

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

President's Committee on Mental Retardation



**A Better Place:
The Contribution of Americans with Mental
Retardation to our Nation's Workforce**

1998 Report to the President

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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

September 30, 1998

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

Dear Mr. President:

On behalf of the President's Committee on Mental Retardation (PCMR) we are pleased to offer you the 1998 Report to the President: *A Better Place: The Contribution of Americans with Mental Retardation to our Nation's Workforce.*

This report is the result of the Committee's continuing effort to bring together a broad representation of stakeholders to carve out a path for future services and supports for people with mental retardation. This Report includes specific recommendations from the PCMR Employment Summit: Designing Change which addresses significant barriers to the achievement of the goal of a real job in ones community with an opportunity to grow and maximize ones potential. In addition, PCMR is delighted to report the continued success of the PCMR Next Generation Leadership Symposium and the fourth annual PCMR National Collaborative Academy on Mental Retardation.

PCMR wants to extend a sincere thank you to the report writer, **John Kregel**, Ed.D., Virginia Commonwealth University, whose passion in life is to create employment opportunities for people with disabilities. He has effectively brought together the collective thoughts and recommendations from the diverse gathering at the PCMR National Employment Summit into a document that is true to the PCMR mission and tradition of establishing a road map for the future in the field of mental retardation.

A special thanks to **Yolande Bestgen**, PCMR Director of Special Projects, who brought together the cross section of participants for the PCMR National Employment Summit who served as the catalyst for significant and targeted discussions on employment. We also want to recognize **Richard Swartz** for the cover design and **Kate Billings** for her work on the text graphics.

It is the energy of all of the people gathered at each of these nationally recognized events that continues the spirit of this President's Committee for lifelong inclusion for people with mental retardation

Valerie J. Bradley
Chair

Gary H. Blumenthal
Executive Director

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.

The President's Committee on Mental Retardation was formally established by Executive Order in 1966 by President Lyndon B. Johnson and directed to focus on issues related to mental retardation and to guide Federal policy to address this critical concern of so many American citizens.

Since 1993 PCMR has, with renewed energy, effectively impacted disability policy within States/Territories, and Native American Tribes; established a movement for future leaders in the field; and set the stage for employment services and supports for the future. The PCMR publications are utilized as texts in Universities, training tools for direct service professionals and serve as innovative guides by policy-makers.

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

Through the collaborative support of Federal agency partners, PCMR held three national events in 1998. The PCMR *National Employment Summit* was co-sponsored by The Social Security Administration; the *Next Generation Leadership Symposium* and the *National Collaborative Academy on Mental Retardation* were co-sponsored by the Office of Special Education and Rehabilitative Services, The Social Security Administration, Administration on Developmental Disabilities, Administration on Native Americans, and the National Institute on Child Health and Human Development.

NEXT GENERATION LEADERSHIP SYMPOSIUM

The President's Committee on Mental Retardation convened its third annual Next Generation Leadership Symposium. The 1998 Symposium attracted nearly 300 participants, representing 40 States and the District of Columbia. This Symposium provides a forum for young leaders to interact with peers, discuss and to develop recommendations concerning service trends, supports, and advocacy for people with mental retardation. The ultimate goal is to train and retain young leaders who exemplify the highest ideals and standards of public service in the field of mental retardation. The culmination of this 1998 Symposium will be a special report with recommendations presented to PCMR.

Three leaders were recognized during this event as recipients of the Elizabeth Monroe Boggs Award for Young Leadership. The following were presented this prestigious national award in recognition of their valued and outstanding leadership:

Joseph P. Meadours, Northport, Alabama is past president of People First of Broken Arrow (OK) and People First of Oklahoma. As a consultant to the University of Oklahoma, Mr. Meadours served as a teacher's aide and helped train individuals to serve effectively as a job coach for persons with mental retardation. His current position is Co-Director of the Celebration of Community Living Program in Alabama, which is jointly sponsored by the Civitan Research Center and the University of Alabama at Birmingham. The purpose of this program is to identify and recognize individuals with mental retardation who are residing successfully within the community so they may serve as role models for others.

Rocky Nichols, Topeka, Kansas, has served in the Kansas House of Representatives for six years. Representative Nichols serves on the powerful Appropriations Committee and is one of the strongest supporters in the Kansas Legislature for community services for people with disabilities. He

was a key player in the passage of the Kansas landmark disability rights legislation, the Developmental Disabilities Reform Act. This Act, passed in 1995, assures that the choice of Kansans with disabilities are honored when they seek community services and guarantees that people with disabilities are treated with respect and honor. He is a strong advocate for People First and works hard to educate his colleagues on both sides of the aisle and in both chambers with regard to legislation that is important to ensure that people with disabilities have access to the lifestyles they choose.

Liz Obermayer, Boston, Massachusetts, holds the distinction of being the first self-advocate to work for a State Office of Mental Retardation as a Self-Advocacy Specialist. In this role, Ms. Obermayer does public speaking about self-advocacy and important issues in the lives of people with disabilities, serves as a member of the quality enhancement Service Tool Team and provides training and mentoring to self-advocates and other groups. One of her many leadership skills is her effectiveness as a communicator. As a plenary speaker at the 1998 American Association on Mental Retardation (AAMR) meeting, Ms. Obermayer delivered an impassioned presentation about inclusion and the importance of full participation of self-advocates in the work of AAMR. Ms. Obermayer is a Trustee of the Howe Library and an articulate communicator to a wide variety of audiences.

NATIONAL COLLABORATIVE ACADEMY

The fourth annual PCMR Academy brought together teams from five States including Minnesota, New Jersey, New Mexico, South Carolina and Virginia, The Hopi Tribe and the Territory of Puerto Rico. For four intense days Teams were educated on cutting edge service and support systems and innovative policy initiatives. These teams included: Governor's Representatives, State Legislators, Tribal Council leaders, State Budget Directors, Medicaid Directors, people with mental retardation, family members, business leaders, Commissioners of MR/DD, Education, Health and Vocational Rehabilitation, service providers and representatives from key

organizations including Developmental Disability Councils and Protection and Advocacy.

This working retreat supported each Team's efforts in designing an action plan specific to the unique needs of citizens with mental retardation of the participating States, Tribe and Territory. Each plan carried the basic values and principles of lifelong community inclusion for people with mental retardation. The long-term value of this continued project is reflected in the significant impact the PCMR Academy has had on issues of institutional closure, inclusive education, family and individual supports and reduction of community waiting lists.

EMPLOYMENT SUMMIT: DESIGNING CHANGE

In January of 1998 PCMR held the by-invitation-only, *National Employment Summit: Designing Change*. This unique Summit brought together a cross section of individuals from across the Nation to participate as members of Design Teams to identify best practice services and Federal policy recommendations resulting in community employment for people with mental retardation. Design Team members included employers, people with mental retardation, family members, researchers, service providers, advocates and State and Federal policy-makers. PCMR identified concerns of high unemployment and limited job opportunities within the community for people with mental retardation and challenged the 75 participants to design a future that removed barriers and created opportunities for employment. The outcomes and recommendations are reflected as the body of this **1998 Report to the President. A Better Place: The Contribution of Americans with Mental Retardation to our Nation's Workforce**

A Better Place: The Contribution of Americans with Mental Retardation to our Nation's Workforce

A BETTER PLACE

Jessica T is a 29-year-old woman who lives in a southern State. Jessica was born with Down syndrome and medical complications that threatened her life at the time of her birth. Jessica's parents were told that, because of her medical problems, she would not live to be five or six years old. They were told that she would be "better off" in an institution—better for Jessica and better for her family – but they ignored this advice and Jessica started attending school at the age of six.

While in school, Jessica was labeled as having "multiple disabilities". She spent her school years in segregated classrooms for students with mental retardation. She was able, however, to attend both an elementary school and, later, a high school very close to her home—the same school her brothers and sisters attended

Jessica graduated from high school in 1992. Through assistance provided by a local supported employment program and with the help of one of her neighbors, she found a job as an aide in a local child-care center. She has been working there ever since. She has many job duties, including preparing snacks, feeding children, taking the three and four year olds to the restroom, doing laundry, supervising children as their parents drop them off and pick them up at the beginning and end of each day and assisting during field trips and other special activities.

When Jessica first started her job, the parents of four children who attended the day care center expressed concern to the Director. They had reservations about Jessica serving as an employee. They indicated a concern about the "welfare" of their sons and daughters, knowing that Jessica would be supervising them, feeding them, and helping them to go to the restroom on a daily basis. However, after six years in her job, Jessica has more than demonstrated her ability to do the job and for some time has earned the reputation of being the most popular staff member working at the center. Parents often ask her to babysit for them on weekends when she is not working. At holidays and on her birthday, she receives more gifts and recognition than any other staff member does. When she is not at work, regardless of the reason, people ask about Jessica—where she is and how she is doing.

Jessica's supervisor describes her as a valuable employee, one who is experienced, reliable, trustworthy and well liked by her coworkers and customers. When asked about the contribution Jessica makes to the center, her supervisor says, "That's easy. Our center is a better place in every way because Jessica works here. It's better for everyone—for the employees, for the director, for the children, and for the children's Barents. It's a better place to send your children and a better place to work."

The sentiments expressed by the director of the childcare center reflect the experience of many employers. Incorporating individuals with mental retardation into America's workforce has nothing to do with charity or altruism. It is not about what work can do for the lives of people with mental retardation. It is about the contribution that workers with mental retardation can make to each and every workplace. Employees with mental retardation bring skills, abilities, and positive personal qualities to their jobs. The childcare center is a better place because Jessica is there. All businesses and companies can benefit from the participation of individuals with mental retardation.

ACHIEVEMENTS

Just a few short years ago, individuals with mental retardation faced tremendous obstacles when they attempted to obtain employment in their local communities. Traditionally viewed as incapable of economic self-sufficiency and unable to contribute to their communities, these individuals were often likely to earn token wages performing menial tasks in work activity or adult activity centers. Today, however, hundreds of thousands of individuals with mental retardation are able to earn significant wages in integrated community settings. The success of these individuals has been helped by the changing attitudes on the part of our nation's employers, the development of new service technologies such as supported employment, and initial efforts to

* adapted from "Closing the Shop" by Stephen T. Murphy & Patricia M. Rogan, 1995

restructure our nation's service delivery system for individuals with mental retardation.

Employers as Partners

For many years, the negative attitudes held by business and industry were viewed as an obstacle to the employment of individuals with disabilities. Today, however, significant progress has been made and many employers are developing innovative strategies to recruit, train and retain individuals with mental retardation as members of their workforce. Employers currently face growing labor needs, changing workforce demographics and evolving business models. They are recognizing the value of their employees and are investing their resources to develop skilled, highly productive workers who can enhance the competitiveness of the business.

Across the nation, large and small businesses are developing new and exciting strategies for incorporating individuals with mental retardation as key components of their workforce. In many communities, employers are leading the way with new solutions to long-term problems by actively recruiting workers with mental retardation, featuring them in their marketing and promotional materials, finding unique ways to provide necessary work place accommodations and insuring that they are able to advance within their careers as their skills and experience increase. A number of new employer-driven strategies have been developed.

- ◆ Employer-Based Support Programs—Employers are incorporating supports for individuals with mental retardation into their human resource and disability management functions. In a growing number of businesses, human resource staffs coordinate orientation, training and ongoing support functions that will enable individuals with mental retardation, and other employees with special needs, to make an ongoing contribution to the company.
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- ◆ Mentorship Programs—A number of businesses have had dramatic success designing and implementing mentorship programs, in which a worker with mental retardation is paired with a coworker who has expressed an interest in serving as a mentor. The mentor assists in the initial training of the worker and provides support as needed throughout the course of the worker's employment.

- ◆ Partnerships with Employment Service Providers—In a number of communities across the country, employers are working closely with employment service agencies for individuals with mental retardation to devise and implement cooperative employment programs. Employers are generally responsible for providing jobs, conducting initial training, and providing necessary accommodations. The employment service agency is responsible for identifying qualified applicants and assisting in the development of accommodations as necessary.

Through these activities, employers have learned much about the skills and abilities of workers with mental retardation. As hundreds of thousands of qualified workers have shown, individuals with mental retardation make highly effective employees. The characteristics valued most by employers—reliability, dependability, getting along with coworkers, loyalty to the company, respect for authority—are the factors used most often by employers to describe workers with mental retardation. Those factors that truly "handicap" an individual in terms of their value to an employer—insubordination, unwillingness to work as a member of a team, lack of dependability, substance abuse problems—are the characteristics that employers least frequently ascribe to workers with mental retardation. In today's highly competitive business environment, employers would be shortsighted to overlook this potentially untapped human resource.

Supported Employment

Supported employment began as a philosophical commitment to improve employment opportunities for individuals with mental retardation and provide an alternative to segregated service settings such as workshops and activity centers. It is now a major national initiative with its own technology, enabling legislation and steady funding stream.

Supported employment provides ongoing support to individuals with mental retardation, previously excluded from meaningful employment opportunities, to enable them to succeed in paid employment in integrated work settings. Its success lies in involving the individual with mental retardation and his or her family, the employer and coworkers and human service providers in a combined effort to enable the individual to pursue a self-chosen career. Since its inception as a Federal program in 1985, few rehabilitation initiatives have grown at such a remarkable rate.

- ◆ A proven program that works—Over 100,000 Americans with mental retardation are working in real jobs through participation in supported employment programs, a tenfold increase over the last decade. Supported employment services are available in all 50 States through 4,000 local provider agencies.
 - ◆ A means to economic empowerment—Individuals increase their average annual earnings by at least 500% through participation in supported employment. Persons with the most significant disabilities experience the largest increases.
 - ◆ A vehicle to independence—Nearly three-fourths of all supported employment participants with mental retardation are Supplemental Security Income (SSI) recipients. Almost all of these people experience
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reduced dependence on SSI payments after supported employment and one in four indicate their personal earnings become their primary source of support. It is estimated that supported employment participants pay over \$150 million each year in Federal, State and local taxes.

- ◆ A continually evolving technology—Supported employment has been in existence for a little over a decade, but our service and support technologies continue to improve. Customer-driven supported employment, natural support strategies, and employer mentoring, job carving and other business-based approaches are expanding and improving the original job coach model of supported employment.,
- ◆ A valuable resource to business—Employees with mental retardation enhance employer productivity and corporate competitiveness. Employers indicate that workers hired through supported employment programs exceed their expectations in productivity, reliability and company loyalty. Supported employment makes simple business sense.
- ◆ A cost-effective alternative—In State after State, in both large and small communities, it has been repeatedly demonstrated that supported employment is a cost-effective alternative to other day support options for persons with mental retardation. The long-term costs of supported employment programs are generally 40% to 80% of the costs of adult activity centers or sheltered workshops. Communities that have adopted a supported employment approach generally find that they are able to serve more individuals and achieve improved outcomes for individuals with mental retardation.

Kaposia, Inc., in St. Paul, Minnesota, is a customer-oriented company that provides integrated employment services to about 150 adults with disabilities and community-based, school-to-work transition services for students with severe and multiple disabilities. This was not the case some ten years ago when Kaposia, Inc., founded in 1963, was a self-contained, segregated program that provided independent living, social and recreational skills

training and subcontract work and work activities to people with disabilities considered to be too disabled for sheltered workshops.

Kaposia's transition was a long and painful process that was initially prompted by the public outcry of high taxes targeted for social service programs and fueled by the ongoing demands by program participants desiring more and meaningful work when they were deemed unemployable by employment programs in the community. In recognizing the need for change, Kaposia, Inc. developed a new philosophy and created a vision to become a provider of employment services and cease being a facility where people entered and never left.

*Challenges were many as staff lacked sufficient skills resulting in high turnover, lengthy planning with little action, and families and professional agencies were reluctant. The commitment remained steady as Kaposia, Inc. received systems' change funds, staff were trained, job descriptions were changed, individuals with supportive families desiring employment were placed into jobs as receptive professional agency staff were identified and utilized. Collaborative efforts were established through the development of relationships with the Department of Rehabilitative Services and the business community. Program evaluation activities indicated high satisfaction with services and slowly the conversion process continued via example of one successful placement after another. Barriers continued, foremost, the attitudes of in-house staff in the facility-based work activity program who could not accept the changes that were occurring and often had to make career-altering decisions. Eventually, Kaposia, Inc. stopped accepting referrals to the in-house segregated program and as the last person was placed into employment, the conversion was complete.**

The national supported employment initiative has changed forever our Nation's view of the employment potential and productive capacity of individuals with mental retardation. Negative attitudes and stereotyped beliefs of employers have begun to erode as individuals have repeatedly proven their ability to contribute to business productivity. The program increases consumer earnings, costs less than other alternatives, and reduces individuals' dependence on disability benefits. Most importantly, it has enabled thousands of people to participate more fully in their communities, take pride in their accomplishments, and view themselves as productive individuals. As a supported employee in a hospital supply room explained, "Why do I come to

*adapted from "Closing the Shop" by Stephen T. Murphy & Patricia M. Rogan, 1995

work every day? ... People here need help. They're sick. They would miss me if I weren't here. I would worry about them."

Restructuring our Service System

Nearly 5,000 local community agencies provide vocational services and employment supports to individuals with mental retardation in the United States. Of these, over 3,000 assist individuals in finding jobs within the businesses and industries in their local communities. Slowly, but steadily, our nation's traditional network of sheltered workshops and work activities centers are changing in response to the new realities of consumer empowerment and a preference for integrated, community-based service delivery. Hundreds of new community employment agencies have arisen that provide only integrated employment services. Thousands of existing programs have expanded their service programs to respond to the new paradigms. The rate of change must significantly increase in the future to keep pace with rising demand for supported employment and other integrated employment alternatives. However, our national network of community service agencies has changed substantially over the past two decades.

- ◆ As recently as 1986, only 300 programs across the country provided supported employment or other integrated employment services. Today, over 4,000 agencies provide supported employment to individuals with mental retardation and the figure continues to grow steadily.
 - ◆ Today over 20% of all adults with mental retardation receiving vocational services do so in integrated community settings, up from less than 5% only a decade ago.
 - ◆ In nearly every State in the country, local agencies are significantly downsizing or eliminating their traditional sheltered employment
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programs and converting these programs to community integrated employment.

- ◆ Local community employment agencies serving individuals with mental retardation are redefining the agency mission, developing new partnerships and relationships with business, and incorporating business practices into their service organization and operations.

Avatrac, located in Denver, Colorado, was a thriving sheltered workshop planning to expand its operation serving 248 people with mental retardation in 1985. While exploring other sheltered workshops and learning about supported employment, Avatrac staff recognized that their mission ultimately, through the continuum of services, offered, was to place people into jobs in the community. Hiring a consultant to look at their operation led them to the commitment to convert the workshop into a supported employment program to place people directly into jobs instead of progressing through the costly continuum.

Funding became their biggest obstacle as the Division of Developmental Disabilities (DDD) funds received per person was ceased when each person entered the community. After negotiation, Avatrac was able to creatively arrange with the DDD to fund their activities. When the funding was no longer available, Avatrac turned to the Division of Vocational Rehabilitation where they were able to receive additional funds and continue support for their new employment services.

*Additional barriers to the conversion efforts included staff reluctance to the change due to their limited knowledge and training, lack of interest of participants in leaving the workshop, skeptical families and resistance of other professionals, especially residential service coordinators. Training was provided to Avatrac staff and they adopted a successful team approach. Participants were not forced to leave the workshop but were offered group options such as enclaves to make a slow transition to community employment. The positive experience of others placed in individual jobs provided encouragement to others. Most parents were supportive of the efforts being made and were eager for their sons and daughters to be placed in employment. Today, Avatrac continues the conversion effort and provides services for about 300 people with almost 200 of them placed in community jobs. **

* adapted from "Closing the Shop" by Stephen T. Murphy & Patricia M. Rogan, 1995

The advances and accomplishments of the recent past have been quite remarkable. Individuals with mental retardation have demonstrated their value as productive members of the nation's workforce. Our schools are improving their ability to prepare adolescents with mental retardation for meaningful and rewarding lives in which employment is an expectation, not a dream. Supported employment and other new service technologies have allowed hundreds of thousands of individuals previously viewed as unemployable to obtain and maintain satisfying employment in jobs they chose themselves.

Raised expectations have resulted in dramatic changes in the ways in which States and localities organize and deliver employment services. It would be a tremendous mistake to believe that all that needs to be done has been achieved. We have only begun to fulfill the responsibilities we have and the commitments we've made with our citizens with mental retardation. We now have a unique opportunity to build upon the foundation we have laid and finish the task we have started.

FORCES FOR CHANGE

Kit is a 19 year old high school student with severe mental retardation and autism who lives with her family. Although she has limited expressive language she communicates through her body language and willingness to participate in activities. Kit is dependent on others for her personal and daily living needs.

Kit is enrolled in a self-contained class at a high school. She participates in a community-based vocational education program that provides supported employment services. She has held a part-time job at a restaurant as a food prep worker for more than a year. Her job duties include breading ravioli, eggplant and zucchini sticks and panning loaves of bread for baking. She assists her co-workers with the daily general clean up by taking all dirty pans to the sink area. She works approximately 18 hours a week as part of her school curriculum and earns \$5.00 an hour. Transportation is provided to and from work by the school during the week and her parents on the weekends.

Kit's daily needs while at work are supported by her co-workers, managers, and her job coach. She receives their assistance in taking off and putting on her coat; placing and retrieving items from her locker; clocking in and out; putting on and taking off her hair net, apron, and gloves; washing her hands; replenishing her work supplies and going on break. Technological assistance is also incorporated into her routine. As an example, the manager ordered a magnetic scanning card, which eliminated the need to manually enter her employee number into a computer for clocking in and out. An audio prompting/praising system was developed to provide her consistent intervention and decrease her dependence on others for feedback on her work performance.

*Kit, will soon move from school into adult life in her community with job experience in place and a resume reflecting real work in her hand.**

Now, more than at any other time in our Nation's history, people with mental retardation are actively participating in the economic life of their communities. Over the past quarter century, Federal and State legislative initiatives, advances in rehabilitation and assistive technology, and changes in societal attitudes have combined to revolutionize our Nation's view of the employment potential of citizens with mental retardation. No longer are they viewed as an economic burden to their families and the economy.

In 1998, workers with mental retardation are proving themselves each day to be productive workers and outstanding employees. As we approach the turn of the century, our economy is stronger, our companies are more competitive, and our communities are richer because people with mental retardation are increasingly integrated into our nation's work force.

Despite the undeniable progress of the past 25 years, many problems remain. The majority of adults with mental retardation continue to be excluded from the nation's work force, unable to obtain or maintain employment. Yet, at this time in our history, we have a chance to dramatically improve the employment opportunities of Americans with mental retardation. Various political, economic and social forces are currently

* excerpt from 'Spotlight on Work Support', Virginia Commonwealth University Rehabilitation Research and Training Center, 1998

combining to create a unique opportunity that we should not disregard. We must expand upon those principles we know to be successful and summon the courage and resources necessary to solve the problems we have too long ignored.

Presidential Leadership

"The Americans with Disabilities Act of 1990 is making it possible for millions of Americans to participate more fully in society — through employment, access to public facilities, and participation in community and leisure activities — and to do their part to make us a stronger and better country. At the same time, we are reminded that significant challenges remain. Far too many of the 30 million working-age adults with disabilities are still unemployed, especially those with significant disabilities."

- President Bill Clinton

The recently established Presidential Task Force on the Employment of Adults with Disabilities can serve as the catalyst for the next wave of reform and improvement. The Task Force's primary areas of focus—lack of consumer-driven supports and services, economic incentives to work, elimination of employment discrimination, availability of work place accommodations, and inadequate access to needed health care, transportation, housing, and other supports—are the very issues faced by individuals attempting to enter employment. The challenges faced by the Task Force are difficult, but their successful solution can improve employment opportunities for persons with mental retardation for many years.

Consumer Control and Empowerment

During the decade of the 1990s, the concept of consumer empowerment has become the central value guiding the development of employment policy for individuals with mental retardation. Recent Federal legislation has reflected a clear commitment toward enabling individuals to plan and pursue their own careers. High school students are leading their own transition planning meetings, establishing employment goals and planning for

their lives after graduation. The consumer choice provisions of the 1992 Rehabilitation Act Amendments are designed to allow consumers to choose their own jobs, identify the services and supports they need, and select the person or organization that will best meet their needs. Future reforms being seriously considered include increased use of vouchers, "Ticket to Work" programs, and other alternatives that will allow persons with mental retardation and their families to truly select the services and supports they need.

Social Security Reform

Current efforts to reform Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) recognize that many of the programs designed to support persons with mental retardation actually hinder their chances for employment. The Social Security Administration's Employment Strategy emphasizes consumer control of services. It recognizes that work must result in increased earnings and improved economic status. It further acknowledges the need for access to stable and affordable health care. Most importantly, it is based on the belief that our benefit programs should be a foundation that many individuals can use to achieve independence and pursue their self-chosen careers. People who feel that they can work and desire employment should not be denied access to the services and supports they need to achieve their goals.

A New Relationship With Employers

As more and more individuals have entered the workforce, employers are becoming increasingly aware of the tremendous contribution individuals with mental retardation can make to the success and productivity of both large and small businesses. While discrimination and negative stereotypes remain a significant problem, examples abound of employers who have developed innovative approaches to promoting workforce diversity. These employers are

aggressively recruiting employees with mental retardation, featuring them in efforts to market their products and services, and making available necessary accommodations to guarantee long-term employment success and career advancement. Employers have developed a number of new strategies to hire, train, and retain employees with mental retardation, including employee mentoring and job coaching, job sharing and job carving approaches, formal arrangements with local service providing agencies, and enhanced disability management and employee assistance programs.

The Changing Nature of the American Work Force

"Home-based employment and other forms of workplace flexibility are beneficial to many workers, including the disabled. From working parents to people with disabilities, many people are taking advantage of technology advances that allow them to telecommute and still play an active role in filling the nation's growing job vacancies."

- National Organization on Disability

Structural changes in our Nation's economy will have a significant impact on future employment opportunities. Trends such as corporate downsizing, outsourcing, increased reliance on part-time or contract employees and telecommuting are altering the relationship between workers and their employers. While some fear these trends, current economic changes may actually offer important new opportunities for persons with mental retardation. Downsizing and outsourcing may allow individuals to develop self-employment or entrepreneurial arrangements. Increased use of part-time and contract employees may create chances for the development of job sharing or job carving options. Telecommuting and other flexible staffing arrangements may increase employers' acceptance of the types of reasonable accommodations sometimes required by individuals with mental retardation. When viewed creatively, current workforce trends can be used to promote, rather than hinder, employment of persons with mental retardation.

Technological Advances

Recent advances in technology have changed the lives of everyone in our society. One of the most significant effects of recent improvements is the ease with which individuals can gain access to large amounts of information from their homes or offices. From cellular telephones to voice activated computers, from Internet forums to electronic speech synthesizers, technological advances may hold the key to improved independence and productivity for individuals with disabilities. Many technological applications hold tremendous promise for improving the lives of individuals with mental retardation and providing new opportunities for work force participation. This potential will not be realized, however, if individuals do not have access to this technology. Special care should be taken to insure that individuals with disabilities are included in this information revolution.

THE PARADOX

"At a time when the U.S. unemployment rate is at an historic low and there is a crying need for workers, it is astounding to learn that the employment gap remains so wide. Over 72% of people with disabilities out of the workforce want to work and contribute to the economy."

- Alan A. Reich, President, National Organization on Disability

In stark contrast to the dramatic successes we have experienced and the tremendous opportunities that lie before us, the undeniable reality remains that hundreds of thousands of capable, motivated individuals with mental retardation continue to be excluded from the workforce. In spite of landmark legislation and major efforts to reshape our service delivery system, over two-thirds of all adults with mental retardation remain unemployed. The chronic unemployment of individuals with mental retardation has concerned the President's Committee on Mental Retardation (PCMR) virtually since its inception.

In 1967, PCMR estimated that the unemployment of individuals with mental retardation resulted in billions of dollars of lost earnings each year.

In its 1983 *Report to the President*, PCMR concluded that there were hundreds of thousands of people with mental retardation who were employable but were unemployed because of misconceptions.

In 1994, the PCMR publication, *Journey of Renewal for All Americans*, reviewed the decade that had passed since its 1983 report and found that "...the contemporary employment status of Americans with mental retardation is one of underachievement..."

The exclusion of individuals with mental retardation from our nation's workforce must not be allowed to continue. Failure to incorporate citizens with mental retardation into the labor force wastes a valuable human resource. The cost of dependency in terms of income maintenance programs and other public assistance places a tremendous strain on our nation's economy. Even greater are the human costs of idleness and dependency on the lives of individuals with mental retardation and their families.

The problems that have made unemployment such a troublesome and intractable dilemma are varied and complex. The barriers do not reside within a single agency or program. The obstacles cannot be overcome with a simple regulatory change, a reiteration of legislative intent, or a new program initiative. The root causes of unemployment for individuals with mental retardation are attitudinal, economic and political. Their eradication will require courage and resolve on the part of individuals, their families, business and industry, local communities, and State and Federal governments to undertake fundamental reform that addresses problems too long ignored.

Our Policies Must Match Our Beliefs

*"We must AO disability policy in America away from exclusion towards inclusion... and our policies away from paternalism to empowerment."
- Vice President Al Gore*

The amount of Federal funds spent to support individuals with disabilities exceeds \$200 billion annually and is rising at an alarming rate. Yet, most of these monies are used to provide health care and income maintenance and support. Only a very small percentage of these funds go directly to promote the employment of individuals with disabilities. It is estimated that expenditures for employment and vocational rehabilitation programs total only about 2% of all disability-related expenditures. While our values promote economic independence, in reality our resources are used to support long-term dependence on Federal subsidies.

In many instances the policies and philosophies embodied in various programs are conflicting or even contradictory. Significant efforts are made to provide job training and placement services through supported employment and other rehabilitation and employment programs. At the same time, income support programs such as SSI or SSDI are built on a set of policies and regulations that can severely penalize persons with mental retardation who attempt to leave the program rolls and enter competitive employment. Similarly, the Americans with Disabilities Act is built on the principles of independence and inclusion. Yet a number of Federal programs, such as vocational rehabilitation and Medicaid, provide extensive financial support to sheltered employment and day activity programs that maintain individuals in segregated environments that have traditionally failed to prepare them for competitive employment.

Disincentives in the Benefits System

Many individuals with mental retardation are able to work and desire employment. However, the structure of our disability benefit programs threatens many individuals with loss of income supports and health care coverage if they attempt to work. Entering the work force should enable individuals to increase their earnings while lessening the need for income support. No one should be financially penalized for going to work rather than remaining on benefits. Sadly, for a large number of individuals, their decision to obtain employment doesn't lead to increased personal income. In fact, some may actually be worse off after working, if they lose their cash benefits and health care coverage while simultaneously incurring transportation, health care, clothing and other expenses. Our policies must promote, not punish, the efforts of individuals with mental retardation who desire to leave the disability rolls and become contributing members of their communities.

The Supplemental Security Income and Social Security Disability Insurance programs contain a number of work incentive provisions that are designed to assist individuals attempting to obtain employment. Similar provisions of the Medicare and Medicaid programs attempt to extend health care coverage to individuals entering the workforce. However, these current work incentive provisions are insufficient, under-utilized, and unnecessarily complex. Work incentive programs are often incomprehensible to persons with mental retardation and their families. As a result, motivated and competent individuals often elect to remain removed from the workforce, rather than risk the loss of income supports and health care coverage should they attempt to work.

Waiting For Services

"[Waiting lists are] a problem that is not self-correcting. In most States, continuations of the current practices of providing and financing services is a recipe for more and more people being kept out of a system that is supposed to assist them."
- K Charlie Lakin

Many currently unemployed individuals with mental retardation desire employment and are eager to begin a satisfying, self-chosen career. Yet they are unable to gain access to the services and supports they need to be successful. In many communities, waiting lists for employment services extend for many months or several years. Our current service delivery system simply does not have the capacity to meet the needs of all individuals eligible for and desiring services.

It is estimated that between 75,000 and 100,000 citizens with mental retardation are currently on waiting lists for vocational or employment programs. Most troubling is the fact that even as service capacity expands in individual States the demand for services also increases. In many States, waiting lists for employment services will remain or expand for the foreseeable future. As waiting lists grow, the hopes and expectations of individuals wane and the burden on aging caregivers increases.

The effects of waiting lists on adolescents and young adults exiting secondary special education programs are of particular concern. Students leaving school only to face years of waiting before receiving employment services may lose the skills and abilities they have acquired. Their self-esteem and ability to lead a normal lifestyle may be jeopardized. Effective transition from school to adult life must not mean transition to the frustration and hopelessness of years spent on a waiting list. Young adults with mental retardation must have access to the system that is designed to help them. A number of States have recently begun initiatives to reduce and eliminate waiting lists. While some States are contemplating additional appropriations

for their adult service system, many States are looking at the fairness of current funding practices. Those programs and practices that are viewed as costly or that do not contribute to individuals' independence and productivity must be critically examined. The limited resources available to fund adult employment services will require that we find the moral and political courage necessary to reduce or eliminate current services that do not meet the tests of effectiveness and cost-efficiency. To fail to do so will only exacerbate a problem that is disturbing now and will continue to plague us for the indefinite future.

When All Doesn't Mean All

Many of the major Federal programs designed to promote the employment opportunities of all Americans have effectively excluded individuals with mental retardation from their services and activities. Few students with disabilities participate in programs funded through the School-to-Work Opportunities Act. Youth employment programs funded through the Department of Labor (DOL) have consistently failed to serve people with mental retardation. Concerns have also been expressed that the DOL One Step Career Center programs are not being implemented in a way that will enable them to meet the comprehensive needs of persons with mental retardation.

The President has directed the National Task Force on Employment of Adults with Disabilities to find ways to assure that the welfare to work provisions of the Personal Responsibility and Work Opportunity Reconciliation Act are implemented in a way that does not discriminate against persons with mental retardation and other disabilities.

The mandate and intent of each of these programs expressly encompasses the participation of individuals with disabilities, including persons with mental retardation. Yet, as one individual remarked after attempting to gain access to services through a One Stop Career Center,

"Receiving an invitation doesn't do you any good if there's nothing to do and you don't feel welcome when you get there. You're not sure you belong."

Making Programs Accountable

Far too often, individuals with mental retardation and their families view local Vocational Rehabilitation and Social Security offices as inaccessible and unaccountable. Instead of being perceived as responsive public programs that go the extra mile to make certain that consumers receive the services to which they are entitled, local agencies are often viewed as "gatekeepers" responsible for denying individuals access to critically needed supports. Individuals with mental retardation and their families consistently report that their employment potential is underestimated by the local vocational rehabilitation agencies. They believe that local counselors often use inappropriate and irrelevant evaluation techniques to limit their eligibility for services and try to steer individuals into programs and careers that do not reflect their personal preferences and desires. Similar feelings are frequently reported about services provided in local Social Security offices. Local offices are frequently found to be inaccessible to individuals with physical disabilities or special needs.

From the perspective of individuals with mental retardation, rules and procedures seem so complex and detailed that even the SSA office staff members are unable to clearly explain them or are unaware of specific provisions. New programs and initiatives have been added to both the Vocational Rehabilitation and Social Security programs in recent years. Unfortunately, direct service personnel often have little or no knowledge of the new program elements, which can dramatically hinder implementation of the new programs. For example, supported employment began as a specialized program within the Federal/State vocational rehabilitation system. Even today, many vocational rehabilitation counselors lack sufficient knowledge or commitment to fully implement the program in their local communities. Similarly, many of the recently initiated

Social Security Work Incentives, such as Plan for Achieving Self-Support (PASS), are poorly understood by caseworkers in local SSA field offices.

A Segregated System

Congress has repeatedly expressed a clear preference for integrated employment opportunities that allow individuals to fully participate in their communities. The accomplishments and success of hundreds of thousands of individuals who work in typical jobs in the local workforce is undeniable. Yet, employment services for adults with mental retardation remain overwhelmingly segregated. At both the Federal and State levels, nearly 90% of all funds continue to support segregated vocational services such as activity centers and workshops. Our value statements and official policies universally espouse a preference for integrated employment, but our actions don't match our words.

The extent to which adult activity centers and sheltered workshops should be converted into programs that assist individuals to work in typical jobs in their communities has been a controversial issue in the field of mental retardation. Yet no philosophical, economic or political argument has been provided that justifies a system in which four to five individuals are served in segregated settings for every one person provided the opportunity to work in competitive employment. The Nation's service delivery system is unnecessarily out of balance. It is becoming increasingly clear that the vast majority of individuals with mental retardation and their families, especially families of adolescents and young adults, express a strong preference for integrated employment opportunities.

Most families earnestly desire the opportunity for their son or daughter to work in a real job, indicating they would be interested in other alternatives only when an individual is unable to succeed in an integrated setting with proper supports. Furthermore, individuals who have worked in both segregated and integrated employment settings invariably prefer integrated

employment. Few individuals who have left sheltered employment for a real job ever indicate a desire to return.

Many obstacles to wide-scale conversion of segregated facilities have been identified. For example, inequitable State reimbursement practices often create disincentives to conversion of segregated employment settings. Concerns and fears on the part of staff members can hamper change efforts. Lack of business acumen on the part of human service agencies often makes it difficult to manage large-scale organizational change. These obstacles, however, are logistical barriers that can be effectively overcome, not sound reasons for retaining the status quo.

In 1968 in rural Wisconsin, New Horizons, a small day work and activity center serving individuals with disabilities too severe to perform sheltered work was established. In 1987, the executive director, influenced by leaders in the field, arranged a combined staff/board of director's retreat to conduct a self-evaluation of the center activities. They found that activities offered by the center not only mirrored stereotypic thinking in the United States but perpetuated the belief that people with severe disabilities needed to be taken care of and lacked any skills to perform meaningful work or lead productive lives. With this realization, a vision was created, a new mission statement was developed and the board passed a resolution committing New Horizons to integrated community programming.

Even though there was no intent to close the day activity center this action was followed by opposition. Staff lacked skills and feared job loss. Parents were skeptical of employment due to limited expectations of their sons and daughter. Community agencies and leaders expressed serious concerns about people with disabilities being in the community. Many center participants wanted jobs in the community and their enthusiasm was contagious as it spread to others. Funds were shifted, grants were received and training and technical assistance came from consultants to address staff concerns. Reluctant parents were asked to let center staff try while receptive parents willingly allowed their sons and daughters to be placed into jobs. Community agencies and leaders were provided education and watched as the center evolved from a facility program to an affirmative business and later to an employment program placing every participant into paid jobs, eventually eliminating the need for a facility. Today, New Horizons provides services for 85 people with severe disabilities in supported work settings.

* adapted from "Closing the Shop" by Stephen T. Murphy & Patricia M. Rogan, 1995

Ongoing Discrimination

Employers who have had experience hiring and supervising employees with mental retardation invariably feel that the presence of the worker with a disability has had a positive impact on their business. They overwhelmingly rate the overall work performance of employees with mental retardation quite favorably. People with mental retardation have a positive influence on the entire workforce.

The Americans with Disabilities Act (ADA) has done much to promote awareness of the abilities of persons with disabilities and end blatant discriminatory practices. Unfortunately, employers who have limited or no experience working with individuals with mental retardation still possess some of the negative stereotypes and attitudes that have been the source of discrimination for many years. Some employers still feel that employees with mental retardation will be unproductive workers, who will be prone to injuries and accidents, ostracized by fellow employees, raise insurance costs, and elicit negative reactions from the general public. The experiences of tens of thousands of employers over several decades prove these discriminatory attitudes are not based on fact. Yet they stubbornly persist in the minds of many potential employers.

PCMR RECOMMENDATIONS

The problems that frustrate the employment aspirations of Americans with mental retardation are complex and deeply entrenched in our beliefs and our service delivery system. Attitudinal obstacles endure in the stereotypical attitudes held by a minority of employers and service providers. Economic barriers still remain in our inability to redirect the resources required to provide services and supports to all individuals who desire and are capable of

employment. Political impediments still result in programs that promote exclusion and dependence on income supports—policies that don't reflect our values or what we know is possible. Fortunately, these problems are not intractable. In every instance, solutions are available and within our reach.

Consumer-Driven Services

"No bird soars too high, when he soars with his own wings."

- William Blake

Enabling individuals to plan and pursue their own careers must continue to be the guiding principle of our nation's employment policy for persons with disabilities. Federal and State resources should be allocated to allow consumers to choose their own jobs, identify the services and supports they need, control their own financial resources and select the person or organization that will provide the support.

Consumers must have access to the information and assistance they need to make career choices and select employment supports. They should be fully aware of the employment assistance and support services available to them, the implications of employment on their disability benefits and health care status, and strategies for gaining access to services and using work incentives. Information on the quality of employment outcomes and consumer satisfaction with services should be available to consumers as they choose among providers and select appropriate services.

PCMR recommends:

- ◆ Include a clear legislative commitment toward consumer-driven services into all relevant Federal legislation. Any future expansion of Federal or State resources should be structured to allow consumer control over financial expenditures.
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- ◆ Create and implement voucher, 'Ticket to Work', or other new programs that will allow consumers maximum flexibility to control their financial resources, develop their own employment plans, choose providers and vendors, direct their job-seeking efforts and pay for outcomes based on their satisfaction.
- ◆ Support consumers as they learn to make career choices over time. Make benefits counseling available to individuals using vouchers to make certain they are fully aware of the ramifications of employment choices on their disability and health benefits status.

Make Work Pay

"Once or twice every month I review the employment plans of individuals who receive SSDI. As horrible as this sounds, I usually advise them to make sure that they don't earn over \$500 a month—that they don't increase the number of hours they work But the SSDI rules would make it irresponsible for me to do otherwise"

- An employment counselor in a Midwestern State

Consumers who choose to obtain employment and pursue a long-term career should be rewarded for their efforts. However, the structure of disability benefit programs threatens many individuals with loss of income supports if they attempt to work. The financial disincentives in the current Social Security disability programs are very real and extremely detrimental to persons with mental retardation. Current efforts to enable consumers to keep more of what they earn as they make the transition into the workforce should be supported and expanded.

PCMR recommends:

- ◆ Eliminate the current "earnings cliff" in the Social Security disability program to allow consumers to attempt to enter the workforce without jeopardizing their financial futures. Entering the workforce should enable individuals to increase their earnings while lessening the need for income support.
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- ◆ Redesign the work incentive components of the Social Security benefits programs so that they achieve their intended purpose. Work incentives should not be so complex that they cannot be relied upon, nor well understood.

- ◆ Allow consumers receiving services through the Home and Community Based (HCB) waiver to use more of their earnings to purchase housing, food, clothing and lifestyle benefits as they advance in their careers and take greater employment risks.

Maintaining Health Coverage

"Lack of adequate private health insurance options is a disincentive to leave Social Security programs for work. Few private health plans cover the personal assistance and other types of services that make work possible for many people with disabilities."

- President Bill Clinton

The potential loss of medical benefits or lack of access to adequate health insurance is perhaps the greatest single obstacle preventing large numbers of individuals from leaving the benefit rolls and entering employment. People should not have to choose between obtaining a job and maintaining their medical coverage.

PCMR recommends:

- ◆ Establish Medicare and Medicaid buy-in programs that will provide consumers long-term access to required health care. Create employment incentives for individuals who do not require income support, but need long-term health care to meet their medical needs while working.

 - ◆ Create tax incentives that recognize the need of many individuals with mental retardation for personal assistance, specialized transportation, assistive technology and other special supports.
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Make Programs Accountable to Consumers

Local rehabilitation and employment agencies should be evaluated based on the outcomes they generate as opposed to the services they provide. Federal and State employment monies should be used to support individuals, not programs. A number of reforms should be initiated to increase the responsiveness and accountability of local agencies to consumers and advocates.

PCMR recommends:

- ◆ Allow consumers and families to establish a system of independent evaluations of local vocational agencies. The evaluation system should be focused on employment outcomes and consumer satisfaction, and not duplicate existing certification and accreditation efforts.
- ◆ Disseminate objective employment outcome and consumer satisfaction information to consumers, family members and advocates in local communities. Consumers who are risking their long-term benefits for a chance to return to work should have access to independent information on the quality of services delivered by potential provider agencies.
- ◆ Modify Federal and State rate setting and reimbursement mechanisms so as to compensate providers based on the quality of their outcomes as opposed to simply the amount of services they provide.

Access to Services and Supports

Waiting Lists—Individuals with mental retardation who desire to work should have access to the services and supports necessary to enable them to find and maintain employment. Waiting lists that extend for years and cause individuals to lose hope can not be tolerated. We should curtail the use of

costly vocational alternatives that generate poor employment outcomes in favor of more cost-effective employment options.

Transportation—Lack of access to necessary support services continues to unnecessarily exclude individuals from employment. Many otherwise qualified individuals with disabilities currently remain unemployed, not because they are unable to perform a job, but rather because a lack of transportation prohibits them from getting to and from the employment setting. No one should be precluded from working for lack of transportation.

Assistive Technology—Many individuals with mental retardation can benefit tremendously from assistive technology. All individuals who are currently employed or seeking employment should have access to all aspects of assistive technology, including assessment, device acquisition, training and support. Unfortunately, far too many individuals with mental retardation are viewed as unable to benefit and therefore are excluded from consideration for assistive technology services.

PCMR recommends:

- ◆ Establish policies in each State and locality that promote, support, and share in the costs of reducing and eliminating current and future waiting lists for employment services. Establish specific targets to eliminate waiting lists for employment services within a reasonable period of time.
 - ◆ Develop creative solutions to community-wide transportation problems. Encourage employers to develop cost-effective transportation solutions, including employer travel consortia, private transportation systems, or other strategies. Encourage State or local governments to provide a tax credit for employers who underwrite the costs of transportation for employees with disabilities. Request local communities to pool funding and transportation resources to maximize the cost effectiveness of specialized transportation services.
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- ◆ Continue our current efforts to work collaboratively with computer hardware and software manufacturers to insure that current and future advances in computer applications are accessible to individuals with mental retardation, as well as all other individuals with disabilities.
- ◆ Develop partnerships among public schools, rehabilitation programs, businesses and other private entities to establish and operate programs that will provide personal computers to individuals with disabilities unable to afford them.

Effective Preparation for Employment

High school programs for students with mental retardation should be based on a series of meaningful experiences and knowledge acquired over a number of years. As students make and refine initial career selections, they should have access to a succession of meaningful, community-based employment experiences, including exploration activities, internships, work experiences, mentoring relationships, and employment opportunities. Participation in work experience or paid employment while in high school remains the best predictor of whether an individual will be successfully employed in adulthood.

Many students with disabilities will require short-term or ongoing supports to succeed in post-secondary educational or employment settings. Funding and service arrangements should be in place in communities that allow students to obtain needed services and supports upon leaving school. Each local school district should attempt to insure that exiting special education students make the transition into meaningful post-school employment and educational options.

PCMR recommends:

- ◆ Develop strategies for joint funding of transition initiatives at the Federal level that can serve as models for States and localities. Successful transition programs
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require the active involvement of students, their families, educational personnel, employers, and adult service agency representatives. All participants must be committed to sharing information, responsibility and resources to insure that all necessary components of a local transition program are in place. The key to collaborative efforts is sharing of all resources, not just ideas.

- ◆ Ensure that students with mental retardation have continued access to community-based instruction, career exploration, vocational training, work experience and job placement experiences while in high school. Vocational preparation of students with mental retardation is in no way incompatible with education reform efforts underway in many States.

Careers Not Jobs

Pursuing one's career is a life-long process. Individuals with mental retardation should be allowed to explore an array of alternative careers, select a career that matches their interests and desires, and obtain the training, work experiences and long-term supports necessary to make their goals a reality. At the secondary school level, the focus on careers should extend through all" phases of the employment process, including assessment, exploration, education and training, and gaining access to necessary support services. At the adult level, career goals must change from placement into an initial employment situation to movement through a progression of jobs directed toward the individual's chosen career objective.

PCMR recommends:

- ◆ Focus secondary special education programs on long-term careers and not merely entry level employment. Emphasis should be placed on movement through a series of positions, all directed toward the individual's career objective.
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- ◆ Provide training for adolescents with mental retardation and opportunities to acquire self-determination and self-advocacy skills. Selecting a career and directing one's own transition process is a challenging activity for any adolescent. Local school district should insure that information and training in self-determination and self-advocacy skills is a component of the high school curriculum.

- ◆ Modify vocational rehabilitation and other Federal employment policies to emphasize long-term job retention, promotion and career advancement, as opposed to initial placement into entry-level employment or temporary, subsidized employment opportunities.

Eliminate Segregated Services

Our adult service system for individuals with mental retardation remains extremely out of balance. Individuals served in segregated vocational programs outnumber those in integrated employment alternatives by a ratio of four or five to one. This imbalance defies stated Federal and State policies that identify integrated employment as the preferred service delivery option for individuals with mental retardation. It has created inequitable funding practices that place severe financial disincentives on local provider agencies that wish to convert to integrated employment options. Excessive reliance on segregated options has prolonged the use of high-cost employment alternatives that effectively limit the number of individuals who can benefit from employment programs.

Congress and the Administration have clearly and unequivocally stated their commitment to the expansion of community integrated employment alternatives for individuals with disabilities. Existing Federal employment programs should be reviewed to insure that current practices are consistent with this stated goal.

PCMR recommends:

- ◆ Correct the existing imbalance in Federal expenditures that continue to emphasize segregated as opposed to integrated employment alternatives. Congress and the Administration should work to insure that Federal funds are exclusively used to support community integrated employment alternatives.
 - ◆ Encourage and promote the efforts of individual States to expand community integrated employment opportunities. States should be allowed to use Federal funds to stimulate and support conversion of segregated day services to community integrated employment. Federal reimbursement mechanisms should include clear financial incentives for provision of integrated services.
 - ◆ Eliminate inequitable reimbursement practices that create disincentives to conversion of segregated employment settings. Reimbursement rates should provide clear financial incentives for placement into community integrated employment settings.
 - ◆ Support people, not service agencies. If an individual who is currently receiving services in a segregated setting enters a community integrated employment option, monies used to support the individual's participation in the segregated setting should follow the person into the employment setting. If an individual moves from one community to another within a State, funding for that person should move with the individual and be available to purchase the vocational services he or she chooses in the new community.
 - ◆ Involve consumers and their families in the decision to convert an existing agency, the steps the agency will take to expand community integrated employment, the timeline for program expansion, and the evaluation of
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program success. Consumers should not have major program changes thrust upon them without their full participation.

Access to Needed Services

A number of new and exciting initiatives are underway to promote the economic independence and increased productivity of all Americans with disabilities. At-risk youth, former welfare recipients, Native Americans, and numerous other groups have been the targets of economic development and employment initiatives. Individuals with mental retardation can benefit significantly from participation in these initiatives. Welfare reform, youth employment and school-to-work programs are all mandated by law to promote the inclusion of individuals with disabilities in all aspects of their programs, yet participation by persons with mental retardation remains quite low.

PCMR recommends:

- ◆ Insure that employment programs for adolescents and young adults with mental retardation don't exclude those individuals with the most significant support needs. Persons with significant disabilities are those who can benefit most from participation in supported employment and other integrated employment alternatives.

 - ◆ Increase the participation of students with mental retardation in local programs established through the School-to-Work Opportunities Act initiatives in proportion to their participation in the overall school population.

 - ◆ Increase the participation of adolescents with mental retardation in youth employment programs operated by the Department of Labor's Employment and Training Administration programs and the Department of Education's Office of Vocational Education.
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- ◆ Provide individuals with disabilities and their families the opportunity to realize the full promise of welfare reform by having an equal opportunity for employment through State programs established under the Personal Responsibility and Work Opportunity Reconciliation Act.

Access to Qualified Personnel

A commitment to consumer-driven services demands a change in the way we train and prepare consumers and human service professionals to participate in the employment process. People should have access to skilled and motivated support providers to enable those individuals who want to work to find and maintain satisfying employment. Training should be directed toward consumers, their families, advocates and members, as well as human service professionals.

PCMR recommends:

- ◆ Provide information and training on consumer-driven services directly to consumers, their families, and peer mentors. Training and dissemination resources should be focused on raising people's expectations of employment and meaningful careers and on helping them to secure the supports they need to achieve their goals.
 - ◆ Require each local Social Security office to have an individual on staff who is thoroughly trained as a work incentive specialist(s) who can provide assistance to consumers throughout the entire process.
 - ◆ Encourage local school districts and adult service agencies to target training efforts toward students with disabilities to enable them, to the maximum extent possible, to direct their own career preparation programs. Training efforts should focus on establishing career objectives, directing one's own transition planning meetings, understanding post-school services and effectively advocating for oneself.
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- ◆ Establish subsidized training programs, tuition vouchers, and other "public service" benefits for persons who enter the roles of supporting employment outcomes for persons with mental retardation.

Support for Employers

Employers value their workforce and are accustomed to providing supports to employees who possess a wide range of abilities and needs. They invest tremendous amounts of time and money in their personnel. Employers are using a number of new and innovative strategies to develop and retain high quality workforces—implementing flexible work patterns, redesigning jobs to match the capabilities of workers and developing career paths that consider the abilities and needs of workers at various stages of their careers. These strategies are applicable to all workers and are particularly appropriate to individuals with mental retardation.

Employers overwhelmingly indicate a willingness to hire and retain individuals with mental retardation. They want to make certain that their company possesses the expertise to respond to the needs of employees with disabilities and respond to potential workplace problems.

Significantly, they frequently indicate that they experience difficulties in gaining access to the resources necessary to provide workplace accommodations.

PCMR recommends:

- ◆ Expand the current Work Opportunities Tax Credit so that the economic incentives to employers are equivalent to that provided by the Welfare to Work Tax Credit.
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- + Provide employers convenient access to the information and technical assistance they need to provide training, support and accommodations to individuals with mental retardation on their workforce.

CONCLUSION

"What we can't afford to do is let even one of our human resources slip through the cracks and not be utilized because of some outdated thoughts about disability."

- John Sharp, Texas Comptroller of Public Accounts

At one level, the obstacles that limit the employment of individuals with mental retardation seem overwhelming. Despite our best intentions, our service systems too often promote long-term dependence on Federal subsidies and thwart the desires and preferences of individuals with mental retardation and their families. Individuals who attempt to gain employment are too often threatened with loss of health care and other benefits. Lengthy waiting lists in many States and communities mean that many individuals are unable to gain access to any type of service and are forced into lives of idleness and discouragement. The rate of participation of individuals with mental retardation in major Federal programs designed to meet the employment needs of all our citizens is unnecessarily low. Discrimination continues to occur based on outdated attitudes and stereotypes. In combination, these obstacles have combined to make the unemployment of individuals with mental retardation a chronic problem that has frustrated individuals, their families, service providers and policy-makers for many years.

As we move toward the close of the twentieth century, we enter a period of unparalleled opportunity for change. Individuals with mental retardation continue to express their desires for meaningful and satisfying careers. Advances in technology and public expectations have enabled many individuals to enter the workforce for the first time. Strong Presidential leadership has created a climate of change and commitment to reform that holds the promise of finding new and lasting answers to long-term problems. While the problems are complex and challenging, in most instances, the solutions are obvious and lie within our reach. Legislative changes can

eliminate the disincentives to employment that lie within our current systems. Increased Federal and State leadership can reduce our reliance on segregated programs and enable individuals to gain access to the transportation, health care, and other supports they need to succeed in their chosen career. An increased role for individuals with mental retardation and their families in the design and delivery of services will improve service quality and increase program accountability.

We know what can and must be done. What is required is the combined commitment of individuals and their families, government at all levels, and business and industry to make certain that all individuals with mental retardation who desire to work will be able to obtain access to the services and supports they need to make their goals a reality. To do less will result in forced idleness and dependence that is both unnecessary and damaging to our Nation and our citizens with mental retardation.

APPENDIX
PCMR CITIZEN AND EX-OFFICIO MEMBERS

Valerie J. Bradley
Chair, President's Committee on Mental Retardation
Washington, D.C.

Lorenzo H. Aguilar-Melancon

President
Perspectiva
7380 Remcon Circle
El Paso, Texas 79912
Phone: 915-833-2488
FAX: 915-833-3424

Jane L. Browning

Director
Division of Membership Services
and Publications
National Association of Social Workers
750 First Street, N.E.
Suite 700
Washington, D.C. 20002-4241
Phone: 202-336-8214 1-
800-638-8799, ext.' 214
FAX: 202-336-8312
[E-Mail: jbrownin@naswdc.org](mailto:jbrownin@naswdc.org)

Ann M. Forts

P.O. Box 644
Center Harbor, New Hampshire 03226
Home: 603-253-6721
FAX: 603-279-4582

Sally A. Jochum

Johnson County Developmental Supports
10501 Lackman Road
Lenexa, Kansas 66219
Phone: 913-492-6161, ext. 425
FAX: 913-492-5171
[E-Mail: sally.jochum@jocks.com](mailto:sally.jochum@jocks.com)

Valerie J. Bradley

President
Human Services Research Institute
2336 Massachusetts Avenue
Cambridge, Massachusetts 02140
Phone: 617-876-0426
FAX: 617-492-7401
[E-Mail: valbrad@aol.com](mailto:valbrad@aol.com)

Robert D. Dinerstein, J.D.

Associate Dean for Academic Affairs
Washington College of Law
at American University
4801 Massachusetts Avenue, N.W.
Washington, D.C. 20016
Phone: 202-274-4141
FAX: 202-274-4015
[E-Mail: rdiners@wcl.american.edu](mailto:rdiners@wcl.american.edu)

Arthur M. Hamilton

Minority Leader
Arizona House of Representatives
1700 West Washington
Phoenix, Arizona 85007
Phone: 602-542-3912
FAX: 602-542-4308

Joyce A. Keller

Executive Director
JARC
28366 Franklin Road
Southfield, Michigan 48034
Phone: 810-352-5272
FAX: 810-352-5279

John F. Kennedy, J.D.

President
Reaching Up, Inc.
434 East 52nd Street
Suite 1E
New York, New York 10022
Phone: 212-754-6750
FAX: 212-754-0203

Ruth Luckasson, J.D.

Regents Professor and Professor of Special
Education
College of Education University
of New Mexico Albuquerque,
New Mexico 87131
Phone: 505-277-7231
FAX: 505-277-8360
[E-Mail: ruthl@unm.edu](mailto:ruthl@unm.edu)

Donna Nigh

3009 Hackberry
Oklahoma City, Oklahoma 73120
Phone: 405-751-7708

Michael L. Remus

Executive Director
The Arc of Tennessee
1719 West End Avenue, Suite 300E
Nashville, Tennessee 37203
Phone: 615-327-0294
FAX: 615-327-0827
[E-Mail: mremus@ksbe.state.ks.us](mailto:mremus@ksbe.state.ks.us)

K. Charlie Lakin, Ph.D.

Director
Rehabilitation Research and Training Center
on Community Living
University of Minnesota
214 Pattee Hall
150 Pillsbury Drive
Minneapolis, Minnesota 55455
Phone: 612-624-5005
FAX: 612-625-6619
[E-Mail: lakin001@maroon.tc.umn.edu](mailto:lakin001@maroon.tc.umn.edu)

T.J. Monroe

Disability Rights Consultant 1156
Waycross Road, Apt. A109
Cincinnati, Ohio 45240
Phone: 513-825-5771

Elizabeth C. Pittinger

1101 Virginia Avenue
Pittsburgh, Pennsylvania 15211
Phone: 412-381-1578
FAX: 412-381-1745
[E-Mail: ecpitt@aol.com](mailto:ecpitt@aol.com)

Tom E.C. Smith, Ed.D.

Professor and Associate Dean
College of Education, ED100
University of Arkansas at Little Rock
Little Rock, Arkansas 72204
Phone: 501-569-3016
FAX: 501-569-8694
[E-Mail: tesmith@ualr.edu](mailto:tesmith@ualr.edu)

Barbara Yoshioka Wheeler, Ph.D
Associate Professor of Clinical Pediatrics
University Affiliated Program
Mailstop #53
Children's Hospital of Los Angeles
P.O. Box 54700
Los Angeles, California 90054-0700
Phone: 213-669-2300
FAX: 213-953-0439
[E-Mail: bwheeler%smtpgate@chlais.usc.edu](mailto:bwheeler%smtpgate@chlais.usc.edu)

***The Honorable Donna E. Shalala**
Secretary of Health and Human Services
U.S. Department of Health and Human
Services (DHHS)
200 Independence Avenue, S.W.
Washington, D.C. 20201
Phone: 202-690-7000

***The Honorable Alexis M. Herman**
Secretary of Labor
U.S. Department of Labor (DoL)
200 Constitution Avenue, N.W.
Washington, D.C. 20210
Phone: 202-219-8271

***Harris Wofford**
Chief Executive Officer
Corporation for National and Community
Service (CNCS)
1100 Vermont Avenue, N.W.
Room 6100
Washington, D.C. 20525
Phone: 202-606-5000

***Gilbert Casellas**
Chair
Equal Employment Opportunity
Commission (EEOC)
1801 L Street, N.W., 10th Floor
Washington, D.C. 20507
Phone: 202-663-4900
FAX: 202-663-7022

The Honorable Kenneth S. Apfel
Commissioner of Social Security
Social Security Administration
900 Altmeyer Building
6401 Security Boulevard
Baltimore, Maryland 21235-0001
Phone: 202-358-6000
FAX: 202-358-6077 or 6078

**PCMR STAFF Administration for Children
and Families President's Committee on Mental
Retardation Hubert H. Humphrey Building,
Rm. 352-G
200 Independence Avenue, S.W.
Washington, D.C. 20201-0001
Phone: 202-619-0634
FAX: 202-205-9519**

Gary H. Blumenthal
Executive Director

John L. Pride
Deputy Executive Director

Laverdia T. Roach
Special Assistant to the Executive Director

Yolande Bestgen
Director of Special Projects

George H. Bouthilet, Ph.D.
Research Director

Thelma B. Lucas
Mental Retardation Program Specialist

Joan Williams
Special Projects Specialist

Bena Smith
Program Analyst

Sheila Whittaker
Budget Officer

Peggy Butler
Secretary to the Executive Director

Angie Green
Secretary to the Deputy Executive Director

Terry Lion
Clerk-Typist

Dina Bergman
Clerk-Typist

