically. Those who have such limited incomes that they receive S SI or other public benefits are typically living well below the poverty line. Even if people are employed, they are unlikely to be making more than minimum wage and that is often not enough to provide

Community Living

for adequate housing, preventive medical services, a nutritional diet, the needs of children, etc. Many of the things we do that make us a part of our communities are beyond the reach of people who do not have enough income to cover their family's needs.

Individuals with mild cognitive limitations may not want to admit they need supports because they don't want to admit they have a disability (Bradley, Agosta & Kimmich, 1999). This leaves many of them outside the disability system and dependent on welfare programs like food stamps, housing subsidies and Temporary Assistance to Needy Families (TANF). With recent welfare reform, however, these services have lifetime limits and once the maximum is reached people cannot qualify again.

Resources for people with low-incomes are designed to help with basic needs like food and housing. People with mild cognitive limitations often fail to get the help they need because they do not know these resources are available or how to gain access to them. There is no consistent system to help people find out about services. In addition, these services do not focus on including people in the community (Bradley, Agosta & Kimmich, 1999).

People on TANF are required to go to work as quickly as possible. Unfortunately, in most states, TANF does not make exceptions for people who cannot learn work skills in the time allowed or have chronic problems that prevent them from learning or working. It does nothing to address the problems of those who leave TANF only to take minimum wage jobs that do not provide enough money

to live on but is enough to make the person ineligible for other assistance (like food stamps, health care and subsidized housing).

TANF in some states may exempt people with disabilities from work requirements but it also excludes them from training and other programs that might be beneficial. It does not, however, exempt them from the time limits on benefits. As a result, they run out of benefits and lose TANF eligibility without having a job to replace the income unless the state chooses to continue assistance at the state's expense. People with mild cognitive limitations currently on TANF will be hard hit by the loss of these programs when the time limit is up.

With the current anti-welfare mentality, people with mild cognitive limita-



Community Living

tions who do get services are the most likely to be dropped by governmental agencies that want stricter rules for who can qualify (Bogdan & Taylor, 1999). Because they often seem very competent until you know them well, their needs for explanation, advice, encouragement and help may be hidden (Bradley, Agosta & Kimmich, 1999).

One significant problem people with mild cognitive limitations face is isolation. They need to be connected with other people and to learn to speak for themselves. Self-advocacy groups are gaining in momentum, numbers and strength. They have proven to be powerful avenues that enable people with cognitive limitations to gain self-confidence, learn information about rights and resources, get information to make responsible choices and find the power to take control of their lives. Many people have become empowered to dramatically change their lives for the better with the training and support that comes from participation in self-advocacy groups and self-determination training.

While there are growing numbers of self-advocacy groups across the country, they are not present in every community and the knowledge, resources and support they provide vary widely from group to group. Again, one barrier for people with mild cognitive limitations is that being part of a self-advocacy group means admitting you have a disability—something many people with mild disabilities are reluctant to do.

One of the most successful programs in helping people become connected to their communities was Citizen Advocacy, a concept that gained popu-

larity in the 70s. This program recruited volunteers—members of the community who were connected and successful in dealing with the daily challenges life brings. These volunteers were trained and matched with individuals with cognitive limitations to provide friendship, encouragement, and support in daily activities and resolving problems. Through Citizen Advocacy, people with cognitive limitations learned to be a friend, to access community resources, to make sure a child got the right dose of medicine, to communicate needs and to pursue desires. Despite the incredible success that many of these programs had in building relationships that continued long after the programs ceased, most fell as casualties of the drastic slash in federal funds to support human welfare services that marked subsequent decades.

Most people don't know individuals with mild cognitive limitations even exist, so little attention has been paid to helping them become part of their communities. Our attention has been so focused on individuals with more substantial cognitive and other developmental disabilities that we know very little of this group of individuals whose needs are less obvious. We do not even know how many people have mild cognitive limitations. We know some of the challenges they face but need to identify all of the existing issues and find real solutions. Until we do, people will continue to lead lives of poverty, illness, loneliness, homelessness and fear—lives that fall short of the quality lives they so richly deserve. When we find ways to make communities places that welcome, value and support people with mild cognitive limitations, we will make communities better for all of us.

Community Living

Resources

- Bogdan, Robert and Taylor, Stephen J. (1999). Building Stronger Communities for All: Thoughts About Community Participation for People with Developmental Disabilities in *The Forgotten Generation: The Status and Challenges of Adults with Mild Cognitive Limitations in America*. To be published.
- Bradley, Valerie J., Agosta, John M. & Kimmich, Madeliene. (1999). Social and Community Participation: How to Enhance Supports to People with Mild Cognitive Disabilities in *The Forgotten Generation: The Status and Challenges of Adults with Mild Cognitive Limitations in America*. To be published.

Recommendations in Community living

Public Awareness

As long as the tragedy of the Forgotten Generation remains hidden, people with mild cognitive limitations will continue to lead lives of poverty, illness, loneliness, homelessness and fear without help and without hope.

RECOMMENDATIONS:

- ◆ Make the public and policymakers aware of the fact that people with mild cognitive limitations exist and need ongoing supports to achieve healthy, full, contributing lives.
- ◆ Mount a publicity campaign to increase acceptance of people with disabilities across the country by promoting accomplishments of individuals with disabilities. This campaign should encourage community inclusion and include examples of people being included in housing, being good neighbors, contributing to their communities, embracing diversity, etc.
- ◆ Reach out to the public for input on these recommendations to the President. Ask that they be adapted into public policy at every opportunity.

Further Research and Education

More information and more education are needed on every aspect that impacts on this population. Only then can we understand all of the existing issues and develop meaningful solutions.

RECOMMENDATIONS:

- ◆ Educate private foundations about people with mild cognitive limitations, their needs that are not being met by federal and state resources, and how they can help.
- ◆ Promote research to identify more precisely the Forgotten Generation. There are many questions: How many people fall into this population? Why do people have the challenges they have? How many live in poverty? What is the true economic impact? What strategies could improve the situation? Perhaps the most important question of all is: *How can we encourage and support generic community services to reach out to meet the needs of all people, including those with mild cognitive limitations?*

Community Living

- ◆ Present the findings from this research widely. Teach present and future professionals, educators, generic service providers and others about this population and the strategies that can alleviate the challenges that are faced.
- ◆ Assure that research conducted is designed with the input of individuals with mild cognitive limitations so that the strategies employed respect informed choice and personal dignity.
- ◆ Work with Health and Human Services to develop data on the TANF program and its activities in regard to people with mild cognitive limitations. Publicize the resulting information to all resources that can impact on public policy and enhance the lives of individuals with mild cognitive limitations.
- ◆ Encourage the Administration on Children and Families to invest in a survey to determine the specific outcomes for recipients of public benefits with mild cognitive limitations.
- ◆ Study the effects of federal and state higher graduation standards on youth with mild cognitive

Poverty

Poverty is widespread among people with mild cognitive limitations and affects every area of their lives — having enough food to eat, getting appropriate health care, providing an education for their children, and finding adequate housing.

RECOMMENDATIONS:

- ◆ Increase awareness within the Federal government and Administration about the millions of people with disabilities who live in poverty and who should have access to federal programs.
- ◆ Expand membership of coalitions looking at poverty at the community and state levels to include self-advocates, family members, friends and providers.
- ◆ Promote joint initiatives between developmental disabilities, vocational rehabilitation, education and social services around welfare to work.
- ◆ Establish cooperative demonstrations to work in waiver authority under Section 1115 of the Social Security Act.

Community Living

- ◆ Add the infrastructure development to establish independence accounts through a funded Home and Community Based Waiver service.
- ◆ Raise the minimum wage to a livable wage and eliminate barriers to people saving money, so people can work their way out of poverty.
- ◆ Work with Administration of Children and Families to identify and encourage exempt uses of welfare reform funding for people with mild cognitive limitations.

Enhancing Self-Advocacy

Self-advocacy groups have proven to be powerful supports that enable people with cognitive limitations to gain self-confidence, learn information about rights and resources, get support to make responsible choices and find the power to take control of their lives.

- ◆ be strong self-advocates should start in elementary school.
- ◆ Develop coalitions to build stronger self-advocacy networks on a local, state and national level. The Illinois Self-Help Center, designed to strengthen linkages and develop mutual support strategies, serves as a good model for these coalitions.
- ◆ Expand support for helping people to learn to be strong self-advocates, starting in elementary school.
- ◆ Simplify the reading level of applications, information papers and legal documents.
- ◆ Mandate that all disability and generic services funded through federal resources require the active involvement of individuals in the development, design and evaluation of the supports and services they receive. Assure that self-advocacy training is available so that people with mild cognitive limitations are able to effectively participate in driving the supports and services they receive.
- ◆ Encourage and support self-advocates in joining various advisory committees, coalitions, Boards and other community groups.

RECOMMENDATIONS:

- ◆ Create opportunities in local schools for students to learn about self-determination and making informed choices. Supports for helping people learn to

Community Living

Community Supports And Service Brokerage

People often fail to get the help that they need because generic community service, systems do not understand the needs of people with mild cognitive limitations. They do not know that resources are available or how to gain access to them.

people do not already have a circle of people who can support them, the broker helps to create one. These circles work with the individual to help them lead the lives they want to lead. As the circles of support begin to work well, members begin to take on roles that the broker played and the broker moves into the background, but is still available for assistance.

- ◆ Assure that service brokers are well trained in federal, state and local programs and resources, those designed for people with disabilities as well as those for the general population. People should be able to meet with a service broker at least once a year to learn about changes in Federal and State programs.

RECOMMENDATIONS:

- ◆ Establish information and service brokerage supports that are available to all individuals regardless of their disability. Service brokers are independent contractors who are hired by the individual. Brokers generally assist people with disabilities and their families to plan for the future, get information and identify resources and find service providers and sources for informal supports. They arrange for services, evaluate services and supports, and review the arrangements as needed to address the individuals' changing needs and life circumstances (Bradley, Agosta & Kimmich, 1999).

Brokers can help people to find suitable housing, find a job or make social connections. They work to expand the natural supports that people already have in family and friends. If

- ◆ Provide vouchers so that people with disabilities can hire service brokers who are uniformly trained. With a voucher, people can contract with any broker they choose. They also have the option to leave one broker and contract with another if they are not happy with the services they receive. Having control of funds, more than any other factor, puts people truly in the "driver's seat" when it comes to designing their own futures and the kinds of services and supports they need to reach their dreams.
- ◆ Offer generic supports that are readily available that are not tied to organizations associated with disability groups so that people who do not wish to be labeled as disabled can get the supports they need without the accompanying stigma.

Community Living

- ◆ Work toward more need-based rather than category-based services for everyone. Present services are based on categories of people with disabilities that are tied to particular funding streams. Need-based services would address specific problem areas for all people with needs, regardless of whether they have mild cognitive limitations or not.
- ◆ Assure the money follows the person. Currently the disability service system is based on a system of funding that reimburses providers for providing specific kinds of services. When a person leaves a program, the funding for services stays with that provider. The person may or may not be able to find alternative services that meet continuing needs. If the services are found, adequate funding may not be available to extend the supports to the individual. If the funds followed the individual instead, it would enable the person to purchase services that are consistent yet no more nor less than are truly needed to address individual needs.
- ◆ End waiting lists. Fully fund and/or improve equity in programs for people with disabilities so that those with mild disabilities are able to secure the supports that they need to become more independent and included in their communities.
- ◆ Establish stronger public/private partnerships between local government and private service providers.
- ◆ Foster interagency coordination for school-to-work transition. The Health Care Finance Authority, the Department of Education, Housing and Urban Development, the Social Security Administration and Rehabilitation Services Administration should work together to develop coordinated policies and benefits.
- ◆ Increase the availability of supports for individuals in community living, including personal assistance: a broad resource that can offer assistance in areas such as personal care, mobility, household affairs, transportation, community participation, communication and more. These supports can be secured through flexible cash subsidies such as family and individual support programs.
- ◆ Invest more federal funding to address access to public transportation. A reliable source of transportation is critically important to community inclusion, securing needed supports, economic self-sufficiency, full citizenship, self-determination and choice.
- ◆ Promote and secure universal health insurance to assure that people with mild cognitive limitations have full access to preventive and prescriptive health care.

Community Living

Build Community

People with mild cognitive limitations often have great difficulty making connections in their communities and in identifying those who might provide friendship and support. They need assistance to help build networks of support and acceptance.

with mild cognitive limitations to increase their competence and foster inclusion.

RECOMMENDATIONS:

- ◆ Commission the development of a best practice guide on how to support people with mild cognitive limitations in the community and widely promote this guide.
 - ◆ Sponsor a national conference on building community support structures for individuals with mild cognitive limitations. Foster communication among states to share model program ideas.
 - ◆ Use the local media to match needs to available supports in community programs.
 - ◆ Encourage community groups and associations to reach out to enroll people with mild cognitive limitations as members.
 - ◆ Work with faith communities to build interest in providing supports to people
- ◆ Create more opportunities for individuals with disabilities to participate in established neighborhood activities, recreation, and groups dealing with community issues.
 - ◆ Empower circles of friends in becoming advocates and assure that needed supports are found and maintained. A service broker is an excellent point person to develop a plan of action and facilitate this empowerment.
 - ◆ Fund "citizen advocacy" style natural supports in which a person who is already living a successful, inclusive lifestyle in the community befriends an individual with disabilities to facilitate making community connections, identifying and using resources, fostering relationships and providing support and encouragement.
 - ◆ Involve friends and family in planning for the housing, life-style preferences, needed supports, etc. of children and youth with mild cognitive impairments.
 - ◆ Increase programs of mentoring younger students with disabilities in the schools. This can lead to building greater "circles of friends" in community so students with disabilities can lead inclusive lives as valued citizens as adults.

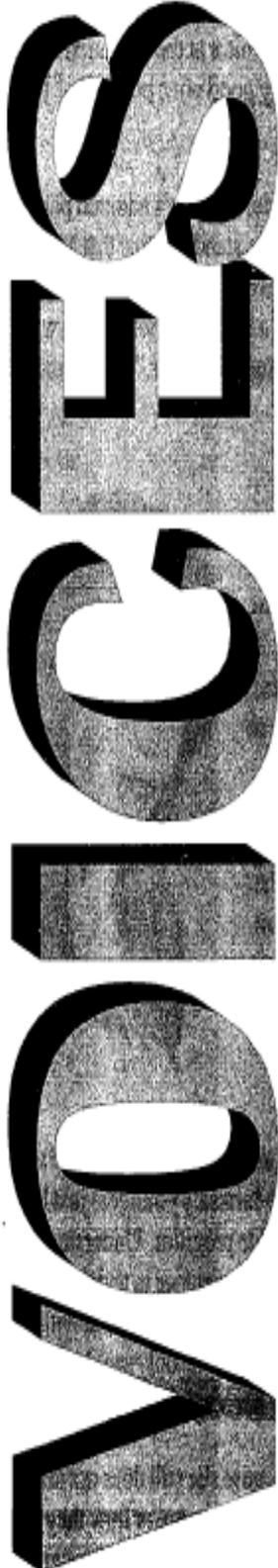


Criminal Justice



Community Living

Barry



At 9:11 p.m. on August 31, 1995, Barry's life was over. Small of stature but long on courage and the outrage of injustice, his mother had lost the battle to save her son's life. Barry's voice has been forever silenced, but his story—complicated and convoluted—will not die. He was a member of the Forgotten Generation whom we must not forget.

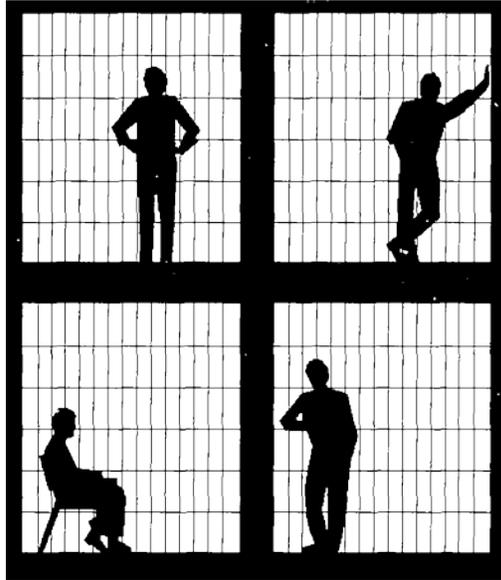
The saga began in early 1983 when a young Air Force nurse was kidnapped, raped and murdered. The issue was black and white—she was white and the two men the police sought were African American. So was Barry and that was an important issue deep in the heart of the South. Deputies arrested him within a few weeks of the murder and soon secured not one, but two confessions. His court appointed attorney never surfaced the issue of Barry's mild cognitive limitations as a mitigating factor in his first trial. Barry was quickly convicted and sentenced to death.

His conviction was not for the kidnapping, rape or murder, for there was no hard evidence that tied him directly to any of these crimes: semen and hair found at the scene were not his. Barry was convicted of being an accomplice, reportedly "confessing" that he was sitting in a car outside of the old farmhouse when the murder occurred. He never confessed to killing the nurse or knowing the murder would occur.

Barry later recanted the confessions, saying that he was coerced into making them. *Five other suspects* testified that they too had been cruelly beaten (two threatened with guns to their heads!) in unsuccessful attempts to make them confess to the same crime. Barry's head was bandaged during his videotaped confessions from the injuries that he sustained. Reportedly, the videotape also shows him frequently glancing away from the camera—apparently being coached as he gave his confessions. Barry later told one of the psychological examiners that he was looking at the Sheriff during the confession. Barry reportedly said that the Sheriff was pointing to Magic Marker colors drawn on cardboard and this was how Barry knew he was supposed to answer "blue" when asked what color of car he was driving the night of the murder. The Sheriff (who went on to serve in a high elected office) denied all charges of abuse and coercion. Barry's confession provided the **ONLY** significant evidence the State had against him, but that was enough to seal his fate.

After a decade of appeals, hope resurfaced. A U.S. District Judge commuted Barry's death sentence to life in prison without

This bright prospect was eclipsed when the Appellate Court overturned the decision and mandated the reinstatement of the death sentence.



Understanding Barry's cognitive limitations, advocates were soon encouraged with the passage of a state law precluding the use of the death penalty on people with mental retardation. Arguments as to whether or not Barry had mental retardation ensued. While Barry was illiterate and had a history of trouble with school, his records held no stated diagnosis of mental retardation. Street wise, Barry was eager to hide anything that would make others see him as weak—the epitome of a young man from the Forgotten Generation.

Several examiners evaluated Barry; only one claimed that Barry was not mentally retarded. This examiner reportedly based her conclusion (an IQ of 87) on the results of a picture test used for World War I draftees who could not read or write English. News reports stated that various tests placed Barry's IQ at 60, 63, 65 and 87. In a published letter to the editor of the major local newspaper, one of the expert witnesses evaluating Barry said that the accused had signed a written confession that he could not even read because he was illiterate. Despite arguments from experts on mental retardation, the judge deemed the issue controversial and would not rule that Barry had mental retardation. The judge then determined that the law that might have saved Barry's life wasn't applicable in his case; yet another judge ruled he was not entitled to a jury determination on this issue of whether he was mentally retarded.

In a letter to the Governor pleading for clemency for Barry, a member of the state parole board that considered clemency for Barry, reportedly noted that the board had never been so clearly divided on an issue or come so close to recommending clemency. She did not believe Barry could have been responsible for the murder and pleaded with the Governor to have mercy. It was Barry's last hope.

Arguments continued until the final hour but the flickering flame of hope soon died. After 12 long years on death row, after the endless days during which Barry's mother lived in fear and the endless nights during which Barry did not know if he would live or die, the Governor denied clemency and signed his final death warrant. In the early darkness of August 31, 1995, the touch of a toxic needle brought an end to Barry's life. Yet, his story lives on as a prime example of the abject vulnerability of people with mild cognitive limitations caught in systems that do not recognize or respond to their plight.

Trevor

In his 30's, Trevor lives with his mom and dad. He has his own car and drives everywhere. For several years, he did odd jobs for a non-profit organization that often held evening meetings.

One evening, there was a group of 13-15 year olds meeting in the building. Trevor was told not to allow them to go down the hallway outside the meeting room. Three of the girls tried to go down the hall; Trevor told them it was off limits. They made fun of him and called him a "retard" because of his speech problem. They tried to push past him anyway. A shoving match resulted and the 3 girls and their parents filed "sexual assault" charges against Trevor, claiming that he grabbed their breasts and buttocks

Trevor's explanation was that he tried to spank the "children" because they wouldn't mind him. He denied touching their breasts. A judge found him guilty but before he was sentenced, Trevor's mom contacted a non-profit disability advocate and asked for help. Not confined by strict governmental definitions of mental retardation, they took — his case and convinced the judge to put Trevor on probation. He was sentenced to 1,000 hours of community service at the advocacy organization and the judge directed them to provide him sex education training (with a lot of emphasis on appropriate touching). Trevor completed his hours and has been doing

for the past four years. Had he not had a strong and knowledgeable advocate, Trevor would have turned out very differently: he would surely have been lost in the horrific, tragic and unrelenting world of a prison!



SEXUAL
ASSAULT
CHARGES
AGAINST
TREVOR

CRIMINAL JUSTICE

Criminal Justice

The criminal justice system is complicated. Few of us understand how it works and find even minor things like reporting a petty crime to be a little overwhelming. People with mild cognitive limitations already have a hard time understanding everyday issues. If they become involved as a victim, witness, or are accused of a crime, it is almost certain that they will not understand the complicated rules of the criminal justice system. They are more likely to be ignored, falsely accused and convicted, and to have their rights violated.

If being a citizen has genuine meaning, it must include an expectation of fair treatment from the criminal justice system. Yet the principles of justice, fairness, and safety are distorted in the presence of mild cognitive disabilities. Defendants with cognitive limitations are often not treated well, and crime victims with cognitive limitations are often disregarded in the present criminal justice system

— Ruth Luckasson, J.D.

If being a citizen has genuine meaning, it must include an expectation of fair treatment from the criminal justice system. Yet the principles of justice, fairness, and safety are distorted in the presence of mild cognitive disabilities. Defendants with cognitive limitations are often not treated well, and crime victims

with cognitive limitations are often disregarded in the present criminal justice system (Luckasson, 1999).

People with mild cognitive limitations have the same rights as other citizens, including the right to legal representation, a speedy trial, to assist in their own defense, and to have their disability appropriately evaluated and acknowledged for any legal significance it may have.

With only a few rare exceptions, policemen, lawyers, corrections officials, probation officers, victims' assistance programs, and judges have little understanding of the challenges and needs of people with cognitive limitations. The system is not prepared to deal with individuals with mild cognitive limitations as perpetrators, witnesses or victims. Often, these professionals are also unaware of the resources that exist with expertise to help develop successful intervention strategies for this population.

The job of the police is to determine if there was a crime and find the person who did it. The police believe that it is the court's job to decide if someone has mild cognitive limitations and whether that had any affect on their involvement in the crime. They do not feel it is their job to determine whether a person understands the charges against them or what it means to confess (PCMR, 1991). Because of that, the cognitive limitations of a person accused of a crime are rarely discovered during police questioning. Unless someone who cares about the person pushes for testing, the question of whether a person is competent to

Criminal Justice

confess or stand trial may not come up at all.

Competency means the person has the ability to understand what is happening. In the criminal justice system competency also means the ability to assist in your own defense. Deciding if a person with mild cognitive limitations is competent can be complicated and difficult because they don't want to admit when they don't understand things. They may say what they think the other person wants to hear. The individual may also have mental health issues. These complications are particularly dangerous when the other person is a police officer trying to get a confession to a crime.

People are also more competent in some situations than they are in others depending on the circumstances, the information and training provided and even the people involved in the situation. For instance, a person with mild cognitive limitations who is innocent may confess to a murder because he is afraid of being hurt, he wants to please the police, or because he believes that if he does confess, he can go home. Because he does not understand what will happen if he confesses, he is not competent. If things are calmer, people take the time to carefully and simply explain issues, and questioners use various checks to assure the individual understands what is happening, the person may be competent.

In 1991, PCMR estimated that approximately two percent (2%) of those in the criminal justice system have mental retardation, about 26,500 prisoners across the country. The rates are probably overstated because the tests are given just after people are brought in and

are in a highly emotional state that affects the results. If they are tested again after they have adjusted, their test scores are generally higher. Using different tests and different examiners also changes how many people are identified. While it is widely believed that the number of people with mild cognitive limitations in the criminal justice system is considerably larger than the number with mental retardation, there is no accurate count (PCMR, 1991).

Mental retardation does not cause a person to be a criminal. People with mild cognitive limitations get involved in crime for the same reasons as other people. They often have a rough childhood with little discipline and are not taught moral values. Broken, dysfunctional families and poor support and encouragement from their family or community are typical. People with mild cognitive limitations do poorly in school, have low self-esteem, have difficulty finding and keeping jobs, and seldom succeed. They fall into the wrong crowd and make errors in judgment. These individuals are followers who are easily manipulated and used by others with more intelligence or experience. They are used as lookouts, to carry drugs or forged checks, and to carry or sell stolen goods (PCMR, 1991).

Once in the criminal justice system there is a delay in identifying people with cognitive limitations, if it is done at all. There is limited understanding of disability and limited resources for testing. Mild cognitive limitations are not apparent, people do not want to be identified with the disability and will try to hide it, there are technical problems in diagnosing it, and most forensic examiners only know about mental illness (PCMR, 1991).

Criminal Justice

Since the criminal justice system is not set up to meet the needs of individuals with mild cognitive limitations, there should be alternative solutions. The most effective approach has been to keep people away from sentencing and jail and give them supports and programs designed for people with mild cognitive limitations. Transdisciplinary demonstration, evaluation, and research projects should be initiated that create techniques, instruments, and standards to be used in the forensic evaluation of juvenile and adult defendants with mild cognitive limitations in the areas of competence to stand trial, competence to confess, competence to waive the right to an attorney, and, for victims, competence to testify or be a witness (Luckasson, 1999).

Just as their disability causes them to be left out of the protections for people accused of crimes, people with cognitive limitations are rarely seen on juries or as witnesses in courtrooms. The legal system assumes that challenges in communication, understanding and memory prevent people from being seen as believable. Yet these individuals not only have the right to be involved in the legal system, with support they can also be powerful witnesses and jurors.

People with mild cognitive limitations are easy targets for crime. They do not always understand when someone else is taking advantage of them and so are more likely to be manipulated, and exploited or be the victims of violence. Yet even if they report a crime, it is not unusual for the police to fail to pursue it because they don't find the person believable. The criminal justice system's limited understanding of this population keeps it from recognizing, interviewing, protecting and supporting people with mild cognitive limitations who are victims of crime.

Resources

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- Pierce, Ray. (1993). Board rejects pardon for Fairchild. *Arkansas Democrat-Gazette Pine Bluff Bureau*, September 18.
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Recommendations in Criminal Justice

A Little Known Problem

There is little awareness of the issues that confront people with mild cognitive limitations when they encounter the criminal justice system.

RECOMMENDATIONS:

- ◆ Convene a Summit on criminal justice issues. Invite key national, state and local players in the criminal justice system, such as the Department of Justice and the International Association of Chiefs of Police, and other national organizations of professionals in the criminal justice system. This Summit should be designed to educate about the many pitfalls the criminal justice system holds for individuals with mild cognitive limitations.
- ◆ Involve key advocacy, self-advocacy and criminal justice groups to work to place and keep this issue on a persistent national agenda for change.
- ◆ Encourage local and state advocacy and self-advocacy groups to pursue activities that can lead to systems change on the local level. Support this effort by providing workshops,

conferences, publications and technical assistance.

- ◆ Explore a variety of ways to intervene early, before people with cognitive limitations enter into the criminal justice system. For instance, training people about situations that might lead to arrest, such as inappropriate touching, public vs. private sexual behavior and taking things when you do not have money can help to avert these behaviors and prevent trouble from occurring in the first place. Education about one's rights when arrested might help someone to ask for an attorney before questioning and prevent a confession to crimes that were not committed.

An Unprepared Criminal Justice System

The criminal justice system is not prepared to deal with individuals with mild cognitive limitations as perpetrators, as witnesses or as victims.

RECOMMENDATIONS:

- ◆ Fund the development of training modules for professionals in every aspect of the criminal justice system.

Criminal Justice

The modules should provide information about people with mild cognitive limitations as victims, as witnesses and as offenders and include issues such as recognition, communication, management, alternative sentencing, protection of rights, and support for people as victims and witnesses.

- ◆ Mandate the use of these modules or comparable training as part of initial and ongoing educational requirements, including college coursework, judicial conferences, bar associations, police departments, etc.
- ◆ Encourage the criminal justice system to work with other agencies to effectively deal with the source of problems to keep people out of that system.

Alternative Dispositions

People with mild cognitive limitations benefit greatly from the design and implementation of alternatives to incarceration.

should promote alternatives that are very flexible and highly individualized. Education and training should be provided to individuals about their rights, how they can get formal and informal supports in the community and other issues pertinent to their situation.

- ◆ Insure that state juvenile and adult criminal law includes diversion programs for people with mild cognitive limitation that can be accessed by judges, probation officials and law enforcement personnel. Such diversion programs could include service brokerage and the use of flexible funds to pay for those supports necessary to keep individuals out of the criminal justice system.
- ◆ Create a system of court-appointed special advocates for individuals with mild cognitive limitations similar to those for abused children (CASA). This would assure that the individual understands rights, is aware of supports available, those involved are educated regarding the issues and assures that rights are protected.

RECOMMENDATIONS:

- ◆ Design a model system for developing alternative dispositions for people with mild cognitive limitations in the criminal justice system. This model

Criminal Justice

The Magnitude of the Problem

We have no clear information about how many people with mild cognitive limitations are involved in the criminal justice system.

RECOMMENDATIONS:

- ◆ Encourage the Department of Justice to conduct a survey of criminal justice facilities around the country to identify people with mild cognitive limitations, including those from culturally diverse backgrounds.

Competency to Stand Trial

Present competency standards address those with mental illness, not those with mild cognitive limitations.

RECOMMENDATIONS:

- ◆ Propose models to determine competency in individuals with mild cognitive limitations in criminal justice standards.

- ◆ Research protocols to enable individuals with mild cognitive limitations to give truly informed consent. Assure that research designs are sensitive to individual privacy and dignity and to cultural issues.

Victims' Assistance

People with mild cognitive limitations are easy targets for crime. The system's limited understanding of this population impedes its ability to provide appropriate supports to these individuals when they become victims.

RECOMMENDATIONS:

- ◆ Provide training and technical assistance for professionals in the criminal justice system when they encounter individuals with mild cognitive limitations as victims.
- ◆ Include individuals with mild cognitive limitations in counseling and classes designed to address victims' needs.
- ◆ Support people when they are assaulted or abused by caregivers. Such cases should be reported and prosecuted.

Criminal Justice

- ◆ Assure that people with mild cognitive limitations who are victimized are able to utilize restraining orders, as other citizens do.

Awareness of Rights and Resources

Individuals with mild cognitive limitations typically do not know about their rights in the criminal justice system, how to protect themselves against crimes and how to recover from these traumas.

RECOMMENDATIONS:

- ◆ Develop a training package for youth and adults with mild cognitive limitations that focuses on criminal justice system issues, such as: civil rights within the criminal justice system, how to reduce the chances of being a victim of crime, what kinds of supports there are in the community to help if you are arrested or become a victim of a crime, etc. Harassment and hate crimes should be included in the issues addressed by the training. Make this training available in local schools and community colleges.
- ◆ Assure that current prevention programs on drugs and early parenting are available to students with mild cognitive limitations.

- ◆ Provide training for educators, counselors and others to prepare them to provide training to their students and to identify potential danger signs that might lead to problems with the criminal justice system. Address issues about people from culturally diverse backgrounds who have mild cognitive limitations in this training.

Participation as Citizens

People with cognitive limitations are rarely involved on juries or as witnesses in courtrooms.

RECOMMENDATIONS:

- ◆ Educate the criminal justice system regarding the abilities of individuals with mild cognitive limitations as well as their rights under the Americans with Disabilities Act to participate as full citizens. Include in this training how accommodations, including the use of technology, can enhance participation of these citizens and others with disabilities as witnesses and jurors.



Citizenship & Civil Rights



Carrie Ann

SEWING



Carrie Ann qualified for special education services in school but was turned down for adult services because her IQ, ranging up to 75 on tests, was too high.

When she was in her 20's, Carrie Ann's mother kicked her out of the house. With no job, no work skills and no home, Carrie Ann began sleeping under a bridge with other homeless people. She traded sex for food and was soon pregnant.

Her hometown, a prim southern city, was in the middle of an avid campaign to get the homeless people off the street. With an atmosphere of strong disapproval of Carrie Ann's life-style, a conservative judge committed her to the state institution. Immediately efforts began to terminate Carrie Ann's parental rights to the unborn baby. This was based on the assumption that she would be a bad mother and the fact that the baby could not stay in the institution with her. A lawyer appointed to Carrie Ann managed to intervene and convinced her to voluntarily sign the baby over to her mother. By doing it voluntarily, Carrie Ann could later reclaim the baby.

Eventually the lawyer got Carrie Ann released from the institution to a group home where she learned living skills and work skills. She was now presumed to be eligible for disability services because she'd lived in an institution, despite her IQ scores. Carrie Ann did extremely well and by the time her son was 4 years old, Carrie Ann was sharing an apartment with him and her mother, working and supporting the entire family.

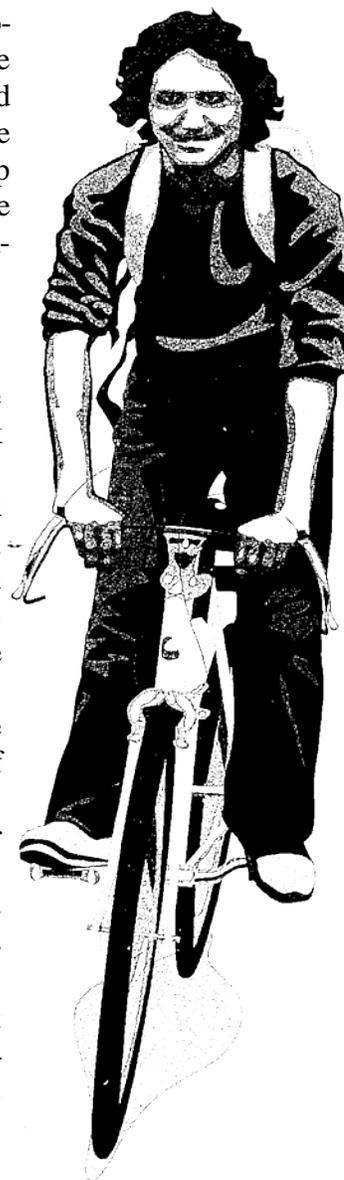
Joe

SEWING

In school, Joe was in special classes about 40% of his day. When he got out of school, he was no longer eligible for disability services. More importantly, he didn't want "special" help. On his own, he got his first job at McDonalds and enjoyed working there for awhile. Life wasn't great, though. His mom died when he was 16 and he didn't get much support from his father. He went through some rough times and even thought about suicide at one point. It was really hard and he wanted to give up, but his brother and his network of friends refused to let that happen. Joe says that if it weren't for his brother and his friends, he might be in jail today. . . or worse. He sure wouldn't be where he is today without them and he wants them to know how much they mean to him.

Things are a lot better in Joe's life today. He lives in an apartment with three roommates who are college kids; he found them through a roommate service. Joe really enjoys his new friends and they help him out with rides from time to time. He cooks his own meals most of the time including lasagna, his specialty.

For exercise, Joe plays golf a couple of times a month and rides his bike to work unless it's raining, then he takes the bus. When Joe lost his last job, a friend helped him to find a great new job as an AmeriCorps volunteer working with a state self-advocacy group to help people with mental retardation move out of the institution. Joe believes strongly that everyone deserves the chance to live a free life in the community. He is very proud of what he does and of his whole life now. Joe keeps in close touch with his brother who also works as a self-advocate in another state. Recently both brothers presented a workshop together at a self-advocacy conference. Joe really enjoys being able to interact with his brother not only as family, but also as two professionals—colleagues who are helping others lead more successful lives.



Nell

Nell is a young woman who lives alone now. Her son was taken away from her due to the Court's belief that she was unable to effectively care for him. Nell understands why her son was removed and agrees that she is not able to adequately care for him right now, but oh, she sure does love him. Nell was granted the opportunity to visit her son frequently; he is in foster care with a family who lives in a small town relatively close to hers.

When she returned to Court several months later, the social worker (who was supposed to be facilitating Nell's visitation with her son) complained to the judge that Nell had not even bothered to visit her son in several months. Fortunately, the judge wisely pursued the situation more thoroughly and discovered that Nell had indeed wanted to visit her son and had tried several times. However, getting to the foster family's home required using several types of transportation along a quite confusing route requiring complicated timing. Nell had set out to visit her son several times but she became lost each time and had to return home. Social services had never considered that she might need assistance to get to her destination nor offered her help. Rightfully frustrated with the social service worker, the judge instructed her that facilitating visitation meant helping people to resolve whatever their transportation needs might be. He ordered social services to make sure Nell had transportation to visit her son even if they had to take her!

Nell is happy to have a new chance to bond with her son and take him presents on his birthday while she is working hard to build a new life for herself.



Citizenship and Civil Rights

People with mild cognitive limitations are full and equal citizens. They have the right to vote, to serve on jury duty, to move about the community, to form relationships with whomever they choose and more.

Since the 1960s, the one key promise has been that the vulnerabilities of individuals with mild cognitive limitations are best addressed through generic health, education, income maintenance, housing and social service programs. The reality, however, is that too often people with mild cognitive limitations cannot deal with the complicated rules for getting government aid and fall through the huge cracks in the nation's generic safety net programs. Evidence of this fact can be found in the overrepresentation of people with mild cognitive limitations in foster homes for neglected and abused children, adult board and care facilities, state prisons and local jails, as well as community mental health systems (Gettings, 1999). Clearly these are barriers that prevent their full participation as citizens.

Barriers to their civil rights include fear, ignorance, prejudice, architecture, transportation, communication, and even policies and procedures. These barriers force people with disabilities to be unnecessarily dependent on other people, segregated, left out, or treated as children. Sometimes, the barriers are a result of deep-seated hatred. More often, however, they are the result of thoughtlessness or

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—Robert Silverstein

For many years people with disabilities, especially those with mental retardation, cognitive impairments and mental illness, were thought to be unable to exercise their rights or participate fully in society. But changes in attitudes and laws and the civil rights movement mean that most people now believe (even if they do not always act on these beliefs) that people with disabilities not only have basic rights but can learn to express and benefit from those rights (Dinerstein, 1999).

Citizenship and Civil Rights

Some people with disabilities may need support to participate fully in community life. That support should follow basic principles.

- ◆ All persons, including those with disabilities, should be able to control their own lives and make their own decisions in their own way.
- ◆ Any limits on this should be of the least intrusive kind.
- ◆ Those who come into contact with people with disabilities, especially professionals and caregivers, should not tell people with disabilities what to do but should help them make their own choices.
- ◆ Limits on a person's rights or choices should change as the person becomes more capable (Dinerstein, 1999).

Making their own decisions doesn't mean that people with disabilities can't ask for help from others. But it does mean people with disabilities have the right to decide whom to include in their decision-making, to whom they should listen and with whom they should consult.

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ask for help from others. But it does mean people with disabilities have the right to decide whom to include in their decision-making, to whom they should listen and with whom they should consult. The people they consult must respect their decisions (Dinerstein, 1999). Obviously, in order for people to make their own decisions, they will need information about their rights and choices and may need training to learn how to exercise those rights.

The issue of informed consent often comes up for people with mild cognitive limitations. It is not just a question of whether they can legally make their own decisions but whether the person has enough information to consent and whether they are deciding on their own. Discrimination can happen when the right of individuals to direct their own lives gets pushed aside because others feel they are not able to make their own decisions. Sometimes a person's rights are simply ignored. At other times legal steps may be taken to remove their ability to decide for themselves.

Guardianship has been used and abused in relation to people with mild cognitive limitations. Laws differ from one state to another and, at times, they are based on stereotypes and the convenience of others rather than the abilities of each person and their need for protection. There are many complicated issues related to guardianship including the feeling of many families that their right to make decisions for their children with mild cognitive limitations should continue after the child is an adult without legal interference. While it can be a way to protect someone who does not have the

Citizenship and Civil Rights

ability to make decisions, guardianship is a serious step because it removes a person's rights permanently.

One of the main reasons parents seek guardianship of their adult children with cognitive limitations is sexuality. It is a difficult issue for parents of these individuals and no issue is more packed with explosive emotions. Parents sometimes feel that by getting guardianship they can control the rights of their son or daughter to choose friends, date, marry or have a relationship. The expression of sexuality is a primary right of human beings. Unfortunately, sexuality is also an area that brings many people with mild cognitive limitations into contact with the law because they have not been given good information on the subject and do not understand the rules. Rather than keeping people from having sexual relationships, we need to teach them how to develop caring relationships and protect themselves from exploitation and disease.

As a result of the history of discrimination against people with disabilities, Congress has passed or changed laws and regulations to state and protect their rights. There are four permanent civil rights laws that protect people with disabilities from discrimination.

- ◆ The Americans with Disabilities Act (ADA) prohibits discrimination on the basis of disability in employment, public services (including transportation), public accommodations (like rest-rooms), and telecommunications.
- ◆ Section 504 of the Rehabilitation Act of 1973, prohibits discrimination

against people with disabilities by programs that get Federal money.

- ◆ The Fair Housing Act of 1968, as amended in 1988, protects people with disabilities from discrimination by landlords or housing authorities.
- ◆ Part B of the Individuals with Disabilities Education Act (IDEA) guarantees all children with disabilities a free appropriate public education (Silverstein, 1999).

There has been tremendous progress in defining and protecting the civil rights of people with disabilities but there is still much to be done. One of the greatest challenges is making sure that people with mild cognitive limitations, who are often invisible to us, know what their rights are so they can exercise them.

One of the greatest challenges is making sure that people with mild cognitive limitations, who are often invisible to us, know what their rights are so they can exercise them.

Resources

- Dinerstein J.D., Robert. (1999). How People with Cognitive Disabilities and their Allies Are Coming Together to Protect their Civil Rights in *The Forgotten Generation: The Status of Adults with Mild Cognitive Limitations in America*. To be published.
- Gettings, Robert. (1999). Renegotiating the Social Contract: Rights, Responsibilities and Risks for Persons with Cognitive Limitations in an Era of Less Government in *The Forgotten Generation: The Status of Adults with Mild Cognitive Limitations in America*. To be published.
- Silverstein J.D., Robert. (1999). Our Nation's Emerging Disability Policy in *The Forgotten Generation: The Status of Adults with Mild Cognitive Limitations in America*. To be published.

RECOMMENDATIONS

Recommendations in
Citizenship and Civil Rights

Citizenship

People with mild cognitive limitations have the right to participate fully as citizens including the right to vote, to serve on jury duty, to move about the community, to form relationships with whom-ever they choose and more.

Empowerment (self-determination, real choice and full participation in and contribution to the community), not paternalism and charity.

RECOMMENDATIONS:

- ◆ Distribute and explain the basic statement and four core principles in user- friendly language sensitive to diversity of culture and language to state, federal, local government and other systems. Regulations, policies and practices must reflect the integration of the following core principles:

Individualization (taking into account each person's unique needs), not relying on labels or generalizations.

Independence, economic self-sufficiency and productivity, not dependence.

Inclusion and integration, not exclusion, isolation or segregation.

- ◆ Build capacity for people to participate in the community at the earliest ages, through mentoring relationships and other empowering experiences.
- ◆ Assure that people with mild cognitive limitations have access to general curriculum on citizenship in school.
- ◆ Educate families how they can encourage active citizenship by participating in community activities as a family and serving as good models.
- ◆ Educate generic service systems about values and underlying realities of people with disabilities including focusing on community. Encourage these systems to provide services to these individuals.
- ◆ Build the capacity of generic systems to hear and address needs and desires of individuals with mild cognitive limitations and their families.
- ◆ Assure that the diversity of culture and language is respected and accommodated in content, communication, information, design, implementation and evaluation of all human service programs and community supports.

- ◆ Encourage advocacy groups to address issues of citizenship for people with disabilities, such as voting and participating in all levels of government.
- ◆ Examine models that support self-determination and promote replication of these models throughout the country.
- ◆ Sponsor a follow-up to the Forgotten Generation Summit to ensure that the work continues on these issues.
- ◆ Educate people with mild cognitive limitations about the resources in their communities that can help in times of need.
- ◆ Encourage the development of a full range of advocacy services from peer support groups to skilled professional advocates knowledgeable about people with mild cognitive limitations.
- ◆ Empower people with mild cognitive limitations to become competent self-advocates through training, involvement in self-advocacy groups and support. This training should begin in school with opportunities to continue learning and supports throughout life.

Advocacy

People with mild cognitive limitations need knowledgeable strong social and legal advocates. They also need opportunities to learn to be good advocates for themselves.

RECOMMENDATIONS:

- ◆ Assure that all people—including those with limited incomes—have access to skilled counsel.
- ◆ Encourage University Affiliated Programs to work with law schools and communicate the core values of individualization, independence, economic self-sufficiency and productivity, inclusion and integration, and empowerment to them so that they are "user-friendly" to individuals with mild cognitive limitations.
- ◆ Assure that individuals who are self-advocates are able to have direct access to the judiciary.
- ◆ Develop systems to help people get information and advice on everyday matters, and support that can prevent issues from escalating to the legal system in many instances.
- ◆ Provide training in self-determination for young people and adults.

Consent

People with mild cognitive limitations are generally capable of giving consent when provided with appropriate supports.

Citizenship and Civil Rights

RECOMMENDATIONS:

- ◆ Educate parents, professionals and the public about the right of individuals with mild cognitive limitations to make choices about issues that affect their lives and ways to assist people to make truly informed choices.
- ◆ Provide training to people with mild cognitive limitations in regard to self-determination including making choices.
- ◆ Require consent for medical issues including but not limited to sterilization, the use of behavior altering medications, surgery, experimental treatments, sexually transmitted diseases, restraints, aversive behavior treatments, denial of basic health care and lifesaving techniques, and testing and referral for organ transplants. Requiring consent carries with it the companion responsibility to provide full information about these procedures, including advantages, disadvantages, possible dangers and potential consequences in easy to understand language.

Guardianship

Guardianship is a legal way to protect a person from making decisions that can hurt them. It has sometimes been used to hurt the people it's designed to protect.

RECOMMENDATIONS:

- ◆ Conduct a Department of Justice funded review and analysis of State guardianship laws with recommendations for how these laws might be revised. This study should identify alternatives to guardianship and how they can be utilized to provide necessary support without diminishing rights and privileges.
- ◆ Encourage the reform of guardianship laws that do not recognize the ability of people with cognitive limitations to be competent, and provide full due process in any type of guardianship proceedings, including representation by counsel. This legislation should assure that the least restrictive option is used, encourage the use of accommodations (for disability and native language) and technology to enhance communication and understanding, and establish a strict process of reviewing the guardianship annually so that it can be modified as circumstances warrant.
- ◆ Mandate the use of simple, easy-to-understand language in forms and papers in the guardianship process.
- ◆ Provide training on self-determination for people with mild cognitive limitations. Self-determination includes issues such as managing money, making informed choices and how to find help when you need it.
- ◆ Provide training to individuals with mild cognitive limitations on issues related to decision-making, guardianships, their rights in the

guardianship

PCMR Report

Citizenship and Civil Rights

process, and resources that can help them understand complicated legal papers and assure that their rights are protected.

- ◆ Provide education and training to families of individuals with mild cognitive limitations on issues of autonomy, self-determination and the dangers of overprotection.



Parental Rights

People with mild cognitive limitations can be caring, concerned and competent parents if appropriate support services are in place.

RECOMMENDATIONS:

- ◆ Assure that people with mild cognitive limitations are able to participate in parenting classes while in school or as young adults.
- ◆ Offer Planned Parenthood services and parenting classes for individuals with mild cognitive limitations early in the child welfare process.
- ◆ Help people with mild cognitive limitations to identify and network with natural supports that may exist, such as extended families, neighbors, church members and others who might provide information, advice or assistance on parenting issues.
- ◆ Assure that parents with mild cognitive limitations involved in custody and parental rights issues are provided access to legal counsel who are knowledgeable about the needs of this population.
- ◆ Increase affordable access to legal representation by increasing funds to legal services and protection and advocacy services. Tie this new funding to a mandate to use it for representation of individuals with mild cognitive limitations in civil matters, such as guardianship and parental custody.
- ◆ Encourage agencies to involve resources experienced in working with individuals with mild cognitive limitations in providing assistance with child care and child protective services.
- ◆ Urge the Department of Justice to aggressively examine cases on parental rights issues under Title II of the Americans with Disabilities Act.
- ◆ Educate child welfare agencies, family courts and others that individuals with cognitive limitations can be competent and effective parents, and how best to

Citizenship and Civil Rights

Sexuality Rights

People with mild cognitive limitations have the right to have intimate relationships, to get married and to have children and have a full family life.

cate limited information or understanding rather than criminal intent.

- ◆ Assure that sexuality issues are addressed in accreditation standards for services that provide supports to people with cognitive limitations.
- ◆ Develop policies that assure individuals with mild cognitive limitations have the opportunity to express sexuality and be protected against victimization.

RECOMMENDATIONS:



- ◆ Educate parents, professionals and the public as to the right of individuals with disabilities to express their sexuality.
- ◆ Assure that students with mild cognitive limitations are included in school educational programs about human sexuality. This education should also include planning for parenthood and protection against health concerns such as sexually transmitted diseases.
- ◆ Provide information and counseling to individuals with mild cognitive limitations about how to appropriately express sexuality, such as public versus private displays of affection, and sexual expression only when both parties are consenting and without using coercion.
- ◆ Educate those in the criminal justice system about issues of people with mild cognitive limitations around sexuality and to recognize that inappropriate sexual behavior may indi-

Psychological, Familial & Spiritual Well-Being



Marissa

SEWING

She speaks softly but openly about her life. At forty-three, Marissa lives alone in a quiet apartment and works as a janitor at the Salvation Army Day Care Center. Marissa says her life is really good now, but she has been through a lot of pain.

Adopted at an early age by an older couple, Marissa's adopted parents are now deceased. They set high standards for her, standards that Marissa had a hard time fulfilling. She was placed in special education in school and when she graduated, Marissa went to work in a factory. Shortly afterward, she got married to a man she describes as a "tough character." They quickly had four children, then a fifth several years later.

Marissa's husband had problems with alcohol and gambling. He also abused her and the children until, finally, he went to prison. Marissa was in poor physical health most of the time. She also had mental health problems due to the stress of having five children and an abusive husband. All of her children went into foster care and were eventually adopted against her wishes.

Marissa's life has been a lot better since she divorced. It was only after losing her children that she came to the attention of the service system. Now she gets SSI and vocational supports due to her mental health problems. There is a delightful twinkle in her eyes now when she talks about the new love she has in her life.



Recently, Marissa's life took an exciting turn when she was reunited with her youngest son. The woman who adopted Marissa's youngest just happened to work for social services in the parent aide program. Understanding the challenges and difficulties people sometimes experience in trying to raise children, she felt it was in the boy's best interest to develop a bond with his birth mother. Now Marissa can visit her son. Though she only sees him three or four times a year, she is very happy to know her son is doing well.

There is still sadness in Marissa's life because she still does not know about her other four children. Not knowing where they are or how they are really hurts. Her pain has been eased a little now because she's recently been reunited with her own birth family and found new support with her birth parents and siblings. Marissa has had a hard life, full of pain and fear, but it's okay now and getting better every day.

Elisa

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Elisa is a young woman who lives on the sunny West Coast. She is trying hard to be a good parent to her two sons, 20 and 22, but it's hard. Elisa was a victim of child abuse and, later, came to abuse her own children. She wants help for herself and her sons so they can heal from being abused and abusing, but she hasn't had much luck in fording the help she needs. She says that there seems to be a world where people with disabilities live that's different from everyone else's world.



Elisa says that they are living at poverty level and she believes they will become burdens to society because she and her sons cannot function the way others do. Elisa says, "We do not fit into society yet we continue to try, in order to survive."

Elisa says that other children were quite cruel to her when she was young because she looked different from most children. Her head was a little bigger and very round. Even now that she's in her 40s, she says she still does not look like others. "It's like I have gotten stared at all my life because I look different and others couldn't figure out why. . . neither could I until I discovered that me and mine are autistic." She says that the people in our society do not accept the differences that other people have.

Elisa has hope. "There is a place for me and mine in this world," she says. "I just need to find it. It's like the first step to becoming independent is the true realization that I need to take responsibility for myself and my actions. I need to honor the way I am and stop trying to change the world to suit me or change me to match the world. The world is going to continue to be cruel and heartless. . . the system we live in will continue to fail somewhere for someone. I cannot stay stuck in the helplessness of how the system has failed me and mine. The anger does nothing more than hurt me. I am stopping it through understanding. That seems to me to be the only way I can recover from the years of abuse and torment." She also is concerned for her sons, the two most important people in her life, who cannot take care of themselves either.

PSYCHOLOGICAL, FAMILY & SPIRITUAL WELL-BEING

Psychological, Familial and Spiritual Well-being

All of us want to be happy. For most of us being happy means having a family, friends, a home, a job we like and enough money to buy what we need. We want to be with people we care about and who care about us. We want to be able to take care of our families and keep them well and safe. We want to be welcome in the church we have chosen to attend.

When people don't get their basic desires met they are not happy. Unhappy people have poor quality of life and may have behavioral or personality disorders and even symptoms of mental illness.

People with mild cognitive, limitations may struggle to be happy and it is no wonder. They are exposed to stigma and other negative attitudes all through their lives. They are treated as objects to be avoided and find few friends in life. They are likely to be unemployed as adults and are rarely asked for their opinions because people assume they are not smart enough to have any. It is common for them to think badly of themselves and have emotional scars from being made fun of as a child. The most common problem is low self-esteem.

People may give up on getting the things they want and become depressed or withdrawn or they may use extreme behaviors to try and get what they need (Reiss, 1999).

People with mild cognitive limitations may struggle to be happy and it is no wonder. They are exposed to stigma and other negative attitudes all through their lives. Treated as objects to be avoided, they find few friends in life. They are likely to be unemployed as adults and are rarely asked for their opinions because people assume they are not smart enough to have any. It is common for these individuals to think badly of themselves and have emotional scars from being made fun of as a child. The most common problem is low self-esteem (Reiss, 1999).

As adults they struggle to find significant life partners, keep their marriage or other relationships stable, raise children, and make enough money to survive. Most of them have the added problems of low incomes, not being well educated, and not knowing where to find the assistance they need. It is not surprising that many of them have mental health problems and may have difficulty finding happiness.

For those who become parents, the joy of having children is mixed with the added strain of holding the family together and meeting their needs. Having children means having to learn many new things in order to raise them and interacting with

Psychological, Familial and Spiritual Well-being

schools, doctors, and others on their behalf. They must use available resources to be able to care for themselves and their children and learn how to function within a society that does not know how to treat them. Individuals with mild cognitive limitations are not prepared to do this (Tymchuk, 1999).

People with mild cognitive limitations run into difficulties when it comes to belonging to churches, too. In "Spirituality and Self-Actualization: Recognizing Spiritual Needs and Strengths of Persons with Cognitive Limitations," William Gaventa and Roger Peters relate several stories of people with mild cognitive limitations and their faith and experiences with churches. What comes through loud and clear is that church is a source of comfort and strength and, in many cases, an experience that changes lives and behavior. But in every case, churches had to learn how to meet the needs of this part of their congregations.

Many churches, synagogues and temples have classes especially for people with more severe and obvious disabilities. But people with mild cognitive limitations are often left out because no one thinks of them. Religious groups do not always make accommodations to help people with disabilities participate in ceremonies such as baptism or confirmation. This can be because there is an assumption that the disability will make the person unable to understand religion or that they don't need the rituals because they are "special" and already a shoo-in for heaven (Gaventa & Peters, 1999).

People with mild cognitive limitations face hard challenges in relation to their

psychological, familial and spiritual well being. Because their disability is mild, they are not usually eligible for services that are designed to match their needs. So they must seek help from literacy councils, welfare programs, food banks, food stamps, low-income housing programs and other social services that do not make allowances for disability. The search to find the supports and services they need can be even harder because they do not know what is available, may have limited understanding of what is needed, and may not be able to read well. To add to the difficulty, health care, education, social and other services for low income families have been greatly changed or reduced (Tymchuk, 1999).

Though some generic services exist that can provide support, these resources are not well known or used. It is hard for people with mild cognitive limitations to benefit from them because the rules for who is eligible are different for each program, the way income is determined is confusing, and application processes are complicated (Tymchuk, 1999).

Self-advocacy groups enable people to learn about their rights and how to speak out for those rights. Many offer ongoing learning opportunities, a network of support through peers and a vehicle through which both individual and systemic concerns can be effectively addressed. Most of the groups that exist sprang from the avid interest and energies of a few people in a particular area with parallel needs and concerns and most have evolved with little or no financial resources to support the effort. Funding is needed to stabilize existing groups and

Psychological, Familial and Spiritual Well-being

enable them to continue and expand their present supports, and to create and maintain new groups.

Psychological, familial and spiritual well-being are important in order for

people to live fulfilling, happy lives. People with mild cognitive limitations may face their greatest challenges in these areas because their needs are often invisible to the very systems and agencies from which they need assistance.

Resources

Gaventa, William and Peters, D. Min., Roger K. (1999). Spirituality and Self-Actualization: Recognizing Spiritual Needs and Strengths of Persons with Cognitive Limitations in *The Forgotten Generation: The Status and Challenges of Adults with Mild Cognitive Limitations in America*. To be published.

Kane, Ph.D., William, Rogers, Ph.D., Everett M. and Avila, Ph.D., Magdalena. (1999). Community and Culture: World Views and Natural Affiliations as the Basics of Understanding, Trust, Assistance and Support in *The Forgotten Generation: The Status and Challenges of Adults with Mild Cognitive Limitations in America*. To be published.

Reiss, Steven. (1999). The Value-Based Happiness and Mental Health of Persons with Mental Retardation in *The Forgotten Generation: The Status and Challenges of Adults with Mild Cognitive Limitations in America*. To be published.

Tymchuk, Ph.D., Alexander J. (1999). Family Life: Experiences and Outcomes of People with Mild Cognitive Impairments in *The Forgotten Generation: The Status and Challenges of Adults with Mild Cognitive Limitations in America*. To be published.

Resource for Marissa's Story

Webster, Susan Kidd (ed.). (1993). *Preserving the Bond, A Collection of Family Stories*. Madison: Wisconsin Council on Developmental Disabilities.

Recommendations in Psychological, Familial and Spiritual Well-being

Fragmented Support

People with mild cognitive limitations must seek help from literacy councils, welfare programs, food banks, food stamps, low income housing programs, and other social services that are not tailored for their needs—a "mix and mesh of fragmented, isolated services."

RECOMMENDATIONS

- ◆ Base all supports on the following principles:

Collaboration: We need greater collaboration among Urban League, NAACP, self-advocates, health care, mental health, child welfare, disability, vocational rehabilitation, religious organizations, nonprofit groups, private and other pertinent groups. Such groups should have a shared responsibility and a shared capacity to provide supports to all populations. As their missions are parallel, their mission statements should reflect collaboration and an approach that emphasizes the whole person, not just

one aspect of life. This collective mindset should include a shared recognition of the need to change the delivery and content of services.

A proactive holistic approach: All people are entitled to the services and supports that they need. Supports should offer a holistic approach with a focus on pro-action toward enhancing an individual's quality of life issues rather than belatedly reacting to the invariable crises that arise.

Self-determination: Self-determination is a key to a person's happiness and should be available to all people, coupled with the opportunity to experience and practice full citizenship. Supports should seek to enhance the capacity for self-determination and full citizenship through a person-centered and life long focus that drives not only the quantity, but also the quality, of supports that are based in strong values. Professionals and educators should be educated regarding these values and how to thread them through supports provided to individuals from this community.

Empowerment: Supports should empower individuals to gain self-confidence and the ability to speak out and make decisions about their needs and desires, their hopes and dreams. The voice of the individual should be revered in directing a desired future and life goals.

Psychological, Familial and Spiritual Well-being

High quality programs: Mechanisms should exist that assure supports and services provided are of high quality, as defined by the people being supported. Research is needed to identify the magnitude of this population and their needs. Yet the strategies used to gain information should not be invasive and should respect the right of the individual not to participate. Participation must be an informed choice.

Cultural diversity: Key among the principles that should be addressed is to strengthen cultural diversity. While this concept certainly contains aspects of race and ethnicity, it must also embrace tribal issues and sensitivity to gender. Appreciation for the richness that comes from diversity and respect for the traditions within particular cultures are precursors for true inclusion and acceptance—a true community.

Family focus: Just as supports often focus on part of a particular characteristic or need of an individual, so too are individuals supported without consideration of the role they play within their family unit. Particularly in relation to individuals with mild cognitive limitations, issues of family, marriage and parenting are profoundly important. Failure to recognize the impact of the individual on the family or that of the family on the individual results in insensitive supports that can be marginally successful at best. A primary goal must be to strengthen and solidify

Spirituality: There needs to be an increased emphasis on helping the spiritual community recognize and understand the needs of individuals with mild cognitive limitations.

Collaboration

All groups that are working to address a family's needs should work in collaboration so that their needs are supported fully and consistently.

RECOMMENDATIONS:

- ◆ Develop a Collaboration Task Force comprising a major private network of families, self-advocates, advocacy groups, faith-based networks, corporate representatives, culturally diverse groups, tribal governments, Food and Drug Administration, representatives from the National Institute on Health, University Affiliated Programs, and others.

Among the recommended duties of this task force are to rewrite the Developmental Disabilities Act to embrace the principles noted above to facilitate collaboration and cooperation between the public and private sectors, implement the recommendations contained in this Report. This Task Force should work collaboratively to impact federal policy initiatives to support self-determination and

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empowerment, and encourage their respective groups to register to vote and participate in the political process to improve the existing system.

Funding for Self-Advocacy

Federal support is not flexible enough to establish and maintain self-advocacy groups despite the apparent success and relative little expense of these peer support groups.

RECOMMENDATIONS:

- ◆ Create Federal policy initiatives that support self-advocacy groups and activities that enable people to gain in self-knowledge. Self-advocacy groups enable people to learn about their rights and how to speak out for those rights.

Funding should be made available to self-advocates to stabilize existing groups and enable them to continue and expand their present supports and to create and maintain new groups. Representatives from these groups should develop a national agenda and be encouraged and supported in their efforts to fashion a more value-based, respectful and supportive service system.

- ◆ Educate policymakers about the importance of putting money into self-advocacy efforts. Funding should also be forthcoming to support activities that enable people to gain in self-knowledge, explore their heritage and embrace cultural traditions.

Create a series of peer-to-peer teaching videotapes. Support individuals with mild cognitive limitations to talk about the issues on videotapes and share their ideas about how to improve supports, become more empowered, speak out more confidently and other aspects that help to educate their peers and others.

Universally Designed Resources

Generic services should be universally designed and provide accommodations for people who have mild cognitive limitations so that they can make the best use possible of these resources.

RECOMMENDATIONS:

- ◆ Increase the ability of the Temporary Assistance to Needy Families (TANF) program to respond to the

Psychological, Familial and Spiritual Well-being

needs of people with mild cognitive limitations. Those implementing the TANF program should look to the disability community for effective strategies on how to address the needs of individuals with mild cognitive limitations. TANF should also recognize that the families of individuals with mild cognitive impairments have needs beyond those necessary to get and keep a job and address those needs.

Public Education

Neither the public, policymakers nor most human services professionals are aware of the needs people with mild cognitive limitations may have for lifelong supports.

Limited Knowledge of Resources

People with mild cognitive limitations are not aware of the generic or specialized resources that might benefit them.

RECOMMENDATIONS:

- ◆ Create a national institute or clearinghouse. A repository of materials about collaboration and aspects of building supports for people with mild cognitive limitations, their families, and their psychological, familial and spiritual well-being. Existing clearinghouses should be identified and contacted to avoid duplicative efforts.



RECOMMENDATIONS:

- ◆ Sponsor a series of regional conferences to address issues of people with mild cognitive limitations on a broad basis and with the active collaboration of a broad array of partners in the public and private arena. Self-advocates should be leaders in these conferences.

Health & Physical Well-Being



Cathy & David

Cathy lives with her family on the East Coast. She and her husband David are in their 30's and coping fairly well considering their circumstances. Cathy has epilepsy that is, for her, an extremely serious seizure disorder. She has to be on medication continuously. The medication has had a traumatic impact on their lives.

They have four sons from 2 to 10 who are absolutely beautiful. They look perfect with dark hair and eyes. Cathy's physician told her that the medication she took for her seizure disorder is what caused all four of her boys to have severe mental retardation. They are non-verbal (but very vocal) and have pretty extreme behavioral problems. All four are totally mobile and require constant supervision to prevent injury to them.

Cathy's husband David is a very nice man who is patient with the children and devoted to the welfare of the family. He works full time at a blue-collar job and rides the commuter train to work despite the challenges he faces.

Where was the medical community? Cathy did not understand the traumatic effects possible if she had children while on medication. If she was ever told, it was not in terms she could understand. After the first boy was born severely disabled, where was the counseling to help them understand that the medication could have the same devastating effect on their next son and the next and the next? In the most medically sophisticated country in the world, people who live in the "margins" of life, with limited income and mild cognitive limitations often have an added disability—the lack of quality and sensitive medical intervention.



SEVERE
CHILDREN
AND
ADULTS

Walter

For many years, Walter was in an institution for people with mental retardation. It was a period in his life that he never liked talking about it, as there was always an underlying fear that someone might make him go back. Back in those days, very competent people who seemed odd in some way, maybe even just because they looked very different from others, were put in institutions. Today, we have moved beyond that injustice.

Shortly after moving to the community over twenty years ago, Walter met a young man named Alan through a local citizen advocacy volunteer program. Alan had been recruited to be a friend to Walter—to help him succeed in community life. Walter and Alan began to go places together. As they got to know each other, their relationship matured. Alan helped Walter pick out spiffy clothes and find a job at the



local university. Walter taught Alan how to make coffee and what friendship really means. When Walter encountered problems, Alan helped him talk through them, and figure out how to solve them.

With Alan's support, Walter made a place for himself in the world. He became well known in his community, and well liked. He even won an award for becoming a strong self-advocate, successfully taking control of his life. He became a role model for others with disabilities. He also became a valued staff person, proving to be extremely dependable in rain or shine. "Uncle" Walter baby-sat for Alan's children and was a fixture at family holidays and a constant source of comfort in times of strife.

When an aging Walter became ill, Alan made sure that he had good medical care and that he understood what was happening to his health and all about the possible treatments. He went with Walter to the doctor and asked questions Walter didn't think of asking. Walter's final days were filled with the love and comfort of caring friends. At the funeral service, the chapel was filled to capacity with friends and coworkers. Still there are many people that miss Walter's humor and humanity.

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Rosa

Rosa has arthritis and what she calls a "bad digestions disease." She is on a special diet and sometimes gets very sick and has to go in for treatments to relieve the pain or to be able to eat anything again.



Recently, when her Aid to Families with Dependent Children (AFDC) payment was decreased, they lost \$171 a month in income. Then her rent went up. Her food stamps that had gone up to \$87 per month were immediately cut to \$57 due to a \$77 grant she received for her child in place of AFDC. Her Section 8 rent was raised again, \$134 to \$154—no one told her why. She uses the \$77 to buy her daughter food for the month. That leaves \$577.78 for everything else—rent, medical care, phone, electric, school needs, child needs, toiletries and whatever is left after all of her expenses goes to buy her food. Sometimes she gets \$50, sometimes \$30.

In April 1998, Rosa had to for two field trips for her daughter's school. That left no money at all for her food. "I will live on steamed rice and herb tea," Rosa said. She cannot eat the food bought for her daughter or she will become very sick and have to go in for treatments that will take more money, money she doesn't have. "How healthy is this?" she asks.

"We live in America," Rosa says, "Life should not be this way! We did not ask for diseases or injuries. We should not be forced below poverty. We should not be punished and our family punished for our sickness." She describes her situation of not being able to work and not being able to borrow money to live as being caught in a "poverty prison."

Health & Physical Well-Being

HEALTH & WELL-BEING

There are real challenges for people with mild cognitive limitations when it comes to caring for their health and that of their children. One of the first problems is getting health care.

Most Americans obtain their health care coverage through job-related insurance. People with mild cognitive limitations are at a disadvantage because most don't work or their jobs have no health benefits. If they work part-time and their income changes from month to month, they may only qualify for Medicaid part of the time. Supplemental Security Income (SSI) includes Medicaid but is only for those with IQs under 60 or IQs of 60-70 who have other physical or mental disabilities that keep them from working (Campbell, 1999). Many people with mild cognitive limitations will not qualify for SSI. Others qualify because they are on Temporary Assistance to Needy Families (TANF) but these welfare benefits have a time limit.

As an additional problem, states are putting people who receive Medicaid or access it through TANF into managed care. Managed care has strict rules about how to get healthcare and about canceling or missing appointments. The rules and required forms are very difficult for people with mild cognitive limitations to understand (Spitalnik & White-Scott, 1999). Most managed care systems will not know that people have mild cognitive limitations and will not make allowances for their disability.

Mothers with disabilities, particularly cognitive impairments, constitute a growing portion of the TANF caseload. A Kansas study showed 30% of the adult TANF caseload was learning disabled and 26% had IQs at or below 80. People with mild cognitive limitations who receive their access to Medicaid through their TANF status may be more at risk in the movement to managed care because there is no process to identify them, safeguard their rights, and make sure they get the services needed (Spitalnik & White-Scott, 1999).

For those who do get health care, there are additional challenges. Many health care choices require thinking in a way that is very difficult for a person with mild cognitive limitations. One problem is that they often fail to know that a condition needs medical care until it is serious. It is not unusual for people with mild cognitive limitations to use emergency rooms for their medical care. These individuals have difficulty understanding the benefits and risks of medical treatment and what will happen if they do not follow the doctor's advice. Not understanding how what they do affects their health puts them at high risk for things like sexually transmitted diseases, unplanned pregnancies, cigarette smoking, physical and sexual abuse (especially for women), and alcohol and substance abuse. Like other poor people they are at health risk because of poor nutrition and eating habits (Spitalnik & White-Scott, 1999).

Health & Physical Well-Being

These individuals have difficulty understanding the benefits and risks of medical treatment and what will happen if they do not follow the doctor's advice. Not understanding how what they do affects their health puts them at high risk for things like sexually transmitted diseases, unplanned pregnancies, cigarette smoking, physical and sexual abuse (especially for women), and alcohol and substance abuse.

Taking care of your health means being able to communicate well with your doctor, understand instructions about medications, and be able to understand how much medicine to take and when to take it. Poor education and lack of independent living skills may prevent people with mild cognitive limitations from being able to do all these things for themselves or their children (Spitalnik & White-Scott, 1999).

When they are getting treatment, people with mild cognitive limitations are less likely to admit when they have not followed the doctor's instructions. This can be because they did not understand the instructions or did not understand the relationship between their symptoms and the treatment. They may say their health

is better or the same when it is really worse because they think that is what the doctor or nurse wants them to say (Spitalnik & White-Scott, 1999).

It is doubtful that doctors will realize that they are not getting accurate information from patients with mild cognitive limitations or that the patient even has a disability. No formal curriculum exists for training physicians in the care of people with mild cognitive limitations except in pediatrics. Some pediatricians try to continue to serve their patients once they are adults but pediatricians are not trained to recognize adult diseases. If hospitalized, adults with mild cognitive limitations often have difficulty getting the care they need- because they lack some of the communication skills necessary on an adult hospital unit (Spitalnik & White-Scott, 1999).

People with mild cognitive limitations get left out of national efforts to improve people's health. Healthy People 2010 (HP2010) is a process to help Americans live longer, healthier lives. A major shortcoming of HP2010 is that there is no way to identify people with mild cognitive limitations. Part of the process for HP2010 is the Behavioral Risk Factor Surveillance System (BRFSS) which is a telephone survey of adults used to get information about their health. People with mild cognitive limitations have difficulty answering phone surveys and will not willingly admit their disability. Mild cognitive limitations are usually identified during school years but the BRFSS does not include children (Campbell, 1999).

Traditional public health entities have seen mild cognitive limitations as a condition to be prevented and paid little atten-

Health & Physical Well-Being

tion to the health care of people with the condition (Campbell, 1999). People with mild cognitive limitations are not easily identified by the health care system and are a medically disadvantaged population (Spitalnik & White-Scott, 1999) but diagnosing their disability may cause stigma and labeling that could be worse than the cognitive limitation (Kane, Avila, & Rogers, 1999).

It is clear that people with mild cognitive limitations face tremendous challenges when it comes to health care. Children are usually identified as having mild cognitive limitations during the third to sixth grades when schoolwork gets harder and they begin to lag behind. Most people with mild cognitive limitations, once they leave school, disappear into the general population. However, the problems that became apparent during school do not disappear in adulthood but remain problems even if people are not in the service system (Campbell, 1999). People at especially high risk for disease, injury, and disability often lack the resources to cope with their problems (Kane, Avila, & Rogers, 1999). Health care providers are usually unaware of the disability and the problems it may cause for adults struggling with their own health care and that of their children.

A better approach to solving the problems of adults with mild cognitive limitations is to develop public health policy and programs that support all adults. This would ensure that adults with mild cognitive limitations, whether we identify them or not, would get the services and supports they need (Kane, Avila, & Rogers, 1999).

Resources

Campbell, Vincent A. (1999). The Healthy People 2010 Process and People with Mild Mental Retardation: Difficulties Related to Surveillance and Data Collection in *The Forgotten Generation: The Status and Challenges of Adults with Mild Cognitive Disabilities in America*. To be published.

Kane, Ph.D., William M., Avila, Ph.D., Magdalena, and Rogers, Ph.D., Everett M. (1999). Community and Culture: World Views and Natural Affiliations as the Basics of Understanding, Trust, Assistance and Support in *The Forgotten Generation: The Status and Challenges of Adults with Mild Cognitive Disabilities in America*. To be published.

Spitalnik, Ph.D., Deborah M. and White-Scott, M.D., Sheryl. (1999). Access to Health Services: Improving the Availability of Health Services for People with Mild Cognitive Limitations in *The Forgotten Generation: The Status and Challenges of Adults with Mild Cognitive Disabilities in America*. To be published.

Resource for Rosa's Story

Hoffman, Caroline & Fisher, Amy. (1998). *Families in Poverty: Parents with Disabilities and their Children*. Madison: Wisconsin Council on Developmental Disabilities.

Recommendations in Health & Physical Well-Being

Sensitivity Issues

Cut Across Health Services

Health care professionals are focused on health needs and often lapse in attending to the whole person, in being sensitive to the broader humanity of the people they treat.

RECOMMENDATIONS:

- ◆ Train and encourage health care professionals to be sensitive to issues of race, ethnicity, diversity and culture, as they are relevant throughout the health care arena.
- ◆ Educate health care professionals about the concept of self-determination and of how to help people—including those with mild cognitive limitations to make truly informed health care decisions.
- ◆ Encourage those in the health care industry to have a holistic approach to health care, with sensitivity to the role that a person's overall quality of life plays in their health and physical wellbeing.

Socialization

Adults with mild cognitive limitations often need supports that offer socialization opportunities and that, in turn, improve their health and well-being.

RECOMMENDATIONS:

- ◆ Urge policymakers, legislators and insurance providers to collaborate to provide resources to support alternative funding for social supports for people with mild cognitive limitations.
- ◆ Develop and implement curricula to train providers to address comprehensive psychological factors including sexuality and developmental life span issues of individuals with mild cognitive limitations.
- ◆ Assure that services provided in community based settings supports quality of life. Such services should assure the participation of consumers/ providers in identifying socialization activities that are developmentally focused, and age and gender appropriate.

Health & Physical Well-Being

Surveillance

Numerous factors make it difficult to survey and study the health care needs of people with mild cognitive limitations.

may include special education, public health (birth and death records) Medicaid, vocational rehabilitation, mental health, mental retardation. Critical issues include protection of individual identity, the disinterest of needed participants, and varying diagnostic practices. Consumer involvement is critical to guide the process and govern the use of data.

RECOMMENDATIONS:



- ◆ Assure the federal government develops sampling strategies, questions and survey vehicles in studies of health service access and quality that include adults and children with mild cognitive limitations. Such efforts should be achieved through an interagency effort involving the Department of Health and Human Services, the Social Security Administration, and the Department of Education, collaborating with advocates, consumers and organizations of professionals.
- ◆ Develop state-based individual-related surveillance through the linkage of agency databases.
- ◆ Establish within states interagency committees that include advocates and consumers, to explore the feasibility of linking databases that can address risk factors, identify prevalence, service use, outcomes, secondary conditions, etc. Participants

Final Session



The Final Session



The Summit closed with a plenary session in which representatives of the Work Groups summarized their recommendations for the areas that they addressed. Then several speakers shared their thoughts regarding The Forgotten Generation.

Bob Williams

Bob Williams, Deputy Assistant Secretary for Long Term Care and Disability, began his remarks at the closing plenary by thanking PCMR for having the insight and foresight to convene this Summit to examine issues surrounding people with mild cognitive limitations. "Historically, PCMR has played its most valuable role in helping to inform and shape public policy and other key practices, when it has shed light on the major challenges facing their constituents, and then, proposed strategies to address these challenges in a way that betters, and strengthens, our nation as a whole." Williams indicated that this Summit follows that rich tradition.

When the term mild disability began to surface first in the disability field and later

in public policy, it was used with the best of intentions, Williams noted. However, "the notion of mild disabilities, h t

cognitive or otherwise, tends to be so simplistic, and very much one-dimensional." Some people with mild disabilities may be able to lead a healthy, wholesome, satisfying life-style if they have the supports that they need. For others, difficult life circumstances, such as poverty, compound the limitations and complex supports may be needed just to survive.

"Let me suggest that we could benefit from taking a similar more holistic, ecological approach to disability more generally. We need to continue to look at the level of an individual's disability as one important indicator of the likely support needs he or she probably has. But, we also need to look upon disability as one of many characteristics — like income, family stability, education and work history, as well as race and gender — the interactions of which, taken together, help provide a more in-depth understanding of the person and their support needs."

Williams cautioned the audience to remember that individuals with so called mild cognitive disabilities, represent the majority of those for whom

advocacy organizations like
PCMR, The Arc and AAMR
were

PCMR Report

first formed. A refocus of attention to this group is long overdue. Self-advocates have a wealth of information to share and can teach the rest of us much about this population. In closing, Williams noted that participants should include a focus on assistive technology and increasing the universality of information and information technology.

John Monahan

John M. Monahan, Deputy
Assistant Director,
Administration of Children &
Families, Department of
Health
& Human Services, con-
gratulated participants for their
hard work during the conference
and underscored the importance
of a focus on people with mild
cognitive limitations, people
whose lives have often been
challenged with limited support.

Monahan spoke of the
critical efforts that were being
made to

address this population through Temporary Assistance to Need Families (TANF) and Headstart. Through the TANF program, creative efforts are being made to help people get and stay employed. Supports such as childcare and extended health care benefits are being provided to people in an effort to ease the burden that people often face as they move from welfare rolls into self-sufficiency.

Headstart programs have been greatly expanded. These programs are vital to give children the best start possible in life. They are particularly wonderful resources for families in which parents have mild cognitive limitations as they focus on providing children the stimulation and challenge they need in those early years and can help to spot problems the child might have, such as illness or developmental delays. Headstart programs are also working to prepare the children of today, including those with mild cognitive limitations, to lead healthy, successful lives as the adults of tomorrow.

fect the lives of people with mild cognitive limitations. She applauded the hard work that participants had invested into developing a wide range of powerful recommendations.

Bradley reminded the group that these recommendations would be incorporated into a Report to the President and the collection of papers would be published in a book entitled *The Forgotten Generation: The Status and Challenges of Adults with Mild Cognitive Limitations in America*. A listing of these papers appears on the following page.

Bradley closed the conference by challenging participants to keep the focus on people with mild cognitive limitations alive so that these individuals who are now so prominent in our minds will never be forgotten again.



Valerie Bradley
PCMR Chair

After the groups had reported their outcomes, PCMR Chair Valerie Bradley extended her gratitude to the presenters at the Summit for their inspiring remarks and challenging charges and the authors of the background papers for their efforts to identify the issues that af-

The Forgotten Generation: The Status and Challenges of Adults with Mild Cognitive Impairments in American Society will include the following papers:

Bogdan, Ph.D., Robert and Taylor, Ph.D., Stephen J. **Building Stronger Communities for All: Thoughts about Community Participation for People with Developmental Disabilities.**

Bradley, Valerie J., Agosta, John M. & Kimmich, Madeliene. **Social and Community Participation: How to Enhance Supports to People with Mild Cognitive Disabilities.**

Campbell, Vincent A. **The Healthy People 2010 Process and People with Mild Mental Retardation: Difficulties Related to Surveillance and Data Collection.**

Dinerstein J.D., Robert. **How People with Cognitive Disabilities and their Allies Are Coming Together to Protect their Civil Rights.**

Edgerton, Ph.D., Robert B. **"The Hidden Majority" of Persons with Mental Retardation/Developmental Disabilities.**

Galbraith, Suellen. **A Home of One's Own: What Housing and Social Services Agencies Can Do To Afford People the Dignity and Support for Personal Housing.**

Gaventa, William and Peters, D. Min., Roger K. **Spirituality and Self-Actualization: Recognizing Spiritual Needs and Strengths of Persons with Cognitive Limitations.**

Gettings, Robert. **Renegotiating the Social Contract: Rights, Responsibilities and Risks for Persons with Cognitive Limitations in an Era of Less Government.**

Kane, Ph.D., William, Rogers, Ph.D., Everett M. and Avila, Ph.D., Magdalena. **Community and Culture: World Views and Natural Affiliations as the Basics of Understanding, Trust, Assistance and Support.**

Kregel, Ed.D., John. **Freedom to Work: What Government and Employers Can Do to Assure Income and Health Security while Providing Opportunities and Rewards for Employment.**

Luckasson, Ruth, J.D. **The Criminal Justice System and People with Mild Cognitive Limitations.**

Reiss, Steven. **The Value-Based Happiness and Mental Health of Persons with Mental Retardation.**

Rogan, Ph.D., Pat, Leucking, Richard and Held, Mary, M.S. **Career Development: What Schools, Agencies and Employers Can Do to Help People Identify, Select, Prepare For and Continue to Grow in Careers That Offer a Future.**

Silverstein, J.D., Robert. **Our Nation's Emerging Disability Policy.**

Spitalnik, Ph.D., Deborah M. and White-Scott, M.D., Sheryl. **Access to Health Services: Improving the Availability of Health Services for People with Mild Cognitive Limitations.**

Tymchuk, Ph.D., Alexander J. **Family Life: Experiences and Outcomes of People with Mild Cognitive Impairment.**

Tymchuk, Ph.D., Alexander J, Lakin, Ph.D., K. Charlie, and Luckasson, J.D., Ruth. **Life at the Margins: Intellectual, Demographic, Economic, and Social Circumstances of Adults with Mild Cognitive Limitations in an Increasingly Complex Society.**

Wehman, Ph.D., Paul, Targett, Pam, Eltzeroth, Helen, Green, Howard, Brooke, Valerie, and Barcus, J. Michael. **Support on the Job: What Business, Industry and Government are Doing to Support People with Mild Cognitive Limitations to Achieve Economic Self-Sufficiency Through Employment.**

PCMR Summit Participants

Lorenzo H. Aguilar-Melancon

Magdalena Avila

Carol Beatty

Robert Bogdan

Valerie Bradley

Marie Bristol-Power

Ruth Brousseau Deb

Brown Jessica Butler

Tina Campanella

Vincent Campbell

Kathleen Courtney

Allen Crocker

Virginia Cruz

Curtis Decker

Rene Denfeld

Sheryl Dicker

Robert Dinerstein

Karen Ito Edgerton

Robert Edgerton

Robyn Edwards

Ann M. Forts

Billie Friedland

Suellen Galbraith

William Gaventa

Robert Gettings

Tawara D. Goode

Judith Gran

Victor Hall

Emma Hambright

Paula Hirt

Joe Hollowell

Karen Irick

George Jessien

Sally Jochum

Bill Kane

Ruth Katz

Fred Krause

John Kregel

Charlie Lakin

Sandra Lawson

Ruth Luckasson

Howard Mandeville

Paul Marchand

John Mattingly

Angela McCants

John McClain

Kathleen McGinley

James Meadours

T.J. Monroe

Carolyn Morgan

Barbara Murdock

Donna Nigh

Catherine Nolan

Roger Peters

Elizabeth Pittinger

Dennis Poole

Roseanne Rafferty

Carol Rasco

Don Regan

Steven Reiss

Victor Robinson

Everett Rogers

Robert Silverstein

Rosalyn Simon

Senora D. Simpson

Tom E.C. Smith

Deborah M. Spitalnik

Nancy Sullivan Pam

Targett

Cathy Ficker Terrill

Nancy Thaler Eugene

Thompson Alexander

Sandy Tymchuk Jacquelyn

B. Victorian Shirley Wade

Nancy Ward

Michael Wehmeyer

Barbara Wheeler

Sheryl White-Scott

Kenton Williams

Elise Young

CLOSING THOUGHTS



Closing Thoughts

How incredibly frustrating it must be to, have a difficult time communicating to find it hard to understand, to be daunted by the puzzles that modern life brings, and to look for help only to find closed doors or closed minds. For people with cognitive limitations, the world is often a confusing, frightening and lonely place.

How incredibly frustrating it must be to have a difficult time communicating, to find it hard to understand, to be daunted by the puzzles that modern life brings, and to look for help only to find closed doors — or closed minds. For people with cognitive limitations, the world is often a confusing, frightening and lonely place.

Despite the incredible mountains of money that go into services of every kind, people with mild cognitive limitations are often excluded from the very services they need to

survive, much less to thrive. They are not "disabled" enough for disability services; generic services do not accommodate for the unique learning needs of this population. They are truly the Forgotten Generation.

Throughout the pages of this Report, the problems faced by individuals with mild cognitive limitations have been highlighted in snapshots of people's lives and prose about their challenges. If they are employed, people with mild cognitive limitations are likely to work in minimum wage jobs, only once in awhile or for only a few hours a week; they are the last hired and the first fired. Often they are not able to find and keep jobs because what others infer, they may need to be taught.

People with mild cognitive limitations generally live in poverty. Most are not eligible for disability benefits. Even if they can get Supplemental Security Income (SSI) or Social Security Disability Income (SSDI) their incomes fall well below federal poverty guidelines. Low-income prevents people from being able to find safe and adequate housing; they abound in our homeless shelters. Community life presents its own challenges with people facing expectations that they may not be able to meet in devel-



oping relationships, finding their way around, understanding rules, handling money, being safe, finding help — the list seems endless.

Sometimes people with mild cognitive limitations come in contact with the criminal justice system, a system that is not able to deal adequately with their needs. Unequipped with the necessary knowledge or training, the system fails to assure protection of rights and equal justice. In civil rights, people with mild cognitive limitations fare no better. Often stereotypes and misguided efforts to protect lead to the loss of rights, choice making, and children —even freedom. The stress-filled world of this population often results in mental health concerns and difficulty finding personal fulfillment and happiness. Health issues are equally sad:

preventive efforts are rare and when people do get health services they often cannot understand the doctor's instructions. Among the general medical community, there is little understanding of the need to make instructions simpler, to follow-up with people to assure they understand, to get viable information regarding injury and illness or to empower people to be more responsible in their personal care.

When seen as a whole, these challenges are awesome. It is hard to believe that in a society in which information zooms past us in papers, on TV, and over the Internet, this large group of Americans has remained hidden for so many years. They are hidden no longer.

Also within these pages are recommendations in every area of life, recommendations that can bring us closer to the inclusive, supportive society this great country should nurture. These prescriptions have major themes threaded throughout that are worthy of mention.

Universal Design

- ◆ All services should adopt policies, procedures and practices that welcome and are accessible to all people, including those with physical or cognitive limitations. Accommodations for people with mild cognitive limitations, such as putting forms, questionnaires and other documents into "real"

that is easily understood by all and providing verbal counseling in simple and repetitious terms, take sensitivity and a little extra time, not great expense. Universal design demands that all professionals be provided the information and training they need not only to understand the needs of this population but also to respond with sensitivity, compassion, and effective accommodations.



Prevention

- ◆ Certainly prevention should be a powerful focus in health care, but it is also the only way to address the many problems facing individuals with mild cognitive limitations. Appropriate supports can work to prevent unemployment, poverty, homelessness, mental health problems, incarceration, and needless illness if they are readily available and responsive to the needs of this population.

Empowerment

- ◆ Throughout the recommendations are thoughts of empowering people with mild cognitive limitations to become better advocates for themselves in all areas of life. To do that, information, training and supports are needed that enable people:

- To learn
- To make choices
- To understand and protect their rights
- To develop relationships
- To find and keep jobs
- To find help that is needed
- To understand their health care needs
- To take control of their lives

Universal Design, Prevention, Empowerment and Support. Woven together these threads can combine to create a strong, enriching environment in which people with mild cognitive limitations can do more than merely survive, they can thrive.

Empowerment also means the use of technology that can enable people to better communicate, understand, work, live independently and so much more.

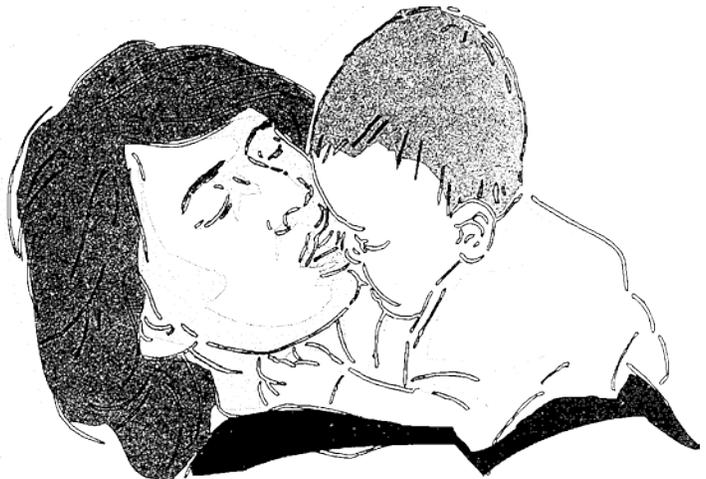
The only hope is action — meaningful, powerful action — that translates these recommendations into realities. Strong and compassionate leadership can make all the difference.

The only hope is action — meaningful, powerful action — that translates these recommendations into realities. Strong and compassionate leadership can make all the difference.

Support

- ◆ People need supports that are responsive to their needs. Sometimes this means generic supports that are available to everyone regardless of disability; at other times it means the need for specialized support such as those provided through disability organizations. Generic and specialized supports are needed in every area from helping people to learn parenting skills to assisting people to negotiate public transportation to assuring people find the health care they need.

The information contained in this report has for far too long lain silent and ignored — lost amid the thousands of other human needs and challenges. Now that it is starkly before us, the question becomes how will we respond. Will this report go the way of so many others before it—destined to be read by a few and shelved by many? If so, a generation of people who have lived forgotten lives will die forgotten deaths. And another generation of children whose lives have just begun will be relegated to the same lonely path.



President's Committee on Mental Retardation



President's Committee on Mental Retardation

Valerie J. Bradley, Chair

President
Human Services Research Institute
Cambridge, Massachusetts

Deborah M. Spitalnik, Ph.D., Vice Chair

Executive Director
University Affiliated Programs of New Jersey
Piscataway, New Jersey

Lorenzo Aguilar-Melancon

Parent Advocate
El Paso, Texas

Jacquelyn Blaney, MSW

Executive Director
Independent Living, Inc.
Baton Rouge, Louisiana

Robert D. Dinerstein, J.D. Associate Dean
for Academic Affairs Washington College of
Law, American University Bethesda, Maryland

Ann M. Forts

Motivational Speaker
Center Harbor, New Hampshire

Sally Jochum

Community Living Coordinator,
Johnson County Developmental Supports
Lenexa, Kansas

Joyce A. Keller

Executive Director of JARC
Southfield, Michigan

John F. Kennedy, J.D.*

President
Reaching Up, Inc.
New York City

K. Charlie Lakin, Ph.D.

Director, Rehabilitation Research and Training
Center on Community Living and Integration
University of Minnesota
Minneapolis, Minnesota

Ruth Luckasson, J.D.

Regents Professor and Professor of Special
Education
College of Education
University of New Mexico
Albuquerque, New Mexico

T. J. Monroe

Disability Rights Consultant
Cincinnati, Ohio

Donna Nigh

Former First Lady of Oklahoma
President, Nigh Foundation

Elizabeth C. Pittinger

Executive Director
Citizen Police Review Board
Pittsburgh, Pennsylvania

Michael L. Remus

Executive Director
The Arc of Tennessee
Nashville, Tennessee

Tom E.C. Smith, Ed.D.

Professor and Associate Dean
College of Education
University of Arkansas at Little Rock
Little Rock, Arkansas

Cathy Ficker Terrill

President Elect, American Association of Mental
Retardation (AAMR)
Vice President, Brain Injury Association
Elmhurst, Illinois

* Mr. Kennedy is now deceased.

Barbara Yoshioka Wheeler, Ph.D.

Associate Professor of Clinical Pediatrics
University Affiliated Program
Children's Hospital of Los Angeles
Los Angeles, California

Sheryl White Scott, M.D.

Director
Adult Health Services
Westchester Institute for Human Development
New York City

Ex-Officio Members

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Chair
Equal Employment Opportunity Commission

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Chair
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Commissioner of Social Security
Social Security Administration

PCMR Staff

Jane Browning*

Executive Director

John L. Pride

Deputy Executive Director

Laverdia T. Roach*

Special Assistant to the Executive Director

George H. Bouthilet, Ph.D.* Research
Director

Parthenia Dinora Special

Projects Assistant

Thelma B. Lucas

Mental Retardation Program Specialist

Joan Williams

Special Projects Specialist

Bena Smith*

Program Analyst

Sheila Whittaker*

Administrative Officer

Peggy Butler*

Secretary to the Executive Director

Angie Green

Secretary to the Deputy Executive Director

Terry Lion

Clerk Typist

Dina Bergman

Clerk-Typist

*current staff



The mission of the President's Committee on

Mental Retardation (PCMR) is to act in an advisory capacity to the President and to the Secretary of Health and Human Services on matters relating to policy and programs affecting services and supports for people with mental retardation.

PCMR Report

Real outcomes for real people. This is the ultimate goal of lifelong inclusion. This is the challenge to the field of mental retardation into the next millennium.