

Voices and Visions:
Building Leadership for the 21st Century

1996 Report to the President

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

President's Committee on Mental Retardation



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

August 1, 1997

**The President
The White House
Washington, D.C. 20500**

Dear Mr. President:

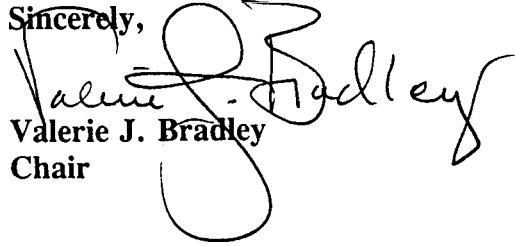
On behalf of the President's Committee on Mental Retardation (PCMR) and future leaders in the field of mental retardation, I am proud to offer you the Committee's 1996 Report to the President, Voices and Visions' Building Leadership for the 21st Century.

As the Committee looked to the 21st century, we recognized an obligation to identify and to support the next generation of leaders in the field of mental retardation. The Committee convened the Next Generation Leadership Symposium in Washington, D.C. on September 27, 1996. Over 250 young leaders representing 40 States, the District of Columbia and Guam gathered to identify the challenges, opportunities and their leadership roles at this unique event.

This Next Generation Leadership Symposium was the centerpiece of the Committee's celebration of 30 years of advocacy and leadership. As these energized young Symposium participants charted territory for the new millennium, PCMR also reflected on a proud and impressive past. The Elizabeth Monroe Boggs Leadership Award was initiated to recognize the life work of this remarkable scholar, researcher, advocate and parent of a child with mental retardation. Three young leaders were honored at the Symposium for their impact in the field of mental retardation in the name of Dr. Boggs.

As PCMR continues its mission for lifelong community inclusion for people with mental retardation, we ask that all stakeholders join with the self advocates, family members, service providers, professionals and advocates who comprise the PCMR as we look with hope, energy and creativity to the next generation of leaders.

Sincerely,

A handwritten signature in black ink that reads "Valerie J. Bradley". The signature is written in a cursive style with a large, stylized initial "V".

**Valerie J. Bradley
Chair**

Acknowledgments

The President's Committee on Mental Retardation (PCMR) is pleased to present its 1996 Report to the President: Voices and Visions: Building Leadership for the 21st Century. This report is the result of the Committee's commitment to building a strong foundation for the future leaders in the field of mental retardation.

The outcomes articulated in this Report to the President reaffirms the mission of PCMR and strengthens the resolve for continued advocacy and leadership into the next millenium. Continuing with the Committee's theme of diversity and collaboration, over 250 young leaders from across the nation were represented at this first ever event. Through active interchange they shared perspectives from their roles as direct support workers, self-advocates, family members, professionals, service providers and researchers. PCMR would like to extend the Committee's appreciation to this next generation of leaders.

A special thanks to Marci Whiteman who developed and supported selfadvocates as active participants in all aspects of the PCMR mission including work as PCMR Committee members and presenters and attendees at the Academy and Next Generation conferences.

PCMR wants to extend its deep appreciation to Tecla Jaskulski, whose incredible talents express the mission of PCMR through her creative writing and depth of understanding of the meaning of inclusion, independence and personal empowerment for people with mental retardation.

The Committee would also like to express its appreciation to Olivia A. Golden, Principal Deputy Assistant Secretary for the Administration for Children and Families (ACF), for her leadership and commitment to the Committee's initiatives.

Gary H. Blumenthal
Executive Director

Elizabeth Monroe Boggs, Ph.D., 1913 -1996

This report is dedicated to Elizabeth Monroe Boggs, an outstanding human being and a major influence in the mental retardation field throughout her adult life. In 1939 Elizabeth Boggs was one of the first women to receive a Ph.D. from Cambridge University in England. Dr. Boggs was working as a theoretical chemist in 1945 when, during the first few weeks of his life, her son David developed severe, lifelong disabilities. She was 32 at the time. She immediately put her science training to work in seeking services and supports. Finding none, Dr. Boggs joined with other parents, in New Jersey and nationally. She became a founder of what was then the Association for Retarded Children of New Jersey (now The Arc) and served as the first woman president for the National Association for Retarded Children which is now The Arc of the United States.

When David was seven, his severe sleep disturbances meant that no one in the household could get any rest. Elizabeth and her husband made the painful decision to move him to a residential placement. At that time, the concept of family supports was unknown.

Elizabeth was dedicated to improving the lives of people with mental retardation and other disabilities. As a scientist she often was a bridge between parents and the professional community at a time when Federal expertise and commitment were minimal. As Federal interest grew during the Kennedy administration, she was appointed to the President's Panel on Mental Retardation and later to the President's Committee on Mental Retardation.

Dr. Boggs played a major role in articulating the rights of individuals with mental retardation. A fact-finding mission to the Netherlands in the early 1960s stimulated action throughout the field and she was the principal author of the 1971 United Nations Declaration of the Rights of People with Mental Retardation. More recently, her leadership with Justin Dart documented the need for the Americans with Disabilities Act. Elizabeth Monroe Boggs was one of the architects of the concept of developmental disabilities as early onset disabilities, and of the Developmental Disabilities Assistance and Bill of Rights Act. She conducted research and provided guidance to the Social Security Administration on the Supplemental Security Income program. Her ability to draw on a broader social welfare context for work in this field, her intellect and her heart, made her truly a Renaissance woman and a treasure of our field.

REPORT TO THE PRESIDENT

Voices and Visions: Building Leadership for the 21st Century

The President's Committee on Mental Retardation

INTRODUCTION

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. Approximately one in ten families are directly affected by a person with mental retardation at some point in their lifetime. Many more are involved as neighbors, classmates, co-workers and friends. Despite many advances in the field, mental retardation continues to present a major challenge to the social, educational, health and economic systems within the United States.

The President's Committee on Mental Retardation was formally established in 1966 to focus on this critical subject of national concern. Since 1974, the Committee has organized national planning, stimulated the development of plans, policies and programs, and advanced the concept of community inclusion and participation for individuals with mental retardation.

To continue to best fulfill its purpose, the Committee has adopted several national goals. These goals recognize and uphold the right of all people with mental retardation to create for themselves a life that reflects independence, self-determination, and participation as productive members of society. They include the assurance of full citizenship rights of people with mental retardation, the provision of all necessary supports to individuals and families, the reduction of the occurrence and severity of mental retardation, and the promotion of the widest possible dissemination of information on policies, programs and service models that foster independence, self-determination and social and economic participation.

The mid-1990s have been a time of renewed activity and commitment for the Committee. For the first time in the Committee's history, President Clinton appointed two leaders in the self-advocacy movement, people who themselves have mental retardation. These individuals are participating actively with the other 19 citizen members and nine public members to address these goals. The Committee is justifiably proud of its recent accomplishments, as well as its major contributions over the past 30 years.

Looking ahead to the 21st century, the Committee recognized an obligation to identify the next generation of leaders in mental retardation, and to begin actively supporting them in their efforts. The Committee therefore convened the Next Generation Leadership Symposium on September 27, 1996, bringing together future leaders from a

wide range of service and advocacy communities. Their recommendations form the heart of this report.

I. Overview: 30 Years of Leaders in the Field of Mental Retardation

The mental retardation activities of Federal, State and local government agencies and foundations and other private agencies are expanding rapidly and require careful review in order that maximum benefits may be achieved. There is a continuing need to mobilize the support of the general public and of specialized professional groups for mental retardation activities. Re-evaluation of existing programs to determine their adequacy and consideration of proposals for new mental retardation activities is necessary.

Executive Order 11280 Establishing The President's Committee on Mental Retardation, May 11, 1966.

The year 1996 marked the 30th year since the President's Committee on Mental Retardation was formally established with Executive Order 11280 by President Lyndon B. Johnson. Throughout the last 30 years the Committee has taken a leadership role in promoting cutting edge reforms in advocating on behalf of people with mental retardation and related disabilities and their families.

THE 1960s

Before the President's Committee on Mental Retardation was formed in 1966, its precursor, the Presidential Panel on Mental Retardation, established by President John F. Kennedy in 1961, conducted an intensive investigation on the status of programs for people with mental retardation. The Panel published the seminal Report to the President: A Proposed Program for National Action to Combat Mental Retardation.

Following President Johnson's formal establishment of the Committee in 1966, members at the first meeting identified a focus on prevention, early intervention, human and legal rights, and public awareness. The Committee conducted public forums across the nation as well as a review of the Federal programs and agencies that were resources for people with mental retardation, and worked with the National Advertising Council and private organizations on an extensive public education campaign.

One of the Committee's first publications was Changing Patterns in Residential Services for the Mentally Retarded. This publication was identified as an historic attempt to document the move toward normalization in services to people with mental retardation. The Committee's introduction of the normalization principle to the American professional community, its publication of Wolf Wolfensberger's classic essay "The Origin and Nature of Our Institutional Models" and other contents, made this an extremely influential publication in the advent of community service development in the United States.

A major milestone took place in 1969 when the Committee's conference on the education problems of children in inner cities resulted in the landmark publication of the

booklet *The Six-Hour Retarded Child*, calling for expansion of special education for children in the public education system.

THE 1970s

The Committee addressed a wide range of issues affecting people with mental retardation during the 1970s, including the significant publication in 1972 of *Transportation and the Mentally Retarded* - a critical issue which remains intractable now, 24 years later. A series of key publications analyzed and defined needed actions, in particular two in 1976: *Report to the President: Century of Decision*, and *Mental Retardation: The Known and the Unknown*.

Legal rights were a major focus throughout the 1970s, including conferences and publications such as *The Mentally Retarded Citizen and the Law*, *The Retarded Offender*, and *Silent Minority*. Support of the self advocacy initiative began through the People First movement. The Committee also presented descriptions of effective programs in community services, education, and employment. In 1976 the Committee published a second edition of *Changing Patterns in Residential Services*, and in 1978 issued *Mental Retardation: The Leading Edge - Service Programs That Work*. The Committee extended its survey of "programs that work" to prevention, reconfirming its high priority on effective prevention strategies, holding an international conference on prevention, and publishing *Prevention Strategies That Work* as the 1979 Report to the President.

THE 1980s

The Committee established a new subcommittee on Systems Simplification to review Federal and State laws, regulations and procedures; identify gaps, overlaps and barriers; and develop policy recommendations for more effective and efficient service delivery. Full citizenship for people with mental retardation was a focus of Committee activity, including employment opportunities and supports, and publication of *From Rights to Realities: Advocacy By and For Retarded People in the 1980s*.

The priority on prevention was reinforced through multiple forums, publications and dissemination of a *Model Guide for State Planning for the Prevention of Mental Retardation and Related Disabilities*. The Committee also continued a major role in international activities, including the United Nations International Decade of the Disabled and liaisons with the Organization of American States, the United States Information Agency, and the Pan American Health Organization.

THE 1990s

During the 1990s the Committee has been revitalized under new leadership, both members and executive staff. Most significantly, President Clinton appointed two self-advocates as Committee members. The Committee also has expanded its support of self-advocates, nationwide. Other milestones include:

- The April 1994 conference and resulting publication, *The National Reform Agenda and People with Mental Retardation: Putting People First*.
- The National Collaborative Academy Initiative, bringing diverse teams of key stakeholders together to plan action steps to improve the lives of people with mental retardation and to facilitate their full inclusion in their respective States and communities.
- Major resource publications on community inclusion and on the issues and concerns surrounding the direct support workforce.
- Policy advisories on the Children's Supplemental Security Income program and Medicaid because of their critical role in maintaining the safety net for people with mental retardation.
- The Next Generation Leadership Symposium and the Elizabeth Monroe Boggs Leadership Award, initiated in 1996.

Committee activities have consistently brought together renowned leaders in the field of mental retardation, as well as providing state-of-the-art information to family members, professionals, and, increasingly, to self-advocates, and the general public.

The past year has been one of the most productive in the Committee's history. In addition to its continued advocacy through Policy Statements on Medicaid and Welfare Reform, the Committee has also maintained collaboration with other Federal agencies, including the Administration on Developmental Disabilities, the Office of Special Education and Rehabilitative Services, the National Institute on Disability and Rehabilitation Research, the National Institute on Child Health and Human Development, and the Social Security Administration. Also as Committee members and as resources drawn from beyond the Committee, self-advocates have played significant roles in Committee activities, including participation in the two major events: the National Collaborative Academy on Mental Retardation and the Next Generation Leadership Symposium.

The Committee recognized the key role of frontline workers in successful community inclusion for people with mental retardation. The critical need to empower and enhance direct support workers was a Committee focus during 1996, stimulated considerably by Committee member John F. Kennedy, Jr., founder of Reaching Up, Inc.. The Committee produced *Opportunities for Excellence: Supporting the Frontline Workforce*, a major resource publication for State and agency policymakers, developed and published in collaboration with Reaching Up. The year 1996 also saw the formation of the National Alliance for Direct Support Professionals, with active PCMR participation.

The Committee pressed the National Collaborative Academy initiative forward on two fronts during 1996. State Teams from the first Academy, held in 1995, reported

considerable progress on the action plans they had developed. For example, Louisiana continued its momentum with consensus building activities and expansion of the Team to the regional level. The highlight was a state of replica of the National Collaborative Academy in June 1996, with nearly 300 attending. Participants explored the issue surrounding systems change for person-centered supports and formed recommendations for change during plenary sessions, concurrent workshops, and intensive Regional Team meetings.

Recognizing the strength of diversity in participation, the 1996 National Collaborative Academy on Mental Retardation continued the successful approach of bringing together a wide range of individuals on each Team. The nine Teams were representative of the collaboration that must occur between advocates, family members, legislators, budget officials, Governors, mayors, educators and the business community, as well as traditional supporters of services for people with mental retardation. Delegations from Massachusetts, Mississippi, the Navajo Nation, Nebraska, Oregon, Pennsylvania, Washington D.C., Wisconsin and Wyoming worked September 28-30, 1996 as partners in developing Collaborative Action Plans to increase opportunities for lifespan inclusion of citizens with mental retardation in everyday life.

Along with the Committee's support of selfadvocacy and enhancement of the direct support workforce, the National Collaborative Academies reflect its commitment to preparation for the 21 st century. The planned continuation of the Academies over the next few years is intended to reach all States by 2001.

The Committee's primary initiative in preparing for the next century, however, is to turn to a new generation of leaders who support the national goals of PCMR. As outlined in the Committee's new Executive Order, these goals are as follows:

- To promote full participation of people with mental retardation in the communities.
- To provide all necessary supports to people with mental retardation and their families for such participation.
- To reduce the occurrence and severity of mental retardation by one-half by the year 2010.
- To assure the full citizenship rights of all people with mental retardation, including those rights secured by such landmark statutes as the Americans with Disabilities Act of 1990, Public Law 101-336 (42 U.S.C. 12101 et seq.)
- To recognize the right of all people with mental retardation to self-determination and autonomy, to be treated in a nondiscriminatory manner, and to exercise meaningful choice, with whatever supports are necessary to effectuate these rights.

- To recognize the right of all people with mental retardation to enjoy a quality of life that promotes independence, selfdetermination, and participation as productive members of society.
- To promote the widest possible dissemination of information on models, programs, and services in the field of mental retardation.

Executive Order 12994 of March 21, 1996, Continuing the President's Committee on Mental Retardation and Broadening Its Membership and Responsibilities

The young leaders of the Next Generation Leadership Symposium consistently reflected these national goals.

II. The Next Generation

It was an honor to be with so many other direct support workers and network with them about common concerns.

Sally Jochum, Community Living Coordinator (Kansas)

It was very exciting to be part of the first Next Generation Leadership Symposium, and very empowering to me and the other young people.

Yona Lunsky, Researcher, The Nisonger Center and Family Member (Ohio)

Bringing together the next generation of leaders in the field of mental retardation was the centerpiece of the Committee's celebration of 30 years of advocacy and leadership. Future leaders - with an emphasis on those under the age of 35 - were invited to the Committee's Next Generation Leadership Symposium at the American University, Washington College of Law, in Washington, DC, on September 27, 1996. More than 250 individuals from over 40 States, the District of Columbia and Guam, responded, including self-advocates, family members, direct support workers and other service providers, public policy advocates, students, AmeriCorps participants, Federal, State and local agency staff, and researchers.

The diversity of the future leaders reflects the democratization of the mental retardation field over the past 30 years, as well as the strong and emerging collaboration between people with disabilities and their families and those who provide services. They came to the Symposium seeking information, opportunities to meet and learn from other young leaders, and an opportunity to make recommendations to the Committee for inclusion in this Annual Report to the President.

The Human Rights Foundation

-Everyone has the right to life, liberty and civility of person.

-No one shall be held in slavery.

-No one should be subject to torture or to cruel, inhumane or degrading treatment or punishment.

-Everyone has the right to recognition everywhere as a person before the law.

-All are equal before the law and are entitled without any discrimination, to equal protection of the law.

The Universal Declaration of Human Rights adopted by the United Nations in 1948.

SUPPORTING YOUNG LEADERS

Self-advocates, family members, direct support workers, and researchers helped the Committee to identify what is needed to support the Next Generation of Leaders:

- Personal courage, to face up to social mistrust and misunderstanding.
- A dream and a vision upon which a career can be developed.
- Friendships and the support they provide.
- Empowerment of direct support workers and collaboration with individuals with disabilities and their families.
- Embrace new ideas coming into the field, and assist young persons to put forward fresh ideas, as new leadership takes the movement forward and carries us into the future.

Leadership in the field of mental retardation comes from people in many different roles: people with disabilities, family members, teachers, lawyers, service providers, administrators, professional advocates, professors and politicians. What these people share is an ability to see what others see, but to see it in a new way. Current and future leaders share a commitment to really knowing and caring about people's hopes, dreams and desires, and to being part of seeing them reflected in people's lives. Behind all of their different roles and approaches, current and emerging leaders share unusual levels of commitment to people, a sense of their own mission, energy, creativity and the ability to work with and for others.

The Committee will continue its support of emerging leaders through continuation of the Next Generation Leadership Symposium, networking with young leaders participating in the initial Symposium, and providing ongoing support to members of the direct support workforce and self-advocates.

THE ELIZABETH MONROE BOGGS AWARD

A highlight of the Next Generation Leadership Symposium was the presentation of the Elizabeth Monroe Boggs Award for Leadership in the field of mental retardation. The Committee chose this in honor of Dr. Boggs' inestimable contributions to the field and to the Committee, and in loving memory of her mentorship of current and emerging leaders. Dr. Boggs cut across all the areas encompassed by the Next Generation of Leaders: public policy, advocacy, service provision, and as a parent - the role closest to her heart. In doing so she developed and promoted a deep love and respect for direct

support workers and they for her. Consistent with one of the Committee's goals for the Symposium, Dr. Boggs also loved to connect people working in one area or field to another, promoting good work around the nation and around the world.

Three young leaders who received the Elizabeth Monroe Boggs Award for Leadership were culled from nominations submitted to the Committee from around the country:

- **Kerri Melda**, a resident of Portland, Oregon, is a Research Associate with the Human Services Research Institute, located in Salem, Oregon, provides leadership in the areas of family support, applied research, and inclusion. Kerri's activities have had a positive impact on enhancing self determination for citizens with mental retardation in Oregon.
- **Tia Nelis**, Naperville, Illinois, is a self-advocate employed by the University of Illinois at Chicago/University Affiliated Program and a leader in the self-advocacy movement. Tia is the Chair and one of the founders of Self Advocates Becoming Empowered, a national organization devoted to strengthening the role of self-advocates, finding alternative living arrangements for people with mental retardation, and seeking the closure of institutions. She has held leadership positions with the Illinois Developmental Disabilities Planning Council and People First of Naperville.
- **Lesa Nitcy Hope**, Atlanta, Georgia, is a professional working with the Atlanta Alliance on Developmental Disabilities. Lesa has made numerous contributions to improving the lives of people with mental retardation, including: providing respite for people with disabilities in her home; training people with disabilities and their family members throughout the State of Georgia in person-centered planning techniques as part of personal futures planning; working with agencies to develop strategic plans that move services to a more person-centered and support orientation; and conducting values training around the State on the principles of participation and inclusion.

The Committee anticipates that the Elizabeth Monroe Boggs Leadership Award will be an annual program, recognizing the hope and talent of people of all ages.

CHALLENGES TO BE ADDRESSED

The Committee and the Next Generation Symposium participants reviewed nine challenges that are part of the recent past and the current world, affecting individuals with mental retardation from infancy through their lifespan:

- The continuing phase-down of State residential facilities and the related uncertainties among many family members that often accompany that process.

- Reducing waiting lists, which in particular are affecting young people waiting for services following their education and aging families who are the primary caregivers.
- Making inclusion work in the school, the workplace and community.
- Maintaining vigilance in managed care policies and implementation.
- Extending employment opportunities.
- Expanding opportunities for people to have homes of their own.
- Supporting direct care professionals through enhanced compensation, training, career opportunities and status.
- Enforcing equity and fairness in the area of criminal justice - currently an oxymoron as it relates to people with mental retardation.
- Realizing the benefits and potential of assistive technology.

These prominent concerns, along with the public policy issues and thoughts on leadership, were considered throughout the Symposium as young leaders met in small groups and developed recommendations in seven areas: Public Policy, Community Development, Education and Early Intervention, Self-Determination and Community Inclusion, Health and Wellness, Civil Rights and Cultural Diversity, and Research and Development.

III. Public Policy: Changes, Choices and Challenges

I intend to spend the next four years doing everything I can to help communities to help themselves; to educate all Americans about what is working and to create, in the process, a national community of purpose. It will require us, however, to believe that our fellow Americans are capable of doing this. This morning I met (Ann Forts,) a young woman from New Hampshire with Down syndrome - one of two people with mental retardation I appointed to the President's Committee on Mental Retardation - who gave me a letter, a resume, and a button. It said "Down Syndrome, " only the "Down" was crossed out and replaced with "Up." Does that person have limits on what she can achieve? Sure, there are some. So do I. So do you. But if you spend all your time thinking about it, you won't think about what will be up instead of down. You must believe in the potential of the American people. We cannot afford to patronize each other with cynicism.

Excerpted from President Clinton's remarks to the Democratic Leadership Council, December 11, 1996.

The Next Generation Leadership Symposium's keynote speech by Representative Patrick Kennedy focused on public policy issues. He identified a wide range of challenges faced by those concerned about people with mental retardation during the past Congressional session, in particular protecting safety nets for our most vulnerable citizens

in the face of pressures to balance the Federal budget and to devolve responsibilities to the States. Representative Kennedy also described his great pride in what his family has done in the area of mental retardation. He urged all participants to recognize the importance of their work and to make their voices heard on Medicaid, on maintaining essential entitlements, and on the assumption of responsibilities at the State level that appropriately address the needs of people with mental retardation and their families.

Kathleen McGinley, Ph.D., The Arc-US Governmental Affairs Office, shared the Committee's concern that changes are being made for expediency and flexibility, but not necessarily in the interests of individuals:

- Choices need to be made based on people's needs and desires, with meaningful options available.
- We need challenges that can be addressed, and to create opportunities - not focus on barriers.

Laurie Rubiner, Legislative Assistant to Senator John Chafee, warned Next Generation Leaders that efforts are likely to continue to convert Medicaid into a block grant, with potential risks to people with mental retardation and related disabilities.

Our role as advocates is to become involved at every level, to stay informed, to work to shape public policy, to identify needs and communicate them, and to work to change the balance of power so that the disability community is better represented. To work against stigma and discrimination, we need to tell our stories effectively, to shape public opinion, and to use the media effectively.

Across all areas of public policy, we must think in the long term - to send the message of the long term benefits of access to health care, to a free appropriate public education, to affordable housing in the community, to effective transition services from school to real jobs in the community, to dependable transportation, and to the essential safety net programs. We need to say that the long term fiscal and human costs are going to be too high if supports are removed in the name of short term budget cuts.

THE LINK BETWEEN POVERTY AND MENTAL RETARDATION

The critical need to preserve the safety net is underscored by an understanding of the association between poverty and mental retardation. There is no denying the substantial association between mental retardation, as defined by measured intelligence, and socio-economic status. Data from the National Health Interview Survey show that risks for mental retardation and related disabilities, learning impairments, and emotional disorders are related to family income.

Although there are some dissenters, the current dominant view is that low socio-economic status creates conditions that predispose some children to mental retardation.

Impoverished women are less likely to be healthy before conception and are less apt to receive adequate prenatal care during pregnancy.

Children born into and raised in relatively disadvantaged circumstances often are deprived of essential educational, health and social support systems. Many are also exposed to environmental threats to normal development such as poor family structure, infectious diseases, inadequate nutrition, lead poisoning and many other difficulties, usually in combination. These factors are associated with severe levels of mental retardation as well as more mild levels, and with numerous other physical and behavioral disabilities. Fetal alcohol syndrome, the leading known cause of mental retardation, while present everywhere in American society, is ten times more prevalent in areas of urban poverty than elsewhere.

Especially when occurring in combination with minority status, poverty also is associated with reduced access to services and supports. Participation is compromised by lack of transportation, lack of resources for school supplies and supports used in the home, lack of information on what is available, and unmet health and mental health needs.

PUBLIC POLICY RECOMMENDATIONS

- Legislation should be passed providing universal health care.
- The Federal budget should be restructured to provide a more equitable distribution of dollars across the board, not just in the pool of resources that is directed toward disability issues.
- Resources for services and supports should be redistributed to put funds or their control directly in the hands of consumers and families, in ways that create a competitive marketplace among providers, both specialized and generic.
- Authorization for the Medicaid program should be changed to permit vouchers. This change would allow Medicaid funds to be used in ways that more specifically meet the needs of the consumers and families the program is intended to help.
- Federal and State Medicaid program reforms should recognize commitments previously made to groups of needy individuals. There should be assurances that current allocations remain dedicated to those who depend on these resources rather than going into State general funds. States should have guidelines and regulations on how Medicaid dollars are spent.
- The impact of managed care on people with disabilities should be scrutinized, including the full range of health and economic ramifications. Safeguards and quality indicators should be developed, tested and implemented.

- Appropriate technical and financial support should be coupled with a legislative mandate to close all segregated settings, including institutions. States should be required to develop comprehensive plans for closing segregated settings, with input from all affected stakeholders. Funds currently supporting these settings should be reallocated to other services chosen by consumers.
- There should be prohibitions against segregated schooling for people with disabilities; existing mandates for education in the least restrictive environment should be monitored and scrupulously enforced.
- People with disabilities, parents and families should have a voice in how policies are shaped and molded for the future, with opportunities for active participation as members of decision making bodies and advisory groups.
- Consumers and parents should be educated about public policy issues, and should be allowed to lead and direct the disability movement into the next century.

IV. Community Development: Opening Doors For Housing and Employment

Please tell President Clinton that I would like to see more State institutions closed. We can help States do this, to get people into homes of their own, doing things in the community and not being stuck on an institutional campus. We also can encourage businesses to hire people with disabilities.

Kevin Parker, Self-Advocate (Oklahoma)

HOUSING

Success of individuals and advocates in housing-related decisions at the local and State levels is one of the most critical components to success both now and in the future. Without the informed involvement of people with disabilities and their advocates as communities develop their future housing strategies, the needs of people with disabilities will continue to be unmet. Because Federal housing policy is affected by Federal, State and local laws, there is an equally critical need for people to be active and informed participants in the legislative process at every level.

Even when the housing needs of people with disabilities have been accurately estimated - rarely reflected in the Consolidated Plans mandated by the Department of Housing and Urban Development - the affordable housing delivery system has been resistant to expanding housing opportunities for people with disabilities. Among the many reasons for this lack of response are a lack of information and understanding of disability issues, stigma, and housing discrimination that continues to occur within the affordable housing system. If people with mental retardation and related disabilities are to have the opportunity to participate and contribute to society - the major premise of the Americans with Disabilities Act - then they must have access to decent, safe and

affordable housing in the nation's communities and neighborhoods. We must begin to open the doors!

Despite the crisis in affordable housing, there are several positive trends in where people with mental retardation are living:

- The number of children with mental retardation and related disabilities in public institutions continues to decline, thanks to the right to a free and appropriate public education under the Individuals with Disabilities Education Act and increased access to family supports. Today about 3,000 children and youth (21 years and younger) live in public institutions, compared with 54,000 in 1977 and 91,000 in 1965.
- The typical size of residential service arrangements is at an all time low, with most States - 29 in all - serving the majority of individuals in settings of six or fewer people.
- Large public institutions continue to be closed in favor of community living arrangements. Nearly 40 percent of the State institutions designated for people with mental retardation and related disabilities that were operating in 1960 have been closed. By 1996, three States and the District of Columbia had closed all State institutions, and four additional States projected total State institution closure by the end of 1998.
- States are increasingly using more flexible approaches to residential services, including supported living programs and replacing community-based Intermediate Care Facilities for persons with Mental Retardation (ICF/MR) with services and supports funded through the Medicaid Home and Community Based Services waiver. In June 1996 there were over 190,000 people receiving services through the waiver program, more than three times the 62,000 participants in June 1992. Over the same period participation in the more costly and institutionally-oriented ICF/MR program decreased by about 20,000.
- The National Home of Your Own Alliance, the Fannie Mae "Home Choice" underwriting experiment, and related State programs have stimulated widespread innovations in making home ownership and control over living arrangements a reality for many people with disabilities. Over 42,000 people with mental retardation and related disabilities receive residential support in homes that they themselves own or rent.

Major barriers remain, however, for many individuals with mental retardation and their families. Despite a steady increase in the total number of people receiving publicly-funded community living support and in the development of community living arrangements, waiting lists have grown larger in many States. A recent study found that States would have to collectively increase their overall residential capacity by 18 percent just to meet current demands, an unlikely scenario in the climate of constraints on public

dollars and flatter State agency budgets. Waiting lists in many States number in the thousands, comprised in particular of people in institutions waiting to move to the community and people with mental retardation who are living at home with aging parents. For example, in Maryland alone, 13 percent of the 5,000 people on the waiting list are in the care of parents aged 80 and older.

There are also wide variations among the States in the extent to which they have moved toward smaller community living arrangements. Although the national average size of residential settings (including institutions still in use) is 3.9 individuals, the range is from 1.3 in Vermont to 18.7 in Virginia. States also vary greatly in the extent to which they have embraced more flexible funding arrangements, in particular under the Medicaid Home and Community-Based Services waiver, and have moved away from the more restrictive facility-oriented ICF/MR program.

EMPLOYMENT

People with disabilities represent an employment resource that has been largely overlooked. As employees they repeatedly get high marks from managers on job-related issues. A U.S. Census study found that 20 million of the more than 29 million working age adults with disabilities in the United States are unemployed; nearly 80 percent of them would like to work but do not.

Since the passage of the Americans with Disabilities Act in 1990, businesses must provide equal opportunity and reasonable accommodations to people with disabilities. The average job accommodation costs employers \$50 or less. Employers prepared to work effectively with workers with disabilities will not only be better able to meet the letter and spirit of this law, but will have a competitive advantage in recruiting and retaining the most qualified workforce possible. There is also evidence that the Americans with Disabilities Act is contributing to increased employment ratios among individuals with severe disabilities.

Supported and competitive employment opportunities continue to expand for people with mental retardation, with more and more individuals working in integrated settings and receiving higher wages than possible in segregated sheltered employment. The total number of individuals with disabilities in supported employment grew from 10,000 in 1987 to approximately 140,000 in 1995. In addition, people with disabilities can increase their annual earnings by up to 500 percent through supported employment, with people with severe mental retardation among those most likely to see significant gains in earnings. There is also evidence that supported employment is cost-effective, costing significantly less than other day support options for people with significant disabilities, such as sheltered workshops or activity centers.

Innovations like Bridges...From School to Work, established by the Marriott Foundation for People with Disabilities, are fostering the employment of young people with disabilities. The program focuses on the transition from school to employment through paid internships for students with disabilities in their final year of high school.

Managers and supervisors receive disability awareness training, while the school system supports students and their families throughout the internship process as well as maintaining regular contact with the program's employer representatives. Other emerging approaches of interest include natural workplace supports, consumer-directed supported employment models, employer-directed support activities, business and corporate initiatives, broader applications of assistive technology, and other workplace accommodations.

Despite these gains and innovations, however, much remains to be done to ensure that adults with mental retardation have opportunities for community employment, fair wages and benefits, and productive activities of their choice. The allocation of State and Federal resources is still heavily skewed toward sheltered employment. People with severe disabilities continue to be under-represented in supported employment. Although thousands of individuals with severe mental retardation are working successfully in competitive employment, negative attitudes and low expectations among both professionals and employers continue to restrict job opportunities. Low wages and part-time employment reduce opportunities for self-sufficiency, along with limiting access to health insurance and fringe benefits.

There are also many barriers to work for people receiving Supplemental Security Income and Social Security Disability Insurance benefits. Even modest employment income can cause people with disabilities to lose their monthly Social Security disability payments, and often, more importantly, to lose the associated health insurance benefits through the Medicaid and Medicare programs. This is an understandably frightening prospect for people with disabilities and their families, especially when many of the jobs that are available do not provide health coverage. Surveys have indicated that loss of health coverage is even more of a concern than the potential reduction of cash assistance for many people.

In addition, the prohibition of Medicaid financing of vocational supports (with limited but beneficial exceptions) continues to create financial incentives for placing people with mental retardation in non-productive "habilitation" settings. This problem was reflected in a recently released evaluation of a five-year Medicaid Community Supported Living Arrangements demonstration in eight States, which found participants most frequently dissatisfied with their daytime activities, primarily because of the exclusion of significant vocational opportunity.

COMMUNITY DEVELOPMENT RECOMMENDATIONS

- Community development should focus on developing partnerships for affordable housing, community employment, and providing supports for people with mental retardation. In developing these partnerships, we must take the time to get to know people as people, not just agencies.
- Community members, including potential employers, need to be better educated about people with disabilities. The language used to describe people with

- disabilities should be modified to promote better understanding and acceptance, including focus on the contributions they can make when given the opportunity.
- The Americans with Disabilities Act should be more strongly enforced concerning people with mental retardation; ADA is not limited to physical barrier issues.
 - People with disabilities need to be in control of where they live and to have choices in their living arrangements. To make this a reality, consumers, family members and service providers must receive improved training and support.
 - Waiting lists must be reduced.
 - People with disabilities should get their fair share of HUD Section 8 resources and should be able to transfer their Section 8 assistance to home ownership.
 - Tax incentives should be provided to employers who hire people with disabilities.
 - To promote employment success, employers and potential employers and co-workers should receive disabilities awareness training that will lead to natural supports.
 - Incentives should be established and disincentives removed so that people with disabilities have access to on-the-job training, internships for job sampling, and other supports to employment and career development.
 - Self ownership of businesses and entrepreneurship should be promoted for people with disabilities.
 - Employment and housing regulations should be flexible enough to allow for highly personalized support plans.

V. Education and Early Intervention: Foundations For Success

I like going to school with my friends. I have great teachers.

Beth Terrill, Student and Self-Advocate (Illinois)

Twenty years of Federal guarantees of a free and appropriate public education under the Individuals with Disabilities Education Act (IDEA) and its predecessors have been an outstanding success. During this time 20 million children with disabilities have received education intended to meet their individual needs. The success of this law and its commitment to providing equal access to education for students, regardless of their disabilities, is reflected in higher portions of students graduating from high school, entering college, and becoming competitively employed. Only 33 percent of older people with disabilities are employed, compared to 57 percent of youth who have benefited from IDEA and who are employed within five years of leaving school.

Although falling short of original goals in funding a portion of special education costs, an increase in Federal appropriations will provide States with nearly \$3.8 billion in assistance in FY 1997. In addition, over \$250 million in Federal resources will provide essential support for developing teacher training models, research on best practices to improve educational outcomes for specific and diverse disabilities, developing educational technology, and technical assistance to educate parents about their rights and responsibilities.

Maintaining these successes, however, requires a renewed commitment in the IDEA reauthorization to addressing the individual needs of each student with disabilities, as identified in their Individual Education Program, with effective supports and incentives for schools, teachers, children and families. State and local education agencies and teaching personnel need support in making inclusion work, especially for students with mental retardation and with severe disabilities. Over five million students with disabilities rely on IDEA for educational opportunities, from early intervention as infants and toddlers to young adults transitioning to the world of work. Although improvements in IDEA can be made during the reauthorization process, this is no time to pull back on the nation's commitment to equal access to education.

EDUCATION AND EARLY INTERVENTION RECOMMENDATIONS

- Resources for education and early intervention should be expanded.
- Teachers should be trained to educate all students, including those with mental retardation and related disabilities and those from culturally diverse backgrounds.
- Teachers and other professionals should be helped to overcome any tendency to prejudge the ability limits of people with mental retardation.
- Student teaching should be done in inclusive classrooms.
- Enhanced teacher training should lead to the creation of a unified educational system and the elimination of separate and parallel general education and special education systems.
- Biases in tests and assessments related to disability and cultural diversity should be removed.
- Parents should be educated and empowered so that they can be actively involved as advocates for their children.
- Beginning with pre-school, education should encourage full inclusion in all areas of community life.

VI. Self-Determination and Community Inclusion: Respecting Each Person as an Individual and as a Citizen

Everyone can get natural support if they are given a chance to be a part of their community. It does not matter if they are a person with a disability or a person without a disability.

James Meadours, Self Advocate (Oklahoma)

Every generation of leaders is challenged to bring new ideas and solutions to the forefront while helping make existing best practices the usual way of doing business. Even more than leaders of recent years, emerging leaders face another dimension: cost containment. Their challenge is to discover ways to enhance the citizenship and satisfaction in the lives of individuals with mental retardation and related disabilities and to do so without increasing expenditures.

Although this is not a wholly new challenge, few can doubt that cost containment will be a more visible aspect of efforts to enhance the lives of people with mental retardation and their families in the future. Leaders are needed who can:

- Help discover better ways of assisting people to live the lives they want that do not depend just on more money.
- Redesign and transform systems from supporting programs to supporting people.
- Learn and teach others how to support increasing numbers of people, including tens of thousands who are waiting for services, with public resources that will grow much more slowly than will demand.

Achieving goals of having each person supported by, happy in and contributing to their communities, will require leaders who can deal creatively with a future that seems fraught with scarcity, complexity and ambiguity.

For people with disabilities to get all they want out of life it is important for them to have loving, caring relationships with other people. Like everyone else, individuals with mental retardation enjoy friendships, activities with people who know and care about them as individuals, and having someone who can provide support when things aren't going well, as well as celebrating each other's successes. Public and private certification programs increasingly recognize relationships as a significant aspect of the quality being provided to individuals, especially in residential programs. Families in many States are also receiving training and other supports to be involved actively in maintaining their relationships with their relative with mental retardation and related disabilities and to participate in person-centered planning.

Although much progress has been made, loneliness and social isolation are still the reality for too many individuals with mental retardation. Many community members need support to become connected with people with disabilities as neighbors, co-workers

and friends sharing common interests. Creative hard work is needed so that civic organizations, churches, community recreation, social programs and other organizations and their members can be recruited and supported in efforts to establish and sustain relationships and natural supports. Next Generation Leaders must give families, support staff and other partners the tools and opportunities they need to make natural supports a reality.

Increased support for self-determination and self-advocacy is also needed. There is increasing recognition that people with mental retardation and related disabilities need the same kinds of people in their lives that all of us need: people who will listen, not assume; who will accept reasonable risk in pursuit of personal goals, not demand perfect safety; who value challenge as fundamentally human, and total protection from failure as debilitating; who will suggest, not dictate, and who celebrate common human values regardless of differing abilities.

People have been helped to become physical citizens of our communities and some have been helped to participate. The next challenge is to fully honor people's citizenship by providing levels of freedom and control over their lives that reflect the values of the society in which they are citizens.

SELF-DETERMINATION AND COMMUNITY INCLUSION RECOMMENDATIONS

- National, State and local commitments are needed to assure that residential, training and other settings that impede people's opportunities for self-determination and community inclusion will be replaced by settings that do not. Implementing these commitments will require a steady and reliable information flow about successful practices that move people from congregate care to homes, jobs and valued roles in their communities, and attention to the disincentives that continue to deprive people with mental retardation of opportunities.
- Self-advocates must be assisted to help themselves, to help each other and to help those who support them to understand what they want and need. Government needs to do better at guaranteeing meaningful involvement of consumers in all aspects of individual services development, funding options, and service operations that affect people with mental retardation. "Nothing about me, without me" should be the prevailing principle.
- The abilities and commitments of professionals, support staff and family members to listen, and to hear people with mental retardation, including those who cannot talk, must be improved. It is important to:
 - Establish person-centered planning, conducted by skilled facilitators, as a preferred strategy when individual services are being planned.

- Train Federal, State and local quality assurance monitors about the nature, benefits and practices of person-centered planning.
- Continue to develop and assure people's access to alternative and augmentative communication tools that accommodate language impairments.
- Expanded funding, demonstration efforts, technical assistance and other supports for supported community living must be increased to enhance State and local agency capacity for services that help people live the lifestyles that they choose. To this end, the Federal Health Care Financing Administration should continue to facilitate State efforts to move Medicaid long term care funds from the ICF/MR program to Home and Community Based waiver services. Federal and State governments should establish mechanisms assuring that housing funds support purchases by and for consumers.
- People's rights and natural tendencies to make changes in their lifestyles as their needs and interests change must be honored. This requires that funding systems be restructured to assure that resources allocated on behalf of people with mental retardation and related disabilities can go with them as they seek changes in their lives and careers, so that funding rigidity no longer traps people in unwanted places and programs.
- Innovations designed to give people more control over their lives and resources must receive greater support, such as through funding models that give people more control over the financial resources allocated for their Medicaid long term supports. Such models should be evaluated and publicized and "fast-track" waivers should be extended to allow demonstrations of individually controlled budgets. Governments at all levels must become much more active in creating expectations and mechanisms that assure consumers a central role in resource utilization, choice of provider, and other aspects of consumer control.
- Communities and their organizations (places of worship, neighborhoods, parks, etc.) must be challenged to accept their obligations for enhancing the community membership of people with mental retardation. Political and moral leaders must speak out about the community's responsibilities and opportunities, particularly as State and local organizations take on relatively greater responsibility for the well-being of people with disabilities. Better information must be generated about States and communities that are models for others in accepting these responsibilities, coupled with greater efforts to acclaim and support successful promotion of community membership.
- Information sharing on how people with disabilities achieve more self-determined lifestyles should be improved and expanded through:
 - Government-supported forums bringing together self-advocates, families and staff to share ideas, energies and mutual commitments.

- Support access to technology-based information opportunities to reach people in different locations.
- Development of print and electronic databases.
- Resources that allow widespread communication about innovations and experiences.
- Natural supports must receive greater attention, including:
 - Recognition of the importance and benefits relative to costs when natural supports are developed and sustained.
 - Government efforts that develop, sustain and study the outcomes associated with natural and other non-traditional long term care and vocational supports.
 - Information dissemination on strategies that foster natural supports.
- Health and safety expectations, rules and monitoring mechanisms must be built around the lifestyles that people want for themselves. Like everyone else, people with disabilities should be spared lives that are dictated solely by what is comfortable to bureaucracies. Government-based quality assurance systems for service programs must recognize that individual differences mean that quality varies from person to person. Efforts to develop, evaluate and publicize innovative approaches to quality assurance/quality improvement must be supported.
- People with disabilities should be taught the importance of learning how to develop a wide range of friends, to form one of the most important keystones in their natural support bridge to full inclusion in their communities.

VII. Health and Wellness: Promoting Optimal Health

For millions of Americans with disabilities, the lack of access to comprehensive health care undermines the promise of the Americans with Disabilities Act for inclusion, independence and empowerment.

Allan Bergman, Advocate, Policy Analyst and Parent (Washington, DC)

There is a continuing health care crisis in the country, one that disproportionately affects children and adults with disabilities and their families. Although new legislation will improve access to health insurance for many with "pre-existing conditions," others will be excluded because they are currently uninsured or are not covered through employment-based programs.

Current health insurance plans are also biased toward acute care, often failing to cover medically necessary services for people with chronic illnesses and conditions.

Managed care, while holding some promise of coordination and of cost effective early intervention and preventive care, presents challenges for people with mental retardation and related disabilities in implementation. Concerns include continuity of care, access to specialists familiar with the individual and with disabilities, and coverage of needed services on a long-term basis. Managed care in both the public and private insurance sectors bears watching to ensure that the needs of people with disabilities are addressed.

The Medicaid program has over 30 years of success as a significant resource to people with mental retardation. This Federal-State partnership has been an essential part of the safety net for individuals and their families, supporting a wide range of acute and long term care services across the nation. Medicaid also is a major resource to local education agencies in supporting children with disabilities, where it is estimated that 30 to 40 percent of special education students under IDEA, from infants to young adults, are also Medicaid-eligible.

Partnerships between education and Medicaid programs are greatly benefitting children with disabilities as well as helping with local special education costs.

Although not implemented as fully as it could be, the Medicaid Early Periodic Screening, Diagnosis and Treatment program has made a major contribution to the health of low income children with disabilities, as well as helping to prevent disabling conditions. Threats to health service access for these children through a Medicaid block grant program and elimination of the Supplemental Security Income benefit for children, with its link to Medicaid eligibility, were defeated through the Administration's leadership. It is generally expected, however, that proposals to limit the Medicaid program and to eliminate Federal safety net guarantees affecting health care will be reintroduced in the coming year.

One of the most exciting areas emerging in health care for people with mental retardation and related disabilities is a stronger focus on health promotion and wellness, rather than the traditional emphasis on disability and impairment. There is growing recognition among both self-advocates and health professionals that we need to work on abilities in health as well as other aspects of daily living, and on changing health care practice to treat the whole person. Exercise, nutrition and spiritual health are critical to everyone, especially those with disabilities.

HEALTH PROMOTION AND WELLNESS RECOMMENDATIONS

- Managed care should be closely monitored and evaluated regarding its impact on individuals with mental retardation and related disabilities, especially the implementation of managed care in long term services.

- Information on State and private insurance managed care implementation, in particular the outcomes for people with disabilities, should be widely disseminated.
- The Medicaid safety net should be protected. State flexibility should continue to be supported, but not to the extent that basic Federal standards for access and quality are eliminated.
- The Medicaid Early Prevention Screening, Diagnosis and Treatment program should be expanded to populations that are socially disadvantaged.
- National health promotion messages should be provided through public service announcements and other public education tools that are culturally and linguistically appropriate.
- Funding should be made available for demographic studies that would identify medical and prevention issues within each State.
- Training for future leaders in health care delivery and policy should include health and wellness for individuals with mental retardation and related disabilities.

VII. Civil Rights and Cultural Diversity: Justice for All

People with disabilities are the most discriminated against population. I hope President Clinton recognizes the need for services and supports that promote community participation and interdependence with others, and the need to support the agencies and staff who work with people with disabilities.

Sally Jochum, Community Living Coordinator (Kansas)

The United States consists of a diverse population, and we must make a conscious effort to meet the needs of all our people. Too often, however, little consideration is given to the needs of African-Americans, Hispanic Americans, Asian-Americans, Native Americans and other members of minority populations with disabilities. People - including some of those with disabilities who are not members of minority groups - tend to ignore the ways that education, employment and empowerment uniquely affect people of color with disabilities. At the same time, there is also growing recognition that it takes different individuals with disabilities to make up a strong and vibrant disability rights movement, with growing recognition of the importance of people of color with disabilities to the movement's survival.

With the passage of the Americans with Disabilities Act in July 1990, the disability rights issue clearly assumed its rightful place as a major civil rights movement in the eyes of the nation. Its implementation has been reflected in increased employment ratios among adults with disabilities, expanded access to commercial, governmental and recreational facilities, and enhanced public awareness of disability rights. Resources also have been significant in reaching individuals with disabilities, to inform them of their

rights under the Americans with Disabilities Act, as well as providing information and training to organizations on compliance.

Continued vigilance is needed, however, to improve ADA implementation. Consistent enforcement needs to be vigorously maintained, along with resources that support cost effective compliance. People with disabilities must have access to advocacy services that can help them use the remedies specified in the Act. This access is particularly important for people with disabilities who are less able to speak for themselves due to poverty, powerlessness, or physical or mental limitations. Rights without remedies are no rights at all.

Individuals who are both members of racial minorities and have a disability commonly meet multiple barriers. Some specific issues facing people of color who have a disability include over-representation in special education, in institutions for people with mental retardation and mental illness, and in the criminal justice system; and the disparity in death penalty cases for African Americans and for people with mental retardation.

There are also strong cultural issues in minority communities that affect people with disabilities, some of which act as barriers to seeking and accepting the services that are available - especially when services and supports are not culturally competent.

CIVIL RIGHTS AND CULTURAL DIVERSITY RECOMMENDATIONS

- Recognize and address the problems faced by people with disabilities whose color, race, religion or ethnic background differs from that of the dominant culture.
- Otherwise qualified immigrants with disabilities should not be excluded from government-funded health and social supports.
- In addressing the need to balance choice and safety issues, clarification is needed on conflicts between civil rights and protective mandates and on liability issues for provider organizations when they fully support the individual civil rights of people with mental retardation.
- State Bar admission examiners and law schools should focus increased attention on disability issues.
- Police officers, judges, public defenders and corrections officials should recognize the presence of people who have disabilities within these systems.
- Alternative sentencing options should be considered for people with mental retardation and related disabilities. Model programs addressing the needs of people with disabilities accused of crimes should be expanded.

- An effort should be made to educate judges, prosecutors, district attorneys, law enforcement personnel and others in the criminal justice system regarding the special problems of people with disabilities who are crime victims.
- Education about people's civil and criminal rights should include discussion of the responsibilities inherent in those rights and the means for enforcing civil rights provisions.
- Education about rights, responsibilities and enforcement should be provided in the language of the person receiving that education.

IX. Research and Development: Informing Policy Decisions

The Symposium gave me renewed energy about my research and a sense of hope for the future. I would like to be creative when addressing issues of supported living, supported employment, mental health and supports that help prevent mental health problems of people with mental retardation. Research can become more relevant and inclusive, with teamwork that includes self-advocates and family members.

Yona Lunsky, Researcher and Family Member (Ohio)

The President's Committee on Mental Retardation and the National Institute of Child Health and Human Development, National Institutes of Health, have worked together since the early 1960s. In 1996 the Institute collaborated with the Committee in supporting the Next Generation Leadership Symposium. Many research advances have occurred over these years that have helped to prevent mental retardation and to improve the lives of people with mental retardation. Mental retardation prevention achievements include vaccines for measles, encephalitis and rubella; Rhogam to prevent rH incompatibility and jaundice that causes bilirubin encephalopathy; PKU screening; and the development of a vaccine for Haemophilus influenzae type b meningitis (Hib), previously the leading cause of acquired mental retardation in the United States. Hib meningitis cases have dropped from about 15,000 per year to less than 200 in 1995.

Current work is rapidly expanding the understanding of genetic mechanisms associated with mental retardation, while work continues on infectious diseases. Advances in molecular medicine are improving our ability to prevent and diagnose mental retardation and related disabilities, and to better manage the care and treatment of disorders. Additional knowledge can be developed to extend these capabilities, coupled with efforts to assure that information already available benefits individuals and families.

Research also can make a significant contribution to the policy debate on services and supports. Research on the links between poverty, nutrition and mental retardation provide solid evidence of the essential need for safety net programs to be maintained. Research on familybased care, on waiting lists and bottlenecks in the service system, and on the shift from services to supports and from facility-based services to supports that are organized on a flexible, person-by-person basis - can inform policy decisions at the

Federal, State and local level. Better knowledge on the sources of variation in the "lived experience" of mental retardation is at the heart of the social policy research enterprise. Information on best practices, as well as practices to be avoided, is essential to program decision-makers and advocates as they examine current systems.

Given the substantial moral and financial investment we make in this country toward the care of people with mental retardation and related disabilities, and in light of the vibrant self-advocacy evident within the disability community, it is imperative that we spend our talents and resources on the most humane and productive modes of support. The needs of families - the most durable support system for people with mental retardation - have long been ignored in public policy arenas. The growth of family support programs, including respite services and cash assistance, is a positive development. The need for alternatives to family-based care is also evident.

The identification of new strategies to smooth out the bottlenecks and to develop new patterns of support is one of our most compelling challenges as we enter the 21 st century. There is also growing impetus for participatory research - research that involves individuals with disabilities in meaningful roles, from design to implementation, and research that is relevant, useful and accessible to those on the front lines of program management and implementation.

RESEARCH AND DEVELOPMENT RECOMMENDATIONS

- People with disabilities should be involved and fully supported in all facets of research on disability issues, including learning how research is conducted.
- Research should clearly be linked to outcomes and action. Relevant research on behalf of people with disabilities should be translated into appropriate policies and implementation. Existing research should be re-examined and used in new ways.
- Key stakeholders and people from different fields, including self-advocates, should be brought together to work toward greater involvement in research with findings in which they have a vested interest.
- Research should be supported that respects the individuality of people with disabilities, including research across the lifespan and on people with different needs and of different cultures.
- Research should be conducted on the effects of family and other environmental factors on children's disabilities and achievements, and on the effects on people with mental retardation and related disabilities of policy decisions in other areas.
- More research should be accessible to the average person so that it can be understood and used. As appropriate, findings should be broadly disseminated to

policy makers, people with disabilities, families, direct support workers and the general public.

- People with disabilities who participate as subjects in research projects should be made fully aware of the meaning of "consent."
- Efforts to encourage the next generation of leaders to become involved in research in the field of mental retardation and related disabilities should be expanded, including outreach, research training opportunities, and broader grant support.
- Research should be funded primarily at the national and not the State level.

X. Summary

The meeting made me feel like a leader. It made me feel important to speak to so many people and helped me think about what job I will have when I grow up. Perhaps I will work for disability rights or be a speaker.

Beth Terrill, Student and Self-Advocate (Illinois)

Symposium participants represent emerging leadership across the nation. From the meeting they brought back new ideas, increased understanding of issues affecting their work and of different approaches being tried around the country, a network of contacts for continuing dialogue, and a renewed dedication to the field of mental retardation. Their enthusiasm for another Symposium was strong; the Committee will convene the second Next Generation Leadership Symposium in August 1997.

Voices of young leaders will also be heard over the next several years as they build on the Next Generation Leadership Symposium experience. Personal visions of leadership include:

- Expanding dialogue with self-advocates.
- Conducting research that makes a difference in people's lives.
- Helping to provide answers to new questions on supported living, supported employment and good mental health.
- Being part of the direct support workers' movement into leadership roles.
- Sharing the power and the glory and helping other self-advocates become leaders.
- Making a difference even if on a small scale - a difference in just one person's life is important.
- Increasing knowledge and sharing it with others.

- Becoming more involved in community education.
- Seeking more knowledge of how the system works and what affects individuals.
- Becoming more politically active.
- Continuing the dialogue with people around the nation.
- Building teamwork between direct support workers and self-advocates.
- Helping communicate the need for effective services and supports.

The spirit of these visions is captured in the following lines by Langston Hughes, presented at the Symposium by Lesa Nitcy Hope in her acceptance of the Elizabeth Monroe Boggs Award for Leadership:

There is a dream within the land with its back against the wall.

To save the dream for one of us, it must be saved for all.

These young leaders are an inspiration who refresh and renew the Committee's spirit.

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Center for Environmental Health
Developmental Disabilities Branch
Health Resources and Services Administration
U.S. Department of Health and Human Services
4770 Buford Highway, NE
Mail Stop F15
Atlanta, Georgia 30341-3724
PH: 770-488-7360
FAX: 770-488-7361

Maternal and Child Health Bureau
Division of Services for Children with Special Health Needs
Health Resources and Services Administration
U.S. Department of Health and Human Services
Parklawn Bldg. - Room 18A-27
5600 Fishers Lane
Rockville, MD 20857
PH: 301-443-2350
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National Institute of Child Health and Human Development
National Institutes of Health
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President's Committee on Employment of People with Disabilities
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Washington, DC 20004-1107
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FAX: 202-376-6219
WEB: <http://www.pcepd.gov>

Office of Special Education and Rehabilitative Services
Secondary Education and Transition Services Branch
U.S. Department of Education
Room 4625, Mary E. Switzer Bldg.
330 C. Street, S.W.
Washington, D.C. 20202
PH: 202-205-8112
FAX: 202-205-8971

Office of Disability
Social Security Administration
Room 545, Altmeyer Bldg.
6401 Security Boulevard
Baltimore, MD 20235
PH: 410-965-3424
FAX: 410-965-6503
WEB: <http://www.ssa.gov/odhome>

Housing and Civil Enforcement Section
Civil Rights Division
U.S. Department of Justice
P.O. Box 65998
Washington, D.C. 20035
PH: 202-514-4713
FAX: 202-514-1116

Division of Adult Education and Literacy
Office of Vocational and Adult Education
U.S. Department of Education
Room 4428,
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Washington, D.C. 20202
PH: 202-205-9872
FAX: 202-205-8973
WEB: <http://www.ed.gov/offices/OVAE>

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1331 F. Street, NW, Suite 1050
Washington, D. C. 20004
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FAX: 202-272-2022
WEB: <http://www.ncd.gov>

Office of Special Institutions
Office of Special Education & Rehabilitative Services
U.S. Department of Education Room 3125,
Mary E. Switzer Bldg. 330 C. Street, SW
Washington, D.C. 20202-2524
PH: 202-205-8555
FAX: 202-205-9252

National Institute on Disability and Rehabilitation
Research Office of Special Education & Rehabilitative Services
U.S. Department of Education
600 Independence Avenue, SW
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National Service Corporation for National Service
1201 New York Avenue, NW
Washington, D. C. 20525
PH: 202-606-5000
FAX: 202-565-2787
WEB: <http://www.cns.gov>

PRIVATE AGENCIES SERVING PEOPLE WITH M/R & DD

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Arlington, Texas 76010
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FAX: 817-277-3491
WEB: <http://www.thearc.org>

American Association on Mental Retardation
444 North Capitol Street, NW
Suite 846
Washington, D.C. 20001
PH: 202-387-1968
FAX: 202-387-2193
WEB: <http://www.aamr.org>

National Association of Protection and Advocacy Systems
900 2nd Street, NE Suite 211
Washington, D.C. 20002
PH: 202-408-9514
FAX: 202-408-9520
WEB: <http://www.protectionandadvocacy.com/index>.

American Network of Community Options and Resources
4200 Evergreen Lane, Suite 315
Annandale, Virginia 22003
PH: 703-642-6614
FAX: 703-642-0497
WEB: <http://www.ancor.org>

National Association of State Directors of Developmental Disabilities Services
113 Oronoco Street
Alexandria, Virginia 22314
PH: 703-683-4202
FAX: 703-684-1395
WEB: <http://www.nasdds.org>

American Association of University Affiliated Programs for Persons with Developmental
Disabilities
8630 Fenton Street, Suite 410
Silver Spring, MD 20910
PH: 301-588-8252
FAX: 301-588-2842
WEB: <http://www.waisman.wisc.edu/aauap>

Association of Public Developmental Disabilities Administrators
9901 Braddock Road
Fairfax, Virginia 22032
PH: 703-323-4002
FAX: 703-323-4252

United Cerebral Palsy Association, Inc.
1660 L. Street, N. W.
Suite 700
Washington, D.C. 20036
PH: 202-776-0406
FAX: 202-776-0414
WEB: <http://www.ucpa.org>

Special Olympics International
1325 G. Street, NW
Washington, D.C. 20005
PH: 202-824-0257
FAX: 202-824-0200
WEB: <http://www.specialolympics.org>

National Parent Network on Disabilities
1727 King Street Suite 305
Alexandria, Virginia 22314
PH: 703-684-6763
FAX: 703-836-1232
WEB: <http://www.npnd.org>

American Speech-Language-Hearing Association
10801 Rockville Pike
Rockville, Maryland 20852
PH: 301-897-5700
FAX: 301-571-0457
WEB: <http://www.asha.org>

National Association of Developmental Disabilities Councils
1234 Massachusetts Avenue, N.W.
Suite 103
Washington, D. C. 20005
PH: 202-347-1234
FAX: 202-347-4023
WEB: <http://www.igc.apc.org\NADDC>

Autism Society of America
7910 Woodmont Avenue Suite 650
Bethesda, MD 20814-3015

PH: 301-657-0881
FAX: 301-657-0869
WEB: <http://www.autism-society.org>

American Occupational Therapy Association
4720 Montgomery Lane,
P.O. Box 31220
Bethesda, MD 20824-1220
PH: 301-652-2682
FAX: 301-652-7711
WEB: <http://www.aota.org>

National Down Syndrome Congress
1605 Chantilly Drive, Suite 250
Atlanta, Georgia 30324-3269
PH: 1-800-232-6372
FAX: 404-633-2817
WEB: <http://members.carol.net/ndsc>

People First International
P.O. Box 12642
Salem, Oregon 97309
PH: 503-362-0336
FAX: 503-585-0287

Joseph P. Kennedy Jr. Foundation
1325 G. Street, NW - Suite 500
Washington, D.C. 20005
PH: 202-393-1250
FAX: 202-824-0351
WEB: <http://www.familyvillage.wisc.edu/jpkf>

Consortium for Citizens with Disabilities
1730 K. Street, NW - Suite 1212
Washington, D.C. 20006
PH: 202-785-3388
FAX: 202-467-4179
WEB: <http://www.radix.net/--ccd>

Human Services Research Institute
2336 Massachusetts Avenue
Cambridge, Massachusetts 02140
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FAX: 617-492-7401
WEB: <http://www.hsri.org>

New Jersey Center for Outreach and Services for the Autism Community (COSAC)
1450 Parkside Avenue, Suite 22
Ewing, New Jersey 08638
PH: 609-883-8100
FAX: 609-883-5509
WEB: <http://members.aol.com/njautism/index.htm>

Community Services for Autistic Adults & Children
751 Twinbrook Parkway
Rockville, MD 20851
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FAX: 301-762-5230

National Down Syndrome Society
666 Broadway, Suite 810
New York, New York 10012
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FAX: 212-979-2873
WEB: <http://www.ndss.org>