

President's Committee on Mental Retardation

Collaborating for Inclusion

1995 Report to the President

U.S. Department of Health and Human Services
Administration for Children and Families

President's Committee on Mental Retardation



Collaborating For Inclusion: 1995



PRESIDENT'S COMMITTEE ON MENTAL RETARDATION
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Administration for Children and Families
Washington, D.C. 20201-0000

June 12, 1996
The President The White House
Washington, D.C. 20500

Dear Mr. President:

On behalf of the Self-Advocates, family members, service providers, professionals and advocates who comprise the President's Committee on Mental Retardation (PCMR), I am pleased to share with you the Committee's 1995 Report to the President, Collaborating for Inclusion.

The Report is a product of cooperation between Federal, State and local officials who have joined together, through the Committee's National Collaborative Academy on Mental Retardation, to support State and local efforts that strengthen our nation's commitment to assure that all Americans have productive and meaningful lives.

The Report articulates the Committee's pride in the tremendous steps that have been taken to include citizens with mental retardation in community life, and also shares a vision for Federal, State and local leaders who wish to work effectively together to promote coherent policies that will support such independence.

The Committee is proud to share the dreams and aspirations of Self-Advocates and family members as eloquently articulated by the PCMR member and Self-Advocate, Ann Forts, who spoke at the National Collaborative Academy on Mental Retardation, and urged State and Federal Policymakers to understand that she and other Self-Advocates "want to see all of the doors opened and want ... the chance to enjoy all of the opportunities that everyone else has the chance to enjoy."

The President's Committee on Mental Retardation is proud to offer this Report for your consideration.

Sincerely,

A handwritten signature in black ink that reads "Valerie Bradley". The signature is written in a cursive style with a long, sweeping tail that extends to the right.

Valerie Bradley
Chair

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Acknowledgments

The President's Committee on Mental Retardation (PCMR) is pleased to share its 1995 Report to the President: Collaborating for Inclusion. The Report represents a concentrated and strategic effort by PCMR to engage Collaborative State Teams to design plans for supporting and promoting the inclusion of citizens with mental retardation in community life. State Teams, including State policymakers such as State legislators, budget officers, and State agency mental retardation/developmental disability personnel, joined with self-advocates, family members, service providers, direct support workers, and educators to design State plans that could maximize each individual's contribution in achieving inclusion in each State and local community.

PCMR would like to extend the Committee's appreciation to Sharon Davis, Ph.D., of the Arc-U.S., for her creativity and diligence in pulling together the recommendations and observations of the participants in the 1995 National Collaborative Academy on Mental Retardation, which constitute the background and basis of the Committee's Report to the President. As well, the Committee is deeply appreciative of the efforts of Tecla Jaskulski for her extraordinary editing and poetic ability to express the concerns and dreams of the Self-Advocates, Family Members, State Policymakers, and PCMR Committee Members who offer this 1995 Report to the President.

The Committee would also like to express its appreciation to the Administration for Children and Families (ACF), Mary Jo Bane, Assistant Secretary and Ann Rosewater, Deputy Assistant Secretary, for their leadership and support of the Committee's initiatives.

Gary Blumenthal
Executive Director

Preface

The President's Committee on Mental Retardation strongly supports the inclusion of individuals with mental retardation in all aspects of community life. To further the prospects of inclusion, in September 1995 the President's Committee sponsored the first in a series of National Collaborative Academies on Mental Retardation, designed to provide information regarding community inclusion to State Teams. State legislators, budget directors, business community leaders, key staff members from each State's Governor's office, family members, and self advocates (people with mental retardation) joined mental retardation service providers and State mental retardation/developmental disabilities agency personnel to form State Teams for this very important meeting. Delegations from Illinois, Louisiana, Maryland, Missouri, North Carolina, North Dakota, and Washington participated and began developing State Collaborative Plans to increase opportunities for including children and adults with mental retardation in everyday life.

The President's Committee on Mental Retardation recognizes that the impetus for change must come from the community and State level. Plans developed by State Teams will need to be refined, implemented, and adjusted many times, as States initiate change and respond to policy reform efforts at the Federal level and requests for innovation from consumers, families, and providers in the State. It is critical that the plans continue to evolve as they are implemented to ensure their maximum success.

During the Academy, the State Teams participated in numerous learning experiences. They heard many examples of how people with mental retardation have become valued members of their communities. Some of the most wonderful examples were given by individuals with mental retardation whose lives have been transformed by changes in how they receive services and supports. Hearing individuals with mental retardation talk about how important it is to be in charge of their own lives and to be included in their communities helped all Academy participants to have a better understanding of the importance of promoting community inclusion and person-centered support systems. State delegations left the Academy with an improved sense of the contributions that can be made by people with mental retardation in the community.

State Teams also heard that promoting self-determination and life-long community inclusion and participation requires new ways of thinking about services for people with mental retardation. No longer is it appropriate to talk about clients receiving services determined solely by mental retardation professionals. Rather, supports must allow people to choose what they want and need rather than what the service system wants to provide them. Supports must be designed for each person based on individual need, and must not require people to leave home or family in order to accept services that are offered. This shift to person-centered supports and inclusion will require changes in Federal and State policies, as well as changes in the way agencies provide services and funds. Although these changes have already begun, there is still much work to be done.

Focusing on support to the journey to inclusion, this Report to the President summarizes the principles emerging from the Academy's deliberations, provides guidelines developed by State Teams to enhance collaborative promotion of inclusion, and presents positions of the President's Committee on Mental Retardation regarding the relevant public policy issues under debate in the current era of reform.

**REPORT TO THE PRESIDENT Challenges to
States: Federal Reform and Community Inclusion of
Citizens with Mental Retardation**

The President's Committee on Mental Retardation

Self-advocates have a simple message for all who will listen: to be included in their communities, and not to be known by the label of mental retardation. Speaking to participants at the National Collaborative Academy in September 1995, self-advocates Ann Forts and James Meadours made the following points:

"I want all of the doors to be opened and I want the chance to enjoy all of the opportunities that everyone else has the chance to enjoy."

Ann M. Forts, PCMR member,
Center Harbor,
New Hampshire

"My dream is to see equal rights for people with mental retardation and other disabilities move from a vision to reality. It is beneficial for everyone to help each other out. We are the best people to help you out - listen to us."

James Meadours, VISTA Volunteer,
Oklahoma People First,
Tulsa, Oklahoma.

We must recognize that those living with mental retardation have much to offer our society and that our strength as a nation depends upon the contributions of all our people. (Bill Clinton, Letter to Academy Participants, September 6, 1995.)

The President's Committee chose inclusion as the theme for the National Collaborative Academy because of its critical importance to people with mental retardation and their families. Academy participants heard from several self-advocates and family members on successes in experiencing inclusion, as well as barriers encountered on the journey to inclusion. The Academy produced principles and guidelines for reconfiguring systems to better support inclusion of people with mental retardation and related disabilities. These were taken back home by the collaborating State Teams, along with specific strategies to help their States get started on making inclusion a reality.

The Academy took place in a climate of intense debate on Federal laws and policies that have an impact on people with mental retardation and their families. Regardless of the final outcomes, it is clear that longstanding assumptions about the role of States in administering Federal programs are changing. Services and supports that promote community participation for people with mental retardation are among those slated for reform. In some cases, laws defining rights and protections important to individuals with mental retardation are being questioned.

The President's Committee on Mental Retardation views these challenges as an opportunity to reexamine how this nation offers services and supports to people with mental retardation: What do people really need and want? How can States best design their service systems to meet these needs efficiently and effectively? How can local communities create supports and enhance inclusion of people with mental retardation?

We present this report to summarize the guidance brought forth at the Academy. We hope that it will provide further support and stimulation to all who care about people with mental retardation as we address the challenges before us.

I. Where We've Been

One Man's Walk Through the Modern History of Residential Services

When I lived at Lake Owasso State institution in Minnesota, you had to ask for everything: "Can you let me out?" "Can I have a can of pop?" "Can I stay up a little bit longer?"

When I moved into a group home, I had to follow all of the rules. I had to go to bed at a certain time, and when I was in bed, I had to be asleep; that was that. I lived with two other guys. We were being watched all the time, 24 hours a day, seven days a week.

Two years ago I got married. My wife and I moved into our own apartment. Now that I have my own place, I make the decisions. I have my own keys. I can let myself out, and let myself back in.

Now I can come and go when I want. I can make my own food, and I decide whether I want to have breakfast or lunch, or when I'm ready for a snack. We can invite friends to stay over. My wife and I decide when the staff comes over. They help us with some things, but we make our own decisions.

Kevin Otley

This excerpt from *The Journey to Inclusion, a Resource Guide for State Policymakers*, developed by the President's Committee and presented to Academy participants to assist their collaborative efforts in promoting inclusion, summarizes the evolution in residential services for people with mental retardation. Various presenters at the Academy reminded participants about changes in values and philosophy that are reflected in how services and supports have been provided to people with mental retardation.

The President's Committee on Mental Retardation was founded in 1966, at the height of the institutional era in providing services to people with mental retardation. Throughout the first two-thirds of the twentieth century, large State mental retardation institutions grew in population, reaching a peak of nearly 200,000 in 1967. The State facilities were often the only resource to families seeking services for their family member with mental retardation. Although many people with mental retardation were never institutionalized, segregation and exclusion from activities outside the immediate family circle were commonplace.

The era of institutional reform began in the mid-1960s, as attention to inhumane conditions in institutions led to demands for improvements. Litigation rulings, such as the landmark *Wyatt v. Stickney* and *Pennhurst* cases, forced institutions to improve conditions. Family members joined with advocacy organizations and policymakers at the Federal level to support national standards for institutional services funded through the Medicaid program. Regulations for Intermediate Care Facilities for persons with Mental Retardation and Related Conditions (ICF/MR) facilities began covering services in State institutions in the early 1970s. Although custodial and medical models prevailed, the initial ICF/MR standards were significant in improving staffing patterns, environmental conditions, and basic rights.

During the 1970s, there was increased understanding that people with mental retardation—including those whose limitations are more severe—can learn, can adapt, and can grow and change. Developmental approaches based on learning theory replaced custodial care in the institutions, and new Federal regulations required State institutions and other facilities certified under the ICF/MR program to provide basic and specialized services designed to increase each person's abilities and skill levels.

This also became the era of deinstitutionalization, as most States and communities developed services for people with mental retardation who were able to leave the State institutions or who had never been placed there. Public Law 94-142 was enacted in 1975, establishing the right to a free and appropriate public education for children with mental retardation and other disabilities.

"Adult activities" for people with mental retardation expanded to include a variety of vocational options as well as continuing to provide day activity programs for those with more severe disabilities. Public expenditures for mental retardation/developmental disabilities rose from \$3.457 billion in 1977 to \$11.733 billion in 1988, of which nearly 48 percent was devoted to community-based services.

Despite the significant increase in community living arrangements and related services, however, many people with mental retardation were still largely segregated from their fellow community members. During the late 1980s, people with mental retardation, family members, advocates, and some service providers began to question the lack of community membership and participation even among individuals who were living in the community. New approaches to community living and to supporting individuals in relation to their unique goals, strengths, and challenges emerged. States and individual provider agencies began experimenting with techniques such as circles of support, person-centered planning, and supported living.

Twenty-eight States competed for eight slots in the Medicaid Community Supported Living Arrangements program in 1990, while the population of State mental retardation institutions fell to 84,732 and the number of people served through the Medicaid Home and Community Based Services waiver rose to 45,203.

By 1992, public expenditures for community-based services nationally had surpassed those supporting care in large facilities. Although ratios varied greatly among the States, all States had increased the portion of expenditures devoted to community services compared to 1988. Forty-seven States were serving a total of 63,206 individuals through Medicaid Home and Community-Based Services waivers designated to expand services in the community for people with mental retardation/developmental disabilities. And self-advocates were increasingly vocal as they challenged all of us to accord them respect as individuals as well as community membership.

As we reach the mid-1990s, there is considerable evidence of progress toward the inclusion of people with mental retardation.

II. Where We Are

As we reach the mid-1990s, there is considerable evidence of progress toward the inclusion of people with mental retardation. Although community presence cannot be equated with community membership and inclusion, it is significant that:

- Only 62,028 people with mental retardation and related disabilities were housed in State institutions as of June 1995, compared to the peak institutional population of 194,650 in 1967.
- About 4,000 children were living in State institutions in June 1994, down from 91,600 in 1965.
- Over half of the 314,503 people with mental retardation/developmental disabilities receiving State-licensed or operated residential services in 1995 were in community living arrangements for six or fewer people.
- The average size of residential service settings had dropped from 22.5 in 1977 to 3.8 in 1995.

In many communities, children with mental retardation are being included in their neighborhood schools. Academy participants heard from Cathy Ficker Terrill, PCMR member from Elmhurst, Illinois, about her successful struggle to have her daughter Beth attend a regular classroom in her neighborhood school. Beth, now ten years old, has multiple health problems along with mental retardation and cerebral palsy. The local school system had never included a child with disabilities like Beth's in a regular classroom. Cathy and her husband had to educate school staff about inclusion and guide the planning for Beth's Individual Education Program, but their advocacy paid off.

As Cathy reported, "Beth is now going to her home school. She is fully included. She has the necessary supports. The professionals have been trained. This year, both she and her aide have been promoted to third grade."

Many adults with mental retardation are working in the community, employed competitively with and without ongoing supports. The Academy heard from Mary Lynn Gladding, a certified child care worker with mental retardation, on her happiness with her job at the Before and After School Program run by the Howard County, Maryland, Department of Parks and Recreation:

What I mostly do for my job is /just set up, I get snacks ready, and I work with the children. And it's not easy. Some of these kids are very challenging, especially in the fifth grade. But really, I love what I do, and it's been three years, almost four.

I get along with the children very well. They know I'm different, but they accept me for what I am. They ask me questions, I ask them questions, and I think we become a tighter knit family with the children, employers and the coworkers.

This is the best job I ever had, working with children. Even when I'm 65 years old, I'm going to retire happy by working with children, because really, what are children if they don't have a positive role model to stand up for them?

Some adults with mental retardation now have the opportunity to own their own homes or hold their own rental agreements, under a variety of "Home of Your Own" initiatives featured at the Academy. Norman and Edith Braley of Eddington, Maine, told participants that having their own three-bedroom mobile home that sits on their own land is "a dream come true" after moving among institutions, group homes, and city apartments for most of their lives.

When Rhode Island created a person-driven support system under CSLA in 1987, a whole new world of inclusion opportunities opened up for Roseanne.

The Braleys require minimal support from the service system and are increasingly accepted as full members of their community. They enjoy gardening, caring for their pets, working in Norman's woodshop, and selling produce from their garden. The *Bangor Daily News* featured them in a front-page article reflecting the community's recognition of the Braleys' value as full citizens.

Another success story came from Lucille Stringer of Warren, Rhode Island, describing the tremendous changes in her daughter Roseanne when she was able to move from her family's home into her own apartment:

In August of 1993, at the age of 33, our daughter, with bag and baggage, left our home and moved into a lovely, bright, cheerful apartment of her choice that she now calls home. Signing her lease and being handed her key was such a red letter day for her. She had "arrived." Having her own mail box, checking her messages on her own answering machine, and having her first pet, a beautiful white cockatiel bird named Sammy, were all so unbelievable to Roseanne-things we all take so much for granted.

What a wonderful change we see in her! She left us virtually a little girl and now has developed into a young woman, full of confidence and self-esteem, and learning to struggle through her problems. She's learning to cook (adding the title of microwave queen), has made new friends, and invites them to dinner. She teaches sign language to a friend, exercises regularly at a "Y" of her choice, and has even learned an important new skill-ordering out with delivery service! We have taken such pride and joy in her accomplishments, all made possible with daily supports under CSLA, the Medicaid Community Supported Living Arrangements program.

Roseanne, who has cerebral palsy and a speech impairment, had finished her education at a time when few choices were available to her. When Rhode Island created a person-driven support system under CSLA in 1987, a whole new world of inclusion opportunities was opened to her. The things in her life now that make it so wonderful are amazingly simple.

People with mental retardation also are being included in the civic life of their communities. James Meadours, an individual with mental retardation, serves his

community in a very direct way. He is a VISTA volunteer with the Tulsa Arc (formerly the Association for Retarded Citizens) in Oklahoma. He works with People First, a self-advocacy organization for people with mental retardation and related disabilities, where he is helping to establish new People First groups and support existing groups. He also serves on the board of directors for the Tulsa Arc and The Arc of the United States, as well as serving as treasurer of Self-Advocates Becoming Empowered, a national organization of self-advocates. He talked frankly to Academy participants about how the opportunity for inclusion in community service had helped him develop:

People with mental retardation and developmental disabilities have come a long way. I remember five years ago when I joined the board at the Tulsa Arc. It was my first time to serve on a board of any kind. Inside of me, I wondered if I was going to do well or if I would fail. At first, I did not understand my role as a board member, but I grew as the organization grew.

Academy participants also continued the celebration of the five year anniversary of the Americans with Disabilities Act (ADA). Bob Williams, Commissioner of the Administration on Developmental Disabilities, reflected on his personal fight for inclusion, as well as reminding Academy participants that our continued effective enforcement of the ADA is promoting significant progress toward inclusion in every facet of American life:

Progress in opening doors which have been slammed in our faces; progress in creating job accommodations and equal opportunities for qualified disabled individuals to work, earn a living, and pay our fair share of taxes; and progress in creating access to a wide variety of goods, services, and supports both in the private and public sectors which have never been available to individuals with disabilities or our families before.

Several presentations to the Academy highlighted advances being made by individual States in promoting inclusion while Bob Gettings, Executive Director of the National Association of State Developmental Disabilities Services Directors noted the expansion of the individual supports model through CSIA and the Medicaid Home and Community-Based Services waiver program. Great differences remain among the States, and within States, regarding the commitment to inclusion of people with mental retardation throughout their life span.

Although movement toward inclusion is widespread, however, gains need constant support and actual progress remains uneven. Lessons learned from the experience of those who have been successful in promoting and reaching inclusion need to be available to those further behind on the journey to inclusion.

Great differences remain among the States, and within States, regarding the commitment to inclusion of people with mental retardation throughout their life span.

III. Guiding Principles for Community Inclusion

The personal stories of people with mental retardation, family members, and others at the forefront of promoting inclusion reflect benefits from pro-inclusion State and Federal policies, and the goodwill and support of individual communities. From these and other presentations to the Academy, the President's Committee has drawn the following principles to guide future policy and program development:

Principle 1: People with mental retardation have the same basic legal, civil and human rights as other citizens.

These rights, as for all citizens, should never be limited or restricted without compelling State interests and due process. Where needed, additional protections should be offered to prevent injustice, abuse and neglect.

Principle 2: People with mental retardation are individuals who, like all other people, have a wide array of interests, needs and capabilities.

Community services and supports should embrace the diversity among people who comprise American society today.

Principle 3: Community services and supports respect individual differences and basic rights of self-determination and autonomy.

Assessment procedures should be utilized that allow and encourage individual differences to be identified. There should be a menu of services and supports available that can be tailored to individual goals, needs and preferences. Adequate resources should be allocated to allow more than one option for services and supports.

Principle 4: The racial/ethnic/cultural membership of individuals and their families is respected at all times.

Assessment procedures should be utilized that reflect an understanding of how cultural values may affect the meaning of information, the importance of specific recommendations, and who makes decisions and how they are made. Services and supports should be available that are sensitive to differing cultural values, practices and priorities.

Principle 5: People with mental retardation are valued members of their communities.

People with mental retardation should actively participate in all aspects of community life including school, work, recreation, organized religious life, and community service.

Principle 6: People with mental retardation live in homes like other people.

Children should grow up in homes with their families or surrogate families, with services and supports available to families as needed. Adolescents and young adults should be prepared for transition to supported living and/or independent living, as

appropriate and desired by the individual. Adults should have opportunities to live in their own homes in communities. Aging adults should receive services and supports that allow them to stay in their own homes.

Principle 7: People with mental retardation receive services and supports that are tailored to their needs, aspirations and preferences.

Children and adults should have opportunities to explore and develop their interests, so that they can make decisions about meaningful things to do with their time. They should be assisted to develop a wide range of friends and associates. Family ties should be strengthened and supported. Adults should make real choices about how they spend their time, how they spend their money, and with whom they associate. Services should result in positive outcomes as measured by consumer satisfaction.

Principle 8: People with mental retardation are prepared for and have meaningful and productive work.

Children should have the opportunity to attend preschool and neighborhood schools with nondisabled peers where they receive an education based on their individual needs. Youth should be prepared for the transition from school to the world of work and adult responsibilities. Adults should have meaningful and productive work opportunities in the competitive work force, and are valued for their voluntary service to their communities. Aging adults should have opportunities to continue employment, if desired; to retire in familiar communities with members of their social network; and to contribute to society through voluntary effort.

The President's Committee believes that these principles will be useful to States during this critical period of policy reform. It is our hope that the events unfolding in Congress and in State capitals will sustain and build on the gains that have already been made by people with mental retardation and other developmental disabilities.

IV. Challenges to Inclusion

When we first decided to sponsor the National Collaborative Academy on Mental Retardation, we thought it was important to focus on State policy making... We did not anticipate the degree to which (it) would become the focus of political changes in Washington nor the extent of the dramatic shift of power that would be extended to States and local communities.

Val Bradley, Chair, PCMR.

Since PCMR's 1994 Report to the President, our nation has again been deliberating the appropriate roles of the Federal and State governments in implementing services for people with mental retardation. Presenters at our 1995 National Collaborative Academy on Mental Retardation acknowledged that the Federal/State partnership is changing in very dramatic ways. Many proposals give much more responsibility than previous policies to States in determining how Federal funds are spent.

Discussions at the Academy also reflected the many challenges States are facing:

- Many people with mental retardation are not receiving the services and supports they need for community inclusion. Relatively few States have engaged in long-term planning that has fully involved stakeholders in designing systems that are flexible and able to respond quickly and effectively to individuals needing publicly funded services and supports.
- States face enormous challenges in responding to changing demographics, such as increased demands for early intervention services for infants and toddlers with developmental disabilities, expanded need for eldercare services, and the need for competence in reaching out and serving people of different cultures.
- All States are struggling to meet the demand for qualified personnel, particularly direct support workers, to serve people with mental retardation.
- States will receive fewer Federal funds over the coming years to meet these challenges, as Medicaid funding is likely to be reduced and capped; welfare reform could restructure public assistance programs and redefine eligibility requirements; and other Federal human service spending is likely to be capped or reduced.
- Managed care is moving ahead rapidly, including the expansion into mental retardation service systems.

These challenges come at a time when gains in inclusion have plateaued in some areas due to the ongoing challenges of funding constraints, resistance to change, and the difficulties of redeploying resources. Advocates and policymakers need to be vigilant to maintain the momentum for greater inclusion as resources are increasingly constrained. Although the growing consensus on the value base for inclusion will continue to help States move forward, they also must be supported in meeting these challenges.

At the same time, there may be some opportunities to promote inclusion and to make the system more able to tailor services to individuals.

Pressures to work within Medicaid budgets and in managed care environments can increase interest in the individual support orientation and, indirectly, promotion of inclusion. States can focus on preserving access to the system and to essential services, while efforts to increase effectiveness and efficiency can emphasize the services valued, needed and chosen by individuals.

V. Guidelines on the Journey to Inclusion

PCMR charged State Teams with the task of addressing how stakeholders could respond to current challenges to maintain and enhance the support systems for people with mental retardation and other developmental disabilities. State Teams reviewed key

policy trends and, guided by the principles emerging from the presentations, outlined each State's planning approach to meet the needs of people with mental retardation and their families. Their deliberations resulted in six general recommendations that we offer as guidance to all States addressing current policy and funding issues.

Guideline 1: Involve all stakeholders when redesigning systems to provide better services and supports for self determination and life-long inclusion of people with mental retardation.

All parties who plan, fund, provide, use and assess services need to be involved in redesigning the service system. Participating stakeholders should include, but not be limited to, key elected and appointed State officials, policy-makers, public and private providers of services and supports to people with mental retardation, representatives of employee organizations, family members, people with mental retardation who are self-advocates, and other advocates. Planning groups need to be broad-based, non-partisan and include minority representation. Involving people with mental retardation and their families is critical, not only because it is their lives that are most directly affected by the decisions being made, but also because they are the ultimate "experts" on the service system and its current strengths and weaknesses. To enhance their contributions, self-advocates should receive supports for attendance and participation in all planning and related activities.

Guideline 2: Focus system change plans on children and adults with mental retardation and their families by incorporating techniques that offer them options and choices for services and supports in community settings.

Individual State system change plans should focus on community inclusion and moving away from segregated environments for children and adults with mental retardation. People must be supported to exercise their rights to self-determination and community inclusion. There should be an array of services and supports available in the community that allow choice and are tailored to individual needs and preferences. Systems should be put in place to make the public-and especially people from diverse and under-represented groups-aware of the options available for people with mental retardation and their families.

Guideline 3: Make sufficient resources available and use them efficiently and effectively to eliminate waiting lists for services and supports.

State Teams called for investigating various means of redeploying resources as one way to use reduced funds more efficiently. They recommended assessing the feasibility of using some of the successful strategies from managed care for providing both acute health care and/or long-term supports, and exploring options for converting program funds into cash or vouchers given directly to people with mental retardation and their families. Current service providers with an investment in facilities should be assisted in conversion strategies that free up funds to develop more flexible support models based on individual and family choice. States also suggested recruiting

community members to provide natural supports to individuals with mental retardation in the workplace and other community settings.

Guideline 4: Ensure that there are direct support personnel who are trained, culturally competent, and adequately paid, with opportunities for career advancement.

States must create and offer personnel development programs that are responsive to the changing patterns of providing services and supports to people with mental retardation. Training of direct support workers and other personnel should be coordinated through the university system, community colleges, adult education programs, and other means, depending on locale and need. States should ensure that teacher training programs prepare all teachers to serve children with mental retardation in inclusive settings. Technology can also be used to educate the work force, through distance learning, and satellite transmissions to reach people throughout the State.

Guideline 5: Empower people with mental retardation and their families to envision, plan and create inclusive lives, with sensitivity to individual needs and cultural differences.

An inclusive community requires that people with disabilities be educated to exercise their rights and responsibilities as citizens, without a presumption of dependency on others for decisions. People must be supported to develop their own capacities and competencies for self-determination. To enable people with mental retardation and their families to have access to the supports they need, State Teams recognized the value of advocates/brokers who can empower people with information on how to access the full range of possibilities for services and supports.

Guideline 6: Enhance the capacity of communities to welcome and support people with mental retardation through public education.

States suggested finding opportunities to tell positive stories through the media about people with mental retardation who are leading inclusive lives in the community. Public education can help communities to become more welcoming places for people with mental retardation, and ordinary citizens will become more willing to become involved in the lives of people with mental retardation and their families. With changed attitudes, we can expect that more businesses will hire people with mental retardation; communities will offer natural supports in transportation, housing, employment, and recreation; and people with mental retardation will have improved access to quality health care.

As 1995 ended, active negotiations were ongoing regarding budget reductions in programs affecting people with mental retardation.

VI. Current Policy Trends and PCMR Recommendations

As 1995 ended, the future of Federal funding for many disability services was uncertain. Active negotiations were ongoing regarding budget reductions in programs affecting people with mental retardation. Much of the discussion centered on creating block grant programs and simultaneously reducing funding to States. The Federal programs Congress was considering for block granting to States included Medicaid, welfare, child protection, child nutrition, job training, and possibly Supplemental Security Income (SSI) for children with disabilities.

To create block grants, the Congress was considering alteration of existing laws and the enactment of changes that would send funds directly to States, with fewer Federal mandates on how those funds are spent. There was discussion of eliminating entitlements, enabling States to have increased authority to make decisions about who would be eligible for funds and services. States and local communities would have greater flexibility in deciding how funds will be spent. Congress also proposed massive changes in the Children's SSI program that would reduce the types of benefits provided and the number of children eligible to receive them.

The ability of States eligible to finance services is inexorably tied to Medicaid policy.

Bob Gettings, Executive Director of the National Association of State Directors of Developmental Disabilities Services, Inc.

MEDICAID REFORM

Medicaid is a shared Federal/State program that provides acute health care and long-term services and supports for 4.9 million people with mental retardation and other disabilities, most of whom qualify because of limited income and thus are eligible for SSI. States that choose to provide Medicaid services must meet all Federal Medicaid mandates, rules and guidelines, while retaining flexibility in selecting optional services and in defining the amount, scope, and duration of covered services. At present, there are 12 mandated services, including nursing home care, inpatient and outpatient hospital services, physician services, and early and periodic screening, diagnosis, and treatment (EPSDT) for individuals under age 21.

In addition, Medicaid has 31 optional services a State can choose to provide, including Intermediate Care Facilities for the Mentally Retarded (ICFs/MR), personal care services, durable medical equipment, and a range of rehabilitation services. States can also qualify for Medicaid waivers that allow them to create their own more innovative variations for providing services. Under the Home and Community-Based Services waiver, for example, States are projected in 1996 to serve approximately 205,000 individuals with developmental disabilities in the community who would otherwise be in ICF/MR facilities, more than a 50 percent increase from 1994.

Congress has proposed reducing the amount of Federal funds provided to States for Medicaid, eliminating existing Medicaid entitlements, and reducing or eliminating the Federal mandates governing how funds are spent.

PCMR RECOMMENDATIONS: MEDICAID REFORM

Medicaid is a cornerstone of funding for services for people with mental retardation. Revisions in policy will dramatically affect the character of services. We must ensure that reform efforts are based on promoting self-determination and inclusion, and that people with mental retardation and other developmental disabilities retain an entitlement to services and supports. The Medicaid program should be refocused as necessary to promote self-sufficiency, opportunities for community inclusion, and protection for the rights of full citizenship.

- **Ensure that people with mental retardation retain their eligibility for services provided under Medicaid.** People must retain their entitlement to essential services and supports. For many, Medicaid is their only hope for health care. Private insurance, if offered at all, is very often prohibitively expensive, and pre-existing conditions eliminate them from the private insurance market. They must also retain critically needed long-term supports that are Medicaid-funded, such as adult day services, personal assistance, and supported living. There is no private coverage or provision of long term care services.
- **Maintain the quality of services and protections.** Medicaid reform proposals call for fewer Federal mandates on how to spend available funds. States need to guard against narrowing eligibility, restricting the array of supports, or reducing standards of quality for services. Efficiencies should come from tailoring long-term supports to each individual's unique needs, rather than limiting benefits and restricting eligibility. People must be protected from abuse, neglect, and economic exploitation.
- **Permit States to develop new models.** With less Federal money, States will have to contribute a greater share of funds to simply maintain the current level of services for people with mental retardation. States should be permitted and encouraged to redeploy existing resources in innovative strategies to meet people's needs in community settings.
- **Put families first.** People with mental retardation and their families must have a voice in determining the services and supports received by each individual and by the family. Policies need to recognize that many families depend on Medicaid to lessen their burden by providing supports and medical services they could not otherwise afford.
- **Consider the effects on school children.** Major reductions in Medicaid will have significant consequences for schools. Medicaid pays for related services such as speech therapy, physical therapy and assistive technology for thousands of children with disabilities who are in special education programs. Although schools have under-utilized the Medicaid program, the loss of those funds will

financially strap school systems currently using it to provide children with such services.

Managed care happens.

Janna Starr, Oregon Advocacy Center, Salem, Oregon.

MANAGED LONG-TERM CARE

Managed care involves various strategies to contain or limit health care costs, such as prior authorization, capitation, and putting providers at risk beyond pre-set funding limits. Until now, managed care has been used almost solely for acute health care. Interest is growing, however, in expanding managed care into long-term care services, including those used by individuals with mental retardation and their families. The existing budget pressures in the States, coupled with the likelihood of decreases in Federal funding, are leading to active development of plans for managed care in long-term care services.

PCMR RECOMMENDATIONS: MANAGED CARE

PCMR recognizes the importance of developing a coherent approach to long-term care that is strongly linked to Medicaid reform. We reiterate the principle of providing services and supports tailored to the needs, aspirations, and preferences of individuals. Long-term services must focus on supporting people's choices in inclusive communities.

- **Include people with mental retardation and their families in planning a managed care system.** Individuals and families depend on community support systems that have taken many years to develop. They must be involved in planning for managed care, to ensure that proposed managed care strategies do not undermine existing support systems that enable people with mental retardation and other developmental disabilities to live as citizens in their communities.
- **Ensure that service systems provide appropriate supports to people with significant health problems.** States and managed care organizations have little experience with managed care for people with mental retardation who may also have specialized health problems. Incentives under managed care plans to keep costs low may penalize people with significant disabilities or health problems, for example, by restricting their access to the specialists most familiar with their needs. Systems must be designed to provide adequate care to prevent decline in health and activity levels, to promote expertise in caring for people with developmental disabilities, and to maintain capacity levels.
- **Maintain quality-of-care standards.** Medicaid managed care programs for people with mental retardation must maintain important quality-of-care standards and consumer protections that have typically been included under Medicaid law. States must guard against reverting to outdated custodial models of inappropriate services for individuals with mental retardation under the guise of cost-saving.

They need to ensure that managed care organizations similarly are required to provide services in line with contemporary service standards, including the ongoing promotion and expansion of opportunities for inclusion and the use of consumer satisfaction measures to monitor quality.

CHILDREN'S SSI REFORM

Several Federal provisions have been debated that could drastically alter the current Children's Supplemental Security Income (SSI) program. This Federal program ensures that low income families who have children with qualifying disabilities receive essential monthly cash subsidies. SSI has made it possible for thousands of families to ease the challenges of coping with a child with disabilities, thereby reducing the need for costly out-of-home placements.

There are proposals calling for elimination of cash entitlements for families, substituting a block grant program for treatment services, and changing the eligibility requirements to exclude some low income children with disabilities currently qualifying for Federal SSI payments. Because most States link Medicaid eligibility to receiving SSI, these children could be excluded from the Medicaid program as well.

PCMR RECOMMENDATIONS: CHILDREN'S SSI

Children who are disadvantaged both because of their disability and their poverty stand to lose the most in the current reform movement. The Children's SSI program has been extremely important in helping their families meet their needs. PCMR supports program refinements that protect the ability of families to keep children with mental retardation at home and to make choices on behalf of their children.

SSI has made it possible for thousands of families to ease the challenges of coping with a child with disabilities, thereby reducing the need for costly out-of-home placements.

- Maintain cash benefits for families of children with mental retardation. Eliminating cash benefits would greatly reduce family autonomy and decision-making. They would be unable to obtain essentials such as food, clothing, shelter and utilities, and for some, dietary supplements, diapers, and special transportation. The limited treatment services being proposed would not meet the very basic needs of these low income families and their children. Simultaneously, PCMR supports increased accountability from families on the use of cash benefits.
- Ensure that eligibility requirements do not exclude qualified children with mental retardation. Both houses of Congress propose to eliminate the Individualized Functional Assessment process that has been used successfully to determine children's eligibility for SSI. More restrictive definitions for eligibility would deny benefits to an estimated 170,000 children currently receiving them. These restrictions would have a devastating impact on children with mental retardation

and their families, since 43 percent (359,871) of the children who now receive SSI have mental retardation. PCMR affirms the importance of refining the functional assessment, but strongly disagrees with its elimination.

- Do not jeopardize the health of children with mental retardation. SSI eligibility allows most children with mental retardation to receive needed health services through Medicaid, as well as Medicaid-waivered services. The loss of Medicaid eligibility may increase the severity of these children's disabilities and could contribute to the development of secondary disabilities that are preventable with access to adequate care. PCMR affirms the importance of the eligibility for Medicaid that is inherent in the Children's SSI program.

THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT

The Individuals with Disabilities Education Act (IDEA) is currently up for Congressional reauthorization. For 20 years IDEA and its predecessor legislation have guaranteed a free, appropriate public education for all children with disabilities, including mental retardation. IDEA's least restrictive environment requirements help ensure that children with disabilities are educated with children who are not disabled to the maximum extent appropriate. They may be excluded from regular educational settings only when the nature and severity of their disability is such that education in those classes with the use of supplementary aids and services cannot be achieved satisfactorily.

Inclusion of all children learning together with necessary supports and services; all children having their unique needs met at the same setting; all children participating in all facets of school life.

Linda Frazey, Teacher, Hoxie Community School, Hoxie, Kansas

The least restrictive environment requirements support inclusion by promoting children's education in regular classrooms with necessary supports and supplementary aids. Unfortunately, the most recent data reported to the U.S. Department of Education by the States indicate that only seven percent of children with mental retardation are being educated in regular classrooms, and another 27 percent are partially included. The rest are educated in segregated environments, where they have few opportunities to meet their neighbors.

PCMR RECOMMENDATIONS:

THE INDIVIDUALS WITH DISABILITIES EDUCATION ACT

The Individuals with Disabilities Education Act achieved access to education for all children with mental retardation. We must remain vigilant to ensure that children are not denied access in the future. We are concerned about proposed modifications to IDEA that would allow children with disabilities who present discipline problems to be expelled and potentially lose their right to education. Movement should continue toward a unified, rather than a dual, school system. Children with mental retardation should have the

opportunity to attend preschool and neighborhood schools with the nondisabled children in their communities, rather than be separate and segregated.

- **Protect the right to appropriate education.** The currently controversial and divisive issue of student discipline should not be allowed to threaten children's right to education. IDEA currently prohibits schools from indefinitely suspending or expelling children who present educational challenges because of their disabilities, such as occasional disruptive behavior. If the policy is weakened, children with disabilities could be expelled from school, ending up at home or on the street—precisely the outcomes that the original framers of the Federal law chose to remedy.
- **Continue support for the policy of inclusion.** Schools have had 20 years to implement the law, yet there are huge variations among States in their inclusion of children with mental retardation in regular classrooms. PCMR supports the expanded efforts of the Clinton Administration to monitor States' implementation of the least restrictive environment requirements of IDEA.

JOB TRAINING CONSOLIDATION

Congress has agreed on the laudable goal of consolidating the government's more than 100 job training programs into a coordinated system that uses Federal dollars more efficiently and effectively. Proposed bills consolidate current programs into block grants and create one-stop career centers to provide employment services. The Vocational Rehabilitation State Grant Program, responsible for addressing the nation's need for job training and rehabilitation and, for competitive and supported employment programs serving people with mental retardation and other disabilities, came under scrutiny as part of the consolidation. At present, the program remains essentially unchanged.

PCMR RECOMMENDATIONS: JOB TRAINING CONSOLIDATION

Employment is an issue of vital concern to people with mental retardation. Very little progress has been made in reducing their unemployment rate of more than 70 percent, in spite of the work success of many people with a range of abilities. As a result, most people with mental retardation are poor as adults. Growth in supported employment in the community has not been matched by a decline in sheltered employment in segregated settings. PCMR supports efforts to ensure that people with mental retardation have access to the range of generic supports available to all who seek employment, as well as specialized assistance as needed to obtain and maintain employment.

- **Ensure access of people with mental retardation to employment services in a reformed system.** One-stop career centers, if enacted, must provide people with mental retardation appropriate accommodations and services, so that they can benefit from the generic job training and placement services offered to others.

Trained personnel need to be available in one-stop career centers to meet the unique needs of people with mental retardation for employment services.

- **Expand employment opportunities for people with mental retardation.** Traditional programs have only met the needs of limited numbers of people. Public policy must ensure that people with mental retardation with a range of functioning levels have sufficient services and supports available for them in competitive employment or other community settings, and are fairly compensated. They must have equal access to participation in the labor force to the same extent as the rest of the community.
- Make the vocational rehabilitation system accountable. Assure that people with mental retardation, including those whose disabilities are severe, work in integrated job settings with fair pay. Enforce provisions requiring that they have choices about the supports they need.

We need more funds so that we can have all the young adults with disabilities be able to work and be able to do their job well, and also to have a choice of what jobs they would like to have and enjoy.

Mary Lynn Gladding, Self-Advocate, Certified Child Care Worker, Columbia, Maryland

THE AMERICANS WITH DISABILITIES ACT

The Americans with Disabilities Act (ADA), often described as the civil rights law for people with disabilities, bans discrimination based on disability. Signed into law in July 1990, the ADA gives individuals with mental retardation and other disabilities civil rights protections like those provided to individuals on the basis of race, sex, national origin and religion. It guarantees equal opportunity for individuals with disabilities in employment, State and local government services, public accommodations, transportation, and telecommunication relay services.

This past year the ADA became a focus of discussions in Congress on unfunded mandates, with some members of Congress charging that the Americans with Disabilities Act was such a mandate. ADA supporters were successful in obtaining provisions in the Unfunded Mandates Reform Act of 1995 (Public Law 104-4) clarifying that civil rights legislation like the ADA, is not an unfunded mandate. This issue may resurface in future debates, however, along with threats to rewrite the ADA and possibly weaken its protections.

PCMR RECOMMENDATIONS: AMERICANS WITH DISABILITIES ACT

PCMR is aware that a great deal of confusion and misconception exists around the ADA and the rights it guarantees. As advocates for people with mental retardation, we must be diligent in helping the Congress and the public accurately understand this legislation. Until the passage of the ADA, Federal protections against discrimination based on a person's disability were scattered and very limited. The Congress concluded

that discrimination existed against people with disabilities, and that they were sometimes denied equal, effective and meaningful opportunities to participate in society.

- Strengthen implementation of the Americans with Disabilities Act. PCMR fully supports the Americans with Disabilities Act and supports President Clinton's pledge to veto any legislation that would diminish its effectiveness. Access to jobs, transportation and public places are each important for full participation in society. People with mental retardation must not be denied participation in any of these life activities based on their disability.
- Erase misconceptions about the ADA. PCMR encourages those who support the ADA to publicize life stories of people with mental retardation who are full citizens in their communities, to communicate with Congress about the benefits to individual citizens, and to educate business owners about meeting their responsibilities under the ADA cost effectively.

VII. PCMR's Commitment to States

With the 1995 National Collaborative Academy on Mental Retardation, the President's Committee on Mental Retardation embarked on an innovative public education approach for States to encourage life span inclusion of people with mental retardation in community life. We broadened our outreach to include non-traditional audiences that influence the success of State policies, programs and services to people with mental retardation and their families.

The Academy expanded the knowledge base of all who directly affect policy development, planning, programs and services to citizens with mental retardation in the seven participating States. We will continue to support these States and others by providing information and encouraging collaboration and action within States to include people with mental retardation in all aspects of community life. The experiences of the States that participated in the Academy in implementing their planned initiatives will serve to guide States across the nation as they face today's challenges.

Support for Upgrading the Direct Service Work Force

We will support States' efforts to enhance services to people with mental retardation by nurturing initiatives to upgrade the quality of the direct service work force. People with mental retardation need high quality services and supports provided by skilled and responsive direct support staff.

Since 1994, as part of a national Task Force on Direct Service Workers, representatives of the President's Committee have been meeting with leaders of national organizations who share our concern about the low wages, high turnover, minimal training, and lack of career opportunities for direct service workers in the developmental disabilities field.

Paraprofessionals represent a large segment of the workforce, and often play a central role within a fragmented service delivery system. From the perspective of a person with mental retardation or other long-term disability, the quality of services and supports is frequently dependent on maintaining a long-term, stable relationship with a skilled, responsive and compatible direct service worker.

The problems associated with the paraprofessional workforce have been chronicled for over 25 years, spanning institutional, community-based and independent living models of service delivery. Indeed, an experienced, well-trained and motivated workforce may be the single most important factor in the delivery of quality services, regardless of the particular service paradigm.

To help develop national consensus, sound public policies, and effective strategies to strengthen the role of direct service workers within an evolving service delivery system, the Committee is working with other national organizations to establish a National Alliance for Direct Service Workers. The Alliance will include representatives from professional and provider organizations, consumer and advocacy groups, academic institutions, government agencies, unions, and private foundations. Members will work together to develop strategies and activities to achieve the following goals:

- Provide better access to in-service training, continuing education, higher education and lifelong learning, for all paraprofessionals.
- Reduce the turnover of qualified personnel.
- Enhance the status and public image of direct support staff.
- Develop nationally recognized standards for the training, practice, supervision, evaluation and credentialing of experienced direct service "master workers."
- Facilitate changes in the service delivery system to create portable career pathways.
- Foster communication and networking among direct service workers from around the country.
- Increase the active participation of paraprofessionals at national and regional conferences.
- Improve the advocacy for and the inclusion of direct service workers in professional associations.
- Disseminate model legislation that provides incentives to agencies for staff training, salary increases, and career ladders for qualified workers.
- Promote research projects and publications that focus on the role of direct service practitioners within an evolving service delivery system.
- Create a national database of direct service workers.
- Strengthen the working relationship and partnership between direct service workers, self-advocates, and consumer groups.

The importance of appropriately trained direct support workers was underscored by PCMR member John F. Kennedy, Jr., speaking to Academy participants:

I have learned that the voices of direct care workers and self advocates come from the heart and the soul of the developmental disabilities field. These groups need to have a far greater role in determining its future direction. Whether it is in a person's home, or school, or job or local neighborhood, direct service workers provide the daily support to assist individuals with developmental disabilities to ultimately lead more active, rewarding lives in their own communities.

Support for Self-Advocacy

PCMR will continue to assist people with mental retardation to create satisfying lives for themselves. To do this, they must be part of the national debate that affects their lives. For the first time in the history of PCMR, two self-advocates are members of the Committee. At PCMR's request, States included self-advocates as members of their State Teams for the National Collaborative Academy, and self-advocates were featured speakers in the Academy.

We will continue to support and enhance self-advocates' meaningful participation in our meetings through orientation sessions and other supports as needed. We will strive to follow the advice self-advocate James Meadours offered at the Academy, and to encourage others to follow it as well:

Listen to us. If you say something over our heads during a PCMR conference, ask a question to make sure we can understand the issues. If not, use more words we can understand so we can make our voices heard and share information. Help us be a part of the group when we need it.

Protecting Civil Rights of People with Mental Retardation

We will continue to fulfill our historic national role in advising the President and the public about the current status of children and adults with mental retardation and their families in the United States. This year we provided our expertise to the nation in many ways as major changes were considered in Federal policy. We spoke out in particular about Children's Supplemental Security Income, Medicaid and the Americans with Disabilities Act.

As we reviewed proposed policy changes during our Academy deliberations, our members repeatedly reminded the participants of the need to do better with more limited resources. They reiterated that the hard fought gains of people with mental retardation to full citizenship and inclusive living could not be compromised. Further, we repeatedly reminded ourselves and the nation that far too many people with mental retardation and their families are not yet beneficiaries of these fundamental opportunities.

Finally, in fulfilling our responsibilities at this time in particular, we have attempted to serve to some degree as a national conscience. We well remember that much of the Federal infrastructure created since our founding occurred as a result of an inability or, in some cases, an apparent unwillingness of the States to adequately meet the needs of

children and adults with mental retardation and their families. While we are optimistic that the nation's commitment to them has substantially improved, we will continue to remind all levels of government of their responsibilities to strive for full community inclusion of all their citizens. We look forward to continuing our efforts with the States to help them achieve this outcome.

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