

REPORT TO THE PRESIDENT

The National Reform Agenda and Citizens with
Mental Retardation: A Journey of Renewal for All
Americans

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

President's Committee on Mental Retardation
Washington, DC

1994

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

Dear Mr. President:

I am pleased to introduce to you the 1994 Annual Report of the President's Committee on Mental Retardation (PCMR) entitled The National Reform Agenda and Citizens with Mental Retardation: A Journey of Renewal for All Americans.

The Report reflects the contributions of 26 self-advocates, parents and family members who as experts in the area of mental retardation, collaborated with professionals in the field and Federal and State partners to produce this Report. It includes recommendations made within the context of welfare and health care reform and more broadly, recommendations that reflect the principles of empowerment, equality and justice.

This document, authored by Dr. Glenn Fujiura of the University of Illinois at Chicago, emanates from the 1994 PCMR Presidential Forum which produced a new vision for Americans with mental retardation and their families. The recommendations provide an ambitious outline for action which reflect the dedication and commitment of the Committee members in meeting their responsibility to work as advocates for persons with mental retardation.

Included in this report is a quote from Linda Preston about her son Elijah, "...They didn't see his disability. They just saw the music in him." It is within the spirit of Linda Preston's dreams for her son, and on behalf of the dreams of my fellow Americans who confront mental retardation and related disabilities daily, that I offer this report for your consideration.

Sincerely,

Donna E. Shalala

Enclosure

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President's Committee on Mental Retardation Members & Staff April 1994 Forum
Advisory Planning Committee

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The President's Committee on Mental Retardation (PCMR) gratefully acknowledges the insight and perceptive analysis of Glenn Fujiura, Ph.D., University of Illinois at Chicago, Institute on Disability and Human Development, who authored the Committee's 1994 Annual Report to the President.

The Annual Report and the Proceedings of the 1994 Presidential Forum, which served as the basis for the Report, were unique in many respects. Reflecting President Clinton's commitment to empowerment and inclusion of all Americans, this Report is historic through the active participation and leadership of many self advocates and parents whose dynamic contributions helped shape the tone of each of the PCMR recommendations. The President's Committee would particularly like to acknowledge the contribution of the 26 self-advocates who were active participants at the Presidential Forum. The Committee is especially grateful to T.J. Monroe of Nashville, Tennessee, and Tia Nelis of Naperville, Illinois, who were Forum Keynoters, along with parent advocates Koquese Collins of Detroit, Michigan, Dawn and Don Merriman of Salina, Kansas, and Linda Charlton of Bel Air, Maryland. The passion, love, and clarity of mission articulated by both parent and self-advocate participants helped guide every discussion held at the Forum.

In composing the Report to the President, Dr. Fujiura was greatly aided by the contributions, writings, and technical papers of the PCMR Forum Advisory Committee and Workgroup Leaders including William E. Jones, Ph.D., Executive Director of the American Association of University Affiliated Programs, chair of the PCMR Forum Advisory Committee and members: Kathy Beyer; David Braddock, Ph.D.; Sharon Davis, Ph.D.; Steve Eidelman; Rob Homer, Ph.D.; Matthew P. Janicki, Ph.D.; K. Charlie Lakin, Ph.D.; David Mank, Ph.D.; Paul Marchand; Jan Nesbit, Ph.D.; Sharon Ramey, Ph.D.; Frank Rusch, Ph.D.; Marsha Seltzer, Ph.D.; Steve Taylor, Ph.D.; Alexander J. Tymchuk, Ph.D.; and Paul Wehman, Ph.D.

The Committee also wishes to express its appreciation for the leadership and guidance of Administration for Children and Families (ACF) Assistant Secretary, Mary Jo Bane; and Deputy Assistant Secretary for Policy and External Affairs, Ann Rosewater.

Additionally, the PCMR would like to express its deepest gratitude to Elizabeth Boggs, Ph.D., and Gunnar Dybwad, Ph.D., not only for their technical writings and expertise, but also their inspiration, wisdom, and lifelong commitment to inclusion and justice for individuals with mental retardation and related developmental disabilities.

PREFACE

In April 1994, leaders from the field of mental retardation were gathered together in a forum sponsored by the President's Committee on Mental Retardation (PCMR). They were asked to evaluate the needs of Americans with mental retardation in the context of the Administration's domestic reform agenda. The Report to the President represents the synthesis of the forum's technical papers, deliberations, and analyses in the areas of education, housing, employment, health, welfare, and long-term care. Three core themes bind together the sections of the narrative and accompanying recommendations.

First, there remain great unmet needs. A significant transformation in the nation's care and treatment of its citizens with mental retardation has occurred. However, it is a transformation yet in progress. The report reflects the tension of the juxtaposition of accomplishments against the sense of urgency for critical tasks yet to be completed. For too many Americans with mental retardation, the reforms of the past three decades are merely unfulfilled promises. This is a central theme for the report's discussion of education, housing, and employment.

Secondly, the real revolution will see the end of the premise of dependency that permeates our systems of care and support. This theme is embedded in key concepts throughout the report -- in the principles of choice and control, in the view of persons with mental retardation as citizens and constituents, and in the calls for meaningful inclusion.

The third and final theme is the fundamental importance of individual dignity. It lies at the heart of report's discussion of health care, welfare, and long-term care. The report's recommendations are made against the backdrop of changes in the landscape of American governance since the April meetings. While we understand there are no convenient and readily implemented solutions for these domestic reform challenges, the needs and injustices described in the report will be as pressing tomorrow as they are today. For Americans with mental retardation, domestic reform must remain on the agenda.

REPORT TO THE PRESIDENT

The National Reform Agenda and Citizens with Mental Retardation:
A Journey of Renewal for All Americans
The President's Committee on Mental Retardation

INTRODUCTION

We stand at a crossroad in the nation's passage into the 21st century. Long-standing assumptions about the relationship of government and citizen in health care, education, employment, and social welfare are being challenged.

The choices made in this national debate will have profound implications for persons with mental retardation. They are among the most vulnerable of American citizens. Like a mirror held before the national renewal effort, the success of reform will be reflected in their lives and well-being.

In the body of the following report, PCMR endeavors to chart the direction of future activities, policies, and strategies for Americans with mental retardation in the context of the President's reform agenda. The assessment represents a distillation of the deliberations and recommendations of leaders in the field of mental retardation during a 3-day PCMR forum in 1994.

I. A PROMISE NOT FULLY REALIZED

"Our goals for Katie include wanting her to feel loved, to give her a sense of high self-esteem so that she can experience life with confidence. She is a very social child and while I think she has a great capacity to make friends, I wonder how other children will accept her. We envision her attending public schools and one day hope to see her graduate from high school. I wonder if she will ever get married, and if she doesn't, I hope someday she has a companion to enjoy life with, and if we could we would like to see her remain as happy as she is today. "

Linda Charlton, Maryland

In her address to the PCMR, Linda Charlton described life with her 2-year old daughter, born with Down syndrome. She spoke of her goals and anxieties over what the future holds. In Linda Charlton's statement is the eloquence of parental love and the aspirations of families everywhere -- that our children find opportunity, dignity, and above all, love.

The nation Katie was born into two years ago is far different for Americans with mental retardation from that first described by PCMR in 1967 in its inaugural report, MR 67. The Committee spoke then of the need to provide education, to improve the quality of institutions, to offer rudimentary services in the community, and to grant persons with mental retardation the elementary rights of citizenship.

The Federal Government responded and transformed national policy -- with prohibitions against discrimination on the basis of disability through the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990, educational mandates in the Education for All Handicapped Children's Act and its amendments, and the institutional reforms and community expansion brought about through Federal legislation and precedent-setting litigation in the Federal courts.

The transformation of national policy affecting people with mental retardation over the past 25 years represents one of the great social reform movements of our time. Policies are now in place at the Federal level that affirm the basic rights and fundamental human dignity of Americans with mental retardation.

And yet, great needs still exist. Aspirations are unfulfilled. Elisha Preston was born 12 years after the publication of MR 67. His mother reflected on the hopes expressed by Linda Charlton -- "I remember taking walks with Elisha when he was an infant. Like any new parent I engaged in lots of idle thought about the future. Those were times of great expectation. I said the same things as Katie's mom. And a decade later my son has had the sweetness and kindness and joy sapped from him by a system and community that has done little but put barriers before him. It makes me want to cry."

Real change and true reform require national leadership. President Clinton proposed a "journey of renewal." In this report, we point out the ways in which this journey will affect Americans with mental retardation. We respectfully ask for your consideration of these recommendations -- recommendations that will transform promises into reality.

II. THE NEW AMERICAN COMMUNITY: OUR SCHOOLS, HOMES, AND PLACES OF WORK

The injustices experienced by people with mental retardation were great in 1967. One half of the nation's 25,000 school districts denied access to children with mental retardation. State-operated institutions, at their peak census of nearly 200,000 residents, were the primary housing option. And the concepts of employment and self-sufficiency were hailed as "revolutionary" in PCMR's inaugural report of that year, which spoke of new ideas and fresh approaches.

Our greatest challenge remains the infusion of new ideas -- ideas that will change, fully and irrevocably, the basic paradigm. Based on exclusion, isolation, and individual deficits, the old service model still stands as an obstacle to true reform. The emerging paradigm is anchored to the values of inclusion, collaboration, and individual determination. Through the Administration's domestic reform agenda, we have the unique opportunity to realize this new vision in the following areas:

- ❖ Special education in the United States is a paradox of intent and effect. In order to redress the inequities created by the exclusion of children with a disability from public school, policy-makers inadvertently created a system predicated on segregation. Special education's status as a parallel system must be challenged.
- ❖ Since 1967 the nation has reduced its reliance on institutional care while dramatically increasing community-based housing. Yet the fundamental premise

- of residential care remains unchanged -- persons with mental retardation are the "occupants" of beds and "clients" of services. We must challenge this premise of dependency.
- ❖ The success of integrated employment -- real work in real jobs -- is in its acceptance as a true goal for persons with mental retardation. Unfortunately, it is treated as only one alternative along the continuum. We must commit ourselves, totally and wholly, to a vision of equal opportunity in the work place.
 - ❖ School, housing, and work have been targets of reform efforts since MR 67. In 1967 the preeminent concerns focused on access to public schools, quality of care in the state-operated institutional system, and lost employment potential. While these continue to be points of concern, the mix of issues is far more complex today. It is no longer solely a matter of where to locate a service, but rather how to redress the balance of power and choice in the service provider-consumer relationship.

We are a nation of individuals bound together by the vision of community and the sense of purpose defined by our citizenship and what America uniquely represents. PCMR's report to the President is based on this fundamental assumption.

What matters most to people with mental retardation and their families is that which is of importance to all Americans -to belong to a larger community that endows its members with dignity anchored in a fundamental respect for the individual. We hope that this aspiration, though not fully realized, will find fuller voice in the reforms proposed by the Clinton Administration.

SCHOOL

"I do not want the "retarded corner" of the school. " Linda Preston, Illinois

The adoption of the Education of the Handicapped Act eliminated the exclusion of children with mental retardation from public education. It also created a "special education" system that is separate both in operation and philosophical foundation. This contrived separateness limits opportunities for those within it, and perpetuates inequities and inefficiencies.

The fundamental goal is unchanged from the early years of mandates -- equity in education. Yet the status of education for children with mental retardation is startling in its disparities. Only seven in 100 students with mental retardation spend their school day in classrooms with other children from their neighborhoods. Eleven out of every 100 students do not have access to their community school, attending totally non-inclusive schools.

The basic premises and character of our dual system of education are found to be wanting. It is time to act.

At the heart of the debate is the contemporary utility of the dual system. Does the division of children -- into those who have a disability and those who do not -- continue to serve an educational purpose?

Segregation does not enhance academic achievement and delays social adjustment. It encourages unnecessary labeling of children. It fosters placement on the basis of administrative convenience rather than educational need. How else to explain the arbitrariness of segregation -- that only 35 percent of Vermont's students are educated in separate classrooms compared to 97 percent in Iowa. Why should a special education student in Alabama be eight times more likely to be labeled "mentally retarded" than one in Arizona or New Jersey? Why should an African-American child in the special education system be twice as likely as a white child to be classified as having mental retardation?

Segregation requires the classification of children in order to communicate their "deficits" and to demand narrow instructional specializations of their teachers. What has this classification and specialization achieved? Dropout rates from special education exceed the national average. Post-secondary school unemployment rates approach 50 percent three to five years after leaving school. The segregated system fostered critical access to education in the early years of the mandates, but it bought neither quality nor equity.

Assumptions of the past often obstruct alternative visions of the future. For students in need of specialized education, we must revisit previous assumptions about where those services are delivered.

PCMR RECOMMENDATIONS: OUR SCHOOLS

The United States achieved access for children with mental retardation. Doors were opened and obstructions overcome. But access has not necessarily translated into equality of education nor quality of outcome. PCMR respectfully requests that you reaffirm the principle of a unified educational system and an end to Federal support for separation. We must unify education for all our children.

THE FEDERAL GOVERNMENT MUST AFFIRM THE PRINCIPLE OF A UNIFIED EDUCATIONAL SYSTEM

- ❖ **End the fiscal barriers to inclusion.** Eliminate fiscal incentives for dual systems. Link Federal funds authorized under The Individuals with Disabilities Education Act (IDEA) to total state school population rather than the number of labelled students.
- ❖ **Let the children come home.** Eliminate fiscal incentives for outof-district placements. Federal funds authorized under P.L. 89-313 should be directly linked to each child's home school district.
- ❖ **Provide a Federal vision.** Unify and apply the reform agenda across Federal agencies. Federal agencies involved in education should coordinate their training, research, policy, and technical assistance missions. The U.S. Department of Education's Office of Special Education and Rehabilitation Services (OSERS)

should make placement-neutral and non-categorical reimbursements to local agencies a requirement of state plans.

- ❖ **Set the agenda.** The Federal government should leverage its influence to effect system change. Set the research agenda on unification and inclusion, evaluate the effectiveness of teacher education curricula to facilitate inclusion, and de-emphasize the labeling of "special education" teachers in personnel preparation efforts. Put teeth into the Federal monitoring process. Establish meaningful sanctions for non-compliance.

HOME

"People need to have control of their front door. " T.J. Monroe, Nashville, TN

PCMR recognizes the moral and legal rights of persons with mental retardation to experience and shape their lives as citizens and as individuals, including the most fundamental right -- to decide where and with whom they will live.

Rare is the person with mental retardation who experiences "home" as do most Americans. Beyond the family home, the major housing alternatives are institutional and other group facilities owned and controlled by others, with people they never chose to live with. They are denied the experience of a "place of one's own" -- an aspiration common to all Americans.

Contemporary options are still largely limited to "homes" that are owned or leased by states, private organizations, foster care programs, board and care providers, or non-profit housing corporations. While we speak of dignity, rights, and inclusion, the sobering fact is that most people with mental retardation living away from their family homes are under the control of other people. Basic models of care are predicated on dependence and the absence of choice.

Owning or renting a home of their own choice (excluding those living in their family home) is currently limited to 8.4 percent of the 347,000 persons with mental retardation receiving services. For the vast majority of people with mental retardation, housing and support services are bundled as "packages" based on group considerations and agency preferences rather than individual needs. The individual in need of supports is often compelled to live in settings where the needed services are provided or, conversely, to receive unnecessary care in exchange for residential support.

Recognition of the consumer's right and capability of home ownership is not without basis in recent experience. People with mental retardation can and do own and rent their own homes all through the U.S. Though little used to date, this is the most rapidly growing type of residential option. In localities across the nation, innovative funding options are being implemented. State governments, including Colorado, Connecticut, Florida, Illinois, New Hampshire, Michigan, New York, Rhode Island, and Vermont, have developed innovative financial assistance programs for cash assistance, leases, rent subsidies, and vouchers.

David Guillet just purchased a condominium in Cumberland, Rhode Island. Formerly a resident of group homes, he, together with his parents, Marge and Lou, were pioneers in the development of home ownership options in the State. Through a

collaborative effort of state agencies, they obtained a low-interest mortgage and a grant for the down payment, closing costs, and furniture. Compared to publicly funded group homes, often with service packages that are not needed and associated staffing expenses, home ownership may be less expensive.

"My son has very severe disabilities," said Mrs. Guillet, "quadriplegic, legally blind, with severe seizures. Yet, I have the same fears for David as I do for my other children who do not have disabilities. We are helping David expand his relationships by introducing David to the fire department, to his immediate neighbors, by holding an open house. The neighbors were wary, assuming the State had purchased the condo. Their perceptions immediately changed when they found out that David was the owner, not some "ward" of the State.

"We have choices now. We pick the support staff. David has complete control of the choices in his life. David can eat what he wants to eat, when he wants to eat. If he wants to wear a blue shirt with green shorts, that's OK. I can see the difference in his eyes. "

The great challenge is to see beyond current service paradigms. Many people with mental retardation who receive residential services live in housing in which services and personal assistance are developed around group considerations and agency preferences rather than individual needs and choices. People with mental retardation are often wrongly viewed by government agencies and service providers as needing "special housing," rather than as individuals with idiosyncratic needs for support.

Changes in Federal policy will be crucial to the development of consumer-controlled housing. The Federal Government has considerable leverage through its housing programs, income support policies, and public information efforts. Through modifications of these programs, the Federal Government can play an affirmative, leading role in housing reform for people with mental retardation.

PCMR RECOMMENDATIONS: OUR HOMES

Twenty-seven years after the onset of deinstitutionalization in 1967, we continue to house an unconscionably large number of American citizens in large non inclusive settings. Residential housing and financing models across the range of residential options remain largely predicated on institutional concepts of care and training. We recommend that the Federal Government should affirm the principles of choice and control in housing policy for people with mental retardation.

THE FEDERAL GOVERNMENT MUST AFFIRM THE PRINCIPLES OF CHOICE AND CONTROL

Separate housing from supports. People should have stable homes while fully exercising their right to choose the agencies and individuals who enter those homes to provide supports. Federal and local policy should affirm the separation in all programs specifically funding services or housing.

- ❖ **Speak with a vision.** Develop a broad-based inter-agency approach to housing. Unify and coordinate Federal efforts to affirm the principles of choice and control. This can be achieved through: (1) a coordinated initiative on personal

housing through the Departments of Health and Human Services and Housing and Urban Development; (2) a modification the Federal commitment of HUD Section 8 rental assistance to include mortgage assistance; and (3) fiscal support of public information programs -- change will be facilitated at the local level when consumers, family members, and advocates know what options are available.

- ❖ **Act on a vision.** Establish consistent housing policies across Federal agencies. The Federal Government can directly facilitate choice and control through modification of existing policy: (1) by permitting recipients of Disabled Adult Child (DAC) or Social Security Disability Insurance (SSDI) benefits (without Supplemental Security Income or SSI) who are eligible for Home and Community Based Services to retain their full DAC or SSDI benefits while receiving waiver services; (2) by permitting people in means-tested programs to save towards home down payments or apartment deposits; (3) by allowing waiver funds to be applied to supplemental housing costs where SSI and available state supplements fall below standards; and (4) by increasing the size and flexibility of housing subsidy programs for impoverished persons with mental retardation.

- ❖ **Encourage states to do what they do best -- innovate.** Fund, support, and develop systems change projects. Experimentation is a hallmark of state systems; facilitate the transition from facility-based care to supported community living through fiscal assistance projects, and collaborative efforts with private financing agencies.

WORK

"Work in a sheltered workshop and make money -- like 79 cents every 2 weeks. "
Tia Nelis, Illinois

In its 1967 Report to the President, PCMR estimated that the potential annual earnings lost because of unnecessary unemployment among persons with mental retardation ran into the billions of dollars.

The 1983 PCMR report concluded, "...there are hundreds of thousands of mentally retarded people who are employable but are unemployed because of misconceptions. The report asked us to raise our expectations.

Today, after a decade of raised expectations, we can point to years of achievement, of research, and of model demonstrations in communities across the nation. Persons with mental retardation have affirmed over and over again PCMR's central belief in their capacity to be productive workers. Tens of thousands have participated in innovative employment programs in real work settings. The Federal Government has infused the principle of equal work opportunity in every piece of disability-related Federal legislation since 1973. Above all else, the decade of demonstration has raised our expectations.

Yet the contemporary employment status of Americans with mental retardation is one of underachievement. A decade after we proclaimed a "decade of progress" in the 1983 report, unemployment rates among adults with mental retardation exceed 70

percent. Why should this be? Why is unemployment such an intractable problem given what we know -- that thousands of persons considered unemployable years ago are now working in real jobs in real work settings?

The weight of Federal and state funding remains largely devoted to segregated services -- 80 cents of every state dollar reimburses segregated rehabilitation services; 90 cents of every Federal dollar support segregated services. While research clearly demonstrates the efficacy of integrated employment, state service systems remain deeply entrenched in segregated models of rehabilitation. Integration in employment is made more difficult by inconsistent Federal regulatory policies, some of which restrict the opportunity for real employment. Work incentive reforms, for example, recently enacted for supplemental security income beneficiaries do not apply to SSDI and disabled adult child (DAC) recipients with mental retardation. For these individuals, employment endangers benefits, even at poverty level wages. In the absence of transitional support, entry into the world of work is fraught with personal risk.

Despite legislative intent, systems of employment training remain bound to funded "slots" into which people must fit. Given the bias of the system, the alternatives, if they exist, are limited. Seven out of 10 persons served in rehabilitation programs are either in separate or non-work day activity type settings. We must personalize supports, let consumers control funds to direct their own programs, and select the types of supports needed. We must create the options so that choices are available.

The goal of real employment and equal opportunity seems almost as distant today as in 1967 or 1983. Though we now know the vision can be realized in practice, the challenge is to make it a reality for more than a select few. Large entrenched systems do not change so readily. We recommend support for greater economic independence for persons with mental retardation.

Seventy percent of persons served in day and employment programs are served in segregated programs; 90 cents of every Federal dollar supports these segregated services.

PCMR RECOMMENDATIONS: WORK

Workers with mental retardation have repeatedly demonstrated their ability to be employed for decent wages with benefits. Like a distant beacon, competitive employment shines as brightly as ever, but across a sea of exclusion and unemployment. PCMR recommends bringing Federal regulatory and fiscal policies into line with Federal principles and ending Federal support for exclusion in the work place.

SUPPORT THE PRINCIPLES OF CONSUMER INVOLVEMENT, CHOICE, AND CONTROL WITH FEDERAL REGULATORY REFORMS.

- ❖ **Bring Federal spending into line with Federal principles.** Require the U.S. Department of Education's Rehabilitation Services Administration (RSA) funding (including Section 110 funds and the required state match) to be employed in support of integrated employment; change financial controls so that consumers exert control over expenditures. Use RSA leverage to modify state agency goals.

- ❖ **Make the system accountable.** Monitor the implementation of the Rehabilitation Act Amendments to assure that consumers are offered services in real work settings and involve them in all stages of program planning. Ensure the adherence of state and local school systems to the employment goals of The Individuals with Disabilities Education Act.
- ❖ **Build capacity.** Choice requires options. Use Federal demonstration funds to stimulate innovations in achieving integrated employment and support replication projects. Ensure the participation of youths with mental retardation in the Administration's school-to-work transition initiatives.
- ❖ **Establish consistent policy across agencies.** Remove limitations on the use of Medicaid for integrated employment; ensure involvement of persons with mental retardation in the many employment and economic development initiatives of the Federal government.

III. THE DIGNITY OF OUR CITIZENS: HEALTH, WELFARE, AND LONG-TERM CARE

In the journey of national renewal we must give priority to reforming those systems that contradict fundamental American values of equality and self-determination. The Clinton Administration has elevated these contradictions to the center of the national debate in health, welfare, and long-term care. How these debates are resolved will be critical to the security of America's citizens, in particular those with mental retardation. Health care reform is a principal priority of PCMR. Americans with mental retardation and their families are especially vulnerable to the effects of discrimination in the health care system. Our struggle will not end until universal coverage is achieved. We concur with the President that "...the human cost far outweighs the risk of responsible change."

Welfare serves many purposes. Above all else, it must support self-sufficiency, productivity, family, and those who cannot care for themselves. Americans with mental retardation are disproportionately affected by pervasive and long-term poverty, unemployment, or long-term dependency. They have very much to gain and very much to lose in the outcomes of the nation's welfare reform. **We must be sure that the interests of people with mental retardation and their families are not lost in the clamor for change.**

Long-term care is a critical ingredient of a comprehensive domestic agenda. The long-term care agenda recommended by PCMR is likewise a critical element in any effort to provide a secure future for people with mental retardation and their families. **The domestic reform agenda is incomplete without a guarantee of home and community-based long-term supports.**

The outcomes of domestic reforms are critical to the well-being and dignity of all Americans. PCMR requests that the needs and the special vulnerability of Americans with mental retardation not be overlooked in the pending reforms.

HEALTH

"No band-aids, real health care reform for all. "

Health care reform campaign button

A moral imperative is nonnegotiable. PCMR believes that health care is a basic

"Seven years ago when Robert was 2 1/2 years old, he started having epileptic seizures. Due to the seizures, Robert is mentally retarded and at times unable to walk or talk. At the time he first became ill, Tom was a first year apprentice with the Sheet Metal Workers Union. Our insurance coverage was 80 percent with 20 percent to be paid by the member. During that period we accrued several tens of thousands of dollars worth of medical bills. As we were a struggling, young two income family making \$20,000 per year, we applied for assistance, only to be denied -- because we were, "just over the maximum income allowed." After six months the insurance company stopped paying for a nurse to help with Rob. I was forced to quit working. We sold the house and took all the equity to pay off the medical bills. The move required Tom to spend four hours on the road each day going to and from work. Robert's illness made him uninsurable because he now had a "preexisting condition," and we became all too aware of how important it was for Tom to keep his job. After the move more admissions followed, and again the bills started mounting. It was at that time we were told to apply for Children's Medical Services. If it were not for this organization we would have been homeless. In October of 1992 our renewal came due and we were denied services based on our income being in excess of the \$22,000 per year maximum. Last year Tom's company was forced to cut back to a 4-day work week. Due to Robert's preexisting condition Tom is locked into his job, even if his employer cuts him back to a 3-day work week. The problems are neverending. Two years ago while lifting Rob, I hurt my back. The injury has left me bedridden and unable to care for Robert many times since. It was one of these times I contacted the local agencies, to get some help taking care of Rob in our home. I was told that if he was on Medical assistance they could send an aide, but because he was ineligible, all they could offer was to institutionalize him.

"I informed them that I would not even consider putting Rob in an institution, and that he would not thrive without the love of his family nor would we. In an institution no one is going to get up during the night, while he is having seizures, and let him know that it's "ok" and that mom loves him. No one in an institution could ever give him the love that we give him at home. This is why we so desperately need health care reform. What has happened to us and many other families like ours is wrong."

Kate Miles, Maryland

Americans with mental retardation and their families are painfully aware of the health care crisis. Their needs are a microcosm of the national crisis. Their voices are part of a larger chorus of Americans with disabilities and their families and of the tens of millions of other citizens with no coverage or inadequate and inferior care in the world's most advanced nation. PCMR's position has an essential predicate -- that health care is a basic right of all Americans. We support your courageous effort to "undertake this journey of change" towards a just and equitable health care system for all.

Like other Americans, persons with mental retardation are remarkably diverse in their health care needs. They cannot be treated as a single constituency. Most have the same basic needs as everyone else. But they have a special vulnerability which is the legacy of discrimination, unemployment, and poverty. Many adults with mental

retardation are often disqualified for Medicaid because their disability is not "severe" or because they are too proud to apply, yet the jobs they can find are usually marginal or part time. As a result they are without the continuity of health care that they particularly need. For these individuals and their families there is a crisis of coverage.

For others, there are complex medical problems and significant health care needs. These individuals have disorders associated with rare or low incidence syndromes, or challenging behavior problems requiring health care professionals with specialized training. Meeting their needs has been complicated by shifts in models of care. Those most severely impaired are now living longer because of medical advances and their numbers are increasing because of improved health care during infancy and childhood. The locus of health care services for this population is in the community. But there is a severe shortage of providers with even the rudimentary expertise in working with individuals with mental retardation. For these individuals, there is a crisis of care in the community.

What do Americans with mental retardation need? Policies affirming guaranteed health coverage that directly address the inequities and arbitrariness of the current care system: universal coverage, limits on out-of-pocket expenses, access to specialists, elimination of work disincentives, and home and community-based long-term services, including personal assistance services.

PCMR RECOMMENDATIONS: HEALTH

For Americans with mental retardation, there is a dual health care crisis -- shrinking coverage and a dearth of skilled practitioners in the community. Both must be addressed. The following recommendations address universal coverage, service delivery, and financing.

Like all journeys into uncharted regions, the nation's passage will be marked by false starts, unexpected turns, and illusory conclusions. For persons with mental retardation and their families, the endpoint of the health care reform battle is clearly marked.

TRUE HEALTH CARE REFORM MUST INCLUDE UNIVERSAL AND COMPREHENSIVE COVERAGE

- ❖ **Do not discriminate.** People with mental retardation must be able to participate fully in the nation's health care system, regardless of age, health, disability status, or income. **Permit no exclusions based on pre-existing conditions.**
- ❖ **Be comprehensive.** People with mental retardation must have access to a health care system that ensures a comprehensive array of health, rehabilitation, personal, and support services across all service categories and sites of service delivery. **Provide access to specialists and other providers.**
- ❖ **Serve the person not the system.** Ensure the appropriateness of health services. People with mental retardation and their families must be assured that comprehensive health, rehabilitation, personal, and support services are provided on the basis of individual need, preference, and choice. **Allow meaningful consumer involvement, accountability, and provision of home and community-based long-term care.**

- ❖ **Be equitable.** People with mental retardation and their families must be assured equitable participation in the nation's health care system and not be burdened with disproportionate costs. There cannot be financial disincentives for serving people with more intensive needs for health services and other supports. **Limit out-of-pocket costs and eliminate lifetime caps on benefits.**
- ❖ **Be efficient.** People with mental retardation and their families must have access to a health care system that provides a maximum of appropriate, effective services that includes effective cost controls as well as a minimum of administrative waste. **Remove work disincentives in health coverage policies.**
- ❖ **Do not exclude.** True health care reform must integrate, not segregate, health services for persons with mental retardation. In the reform of the nation's health care systems, we must vigilantly adhere to the intent of the Americans with Disabilities Act. Ensure equal access. Policies and procedures may not, by design or impact, deny individuals with mental retardation health services by reason of their disability. Rationing, or denial of coverage, or unintended discriminatory effects of neutral policies are violations of the intent of the law.
- ❖ **Build capability.** Prepare service providers and service consumers. Health care providers, including family physicians, need knowledge, experience, and models. Much exclusion occurs not because of lack of skills but because of lack of experience. Similarly, persons with mental retardation and their families must be made aware of their options and rights.
- ❖ **Build capacity.** High quality primary care must be available to all, at all ages. Home health care services must be available.
- ❖ **Do not eliminate options currently available.** Referral to specialist care must be an option within the generic system. For people with atypical medical needs, "comprehensive" services must include referral to the most relevant specialists.

WELFARE

"It defies our values as a nation. "

President Clinton's 1994 State of the Union Address

Welfare in its present form presents a challenge for persons with mental retardation -- economic self-sufficiency, equal opportunity, family support, and above all the dignity and respect that come with being a contributing and productive citizen. The welfare system has personal assets limitations that discourage savings towards future needs. There is a penalty on parents, brothers, sisters, and other family who assume the responsibility of care, even when few viable alternatives exist. Support based on total dependency serves to discourage integration into the work force. PCMR believes an effective system of social welfare should promote the independence of people and reduce their long-term dependence over time. Let people work and save and encourage family support.

Persons with mental retardation are participants in the full range of social insurance programs -- as workers contributing taxes to Social Security, as dependents and survivors entitled to draw on the Old Age, Survivors, and Disability Insurance (OASDI) and Social Security Disability Insurance (SSDI) Trust Funds, and as recipients of means-

tested income assistance. It is on behalf of those who are most economically vulnerable that PCMR addresses its concerns and recommendations.

Two pillars of Federal poverty-related income assistance to persons with mental retardation are the Supplemental Security Income (SSI) program and the Aid to Families with Dependent Children (AFDC). PCMR supports the Administration's scrutiny of AFDC; we urge you to also include changes in the SSI program in the larger welfare reform agenda. SSI plays a central role in the modern configuration of mental retardation services. Benefits now reach more than 700,000 Americans with mental retardation under 65 years of age. Contradictions between social goals and statutory regulations within SSI have long been the object of criticism. The SSI Modernization Panel noted several problems: regulations that discourage personal savings, the harshness of in-kind support penalties on family care, and earned income exclusions that make the transition from welfare to work extraordinarily difficult for potential wage earners with mental retardation. We strongly support the recommendations of the SSI Modernization Project Panel: bring Federal benefit standards in line with our national goals.

PCMR is concerned about the outcomes for persons with mental retardation and their families in the current welfare reform debate. While changes are needed, it is important to consider carefully how any modifications will affect those for whom work mandates are inappropriate. For recipients with mental retardation there is a narrow line between the objectives of welfare reform and unintended neglect. Federal data indicate a rate of functional disabilities among women in the AFDC population to be in the 20 percent range. In addition, some 19 percent of households receiving AFDC benefits have another disabled adult or child present. Of the total AFDC enrollment of 14.1 million, an unknown but potentially large number have mental retardation. In short, many AFDC recipients, children as well as adults, have disabilities and are truly dependent.

In total numbers and potential impact, Americans with mental retardation have a significant stake in the course of welfare reform. In our effort to correct the wrongs of the system, we must not forget those most vulnerable. Do no harm. We urge sensitivity to the unique needs of welfare recipients with mental retardation.

There is a fine line between reform and neglect; in our reforms we must do no harm to those most vulnerable.

PCMR RECOMMENDATIONS: WELFARE

PCMR believes that an effective social welfare system is an investment in human capital. The central reform issue is the use of welfare for the realization of potential. We concur with the Administration that the central objective of welfare reform is to bring today's systems of support into congruence with core American values.

LONG-TERM CARE

We must be cognizant of the role that Medicaid plays in the support of Americans with mental retardation. Realize also that it has been both a bane and bulwark.

Disability is a natural dimension of the human condition. It can touch any life at any time and for many Americans it is manifested as a lifelong need for support. Among this group are significant numbers of Americans with mental retardation. While the composition and character of long term care is in a state of continuous evolution, we can address the basic features that impact most significantly on persons with mental retardation.

The existing Federal supports for long term care services for Americans generally have been characterized as a \$70 billion system that is fragmented and ill-matched to the needs of current recipients. It has a medical bias that results in persons going without services or receiving more intensive services than necessary. These critiques are no less valid when applied to the long-term care needs of persons with mental retardation and their families.

What Americans with mental retardation and their families desire is both more and less than the current system delivers, derived as it is from its institutional precursor. The agenda in long-term care is both a composite and a constituent part of the reform debates on employment, health care, housing, and welfare. What is desired of long-term care is an extension of what is needed generally from our reform efforts -- greater independence, choice, dignity, and inclusion.

To understand the texture of the contemporary long-term care system for Americans with mental retardation one must understand its historical antecedents in the state-operated institutional care system. Over two decades ago Federal Medicaid dollars were used to finance improvements in the state institutions and to create additional capacity in the private sector. Beginning with the Home and Community Based Services (HCBS) waiver in 1981, diversion of Medicaid funds was authorized for community placements of individuals who might otherwise have qualified for an Intermediate Care Facility-Mental Retardation (ICF-MR) bed. Thus it was through the open-ended Medicaid ICF-MR program that states expanded long-term residential alternatives outside of the traditional state operated institutional system.

We must be cognizant of the enormity of the Medicaid program in the lives of persons with mental retardation. Revisions in policy will dramatically affect the character of services. Medicaid ICF-MR and Home and Community-Based Services funds represent the single largest Federal services program in the field. For over 20 years, its institutional component has grown dramatically. Because of its size and institutional origins, Medicaid is both bulwark and bane to long-term care. The funds are a cornerstone of funding in the field. When matched with mandated state and local funds, Medicaid accounts for 52 percent of all financial resources for mental retardation services nationally. Nevertheless, for all the Federal legislative and administrative language expressing commitment to independence and inclusion in the community, only 1.5 percent of this enormous annual Federal investment is used for individualized supports for people with mental retardation.

Needs for long-term care are significant and will grow through the decade. Waiting lists for placements into residential facilities are estimated in excess of 78,000. There are also over 40,000 nursing home residents with mental retardation; many will require transfer to more appropriate settings. There is a large population of adults supported at home with aging parents increasingly unable to provide care. Finally, there

are those 228,000 persons in state institutions and other congregate facilities with over 6 beds for whom more individualized supports are required.

Our concerns in long-term care are mirrored in our recommendations for housing. Despite the contraction of the institutional network, and despite the dramatic growth of individualized supports in the community, the non-inclusive character of the nation's residential services for persons with mental retardation remains fundamentally unchanged. Ending this segregation is our first priority. We must realign the nation's fiscal commitments to bring this about. Federal funding policies must be modified to eliminate fiscal incentives that encourage development of more institution-like care in separated facilities of all sizes. We must bring coherence to long-term care; it must be predicated on the individual not the facility, on personal needs and not professional guilds, on consumer choice rather than service "slots."

PCMR underscores again the interconnectedness of the domestic agenda for Americans with mental retardation. Health housing, and welfare reform will not be complete until the long term care needs are systematically and comprehensively accounted for.

PCMR RECOMMENDATIONS: LONG-TERM CARE

The long-term care agenda for persons with mental retardation is inextricably linked to our reform recommendations in health, housing, welfare, and work. Each is a critical component to long-term care. What is presented below is not a recitation of new and additional services but rather a recommendation for a coherent approach to long-term supports based on the President's call for "People First."

COMMIT FEDERAL POLICY TO THE PRINCIPLES OF INDEPENDENCE AND COMMUNITY LIFE

- ❖ **Permit the states to innovate.** Federal commitments to institutional services spending through Medicaid ICF-MR are enormous, yet we continue to cap the level of Medicaid benefits available for serving people in their own homes. Make the Medicaid Home and Community Based Services a full Medicaid option. Regularly provide residents of ICFs-MR the option to use the Medicaid HCBS Waiver. Permit Medicaid Waiver funds to be used to supplement housing costs.
- ❖ **Provide universal access to individualized long-term care supports through social insurance.** Provide reasonable cost sharing through modest deductibles and co-insurance; uphold personal dignity and self-direction; minimize dislocation; provide only that which is specifically appropriate to the individual; avoid forced impoverishment.
- ❖ **Put people first.** Long-term services must commit to a non-facility based model of care; address the needs of the individual and break free of the "continuum" of care funding options.

IV. EPILOGUE: PUTTING PEOPLE FIRST

The contours of mental retardation in America changed significantly in the 27 years since MR 67. Yet inequities remain, and basic paradigms of care are unchanged. PCMR's recommendations are a challenge to these old assumptions.

Our recommendations must be viewed as mere threads in the larger fabric of an individual's experience. Reform is more than the identification of "optimal" services; what we do cannot be disentangled from the meanings, experiences, and aspirations of the individuals that all these systems of supports are intended to serve. The essence of reform in the field of mental retardation lies in an abiding respect for the person. We are talking about constituents, not clients; citizens rather than recipients -- let us not lose sight of the person in the policy.

"We went to a forest preserve one weekend," recalled Linda Preston." A group of young adults had an impromptu concert with bongos, drums, and other instruments. We went over to listen. One of them gave Elisha some maracas. And for the next hour, Elisha was just one of the bands, making music, dancing and keeping the beat. They didn't see his disabilities. They just saw the music in him."

This is the crossroad. In our journey of national renewal, we must choose to challenge the old assumptions. We must move the nation towards a vision that accords a basic dignity to all its citizens. Let America's fundamental nobility be reflected in the lives of those like Elisha Preston, Katie Charlton, David Guillet, and Robert Miles. Their passage is a journey we will all share.

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