The Journey
to
Inclusion

A Resource
for State Policy Makers

PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

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

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The President's Committee on Mental Retardation (PCMR) is proud to present, JJ& Journey to Inclusion, a Resource Guide for State Policymakers. The Committee is pleased to express its appreciation to authors Tecla Jaskulski, K. Charlie Lakin and Susan Ames Zierman for their insightful examination of the many paths being undertaken by State leaders in each State's respective *journey to inclusion.*

The President's Committee recognizes that efforts to promote inclusion of citizens with mental retardation will be most effective when articulated by more than the traditional allies of such efforts. The National Collaborative Academy on Mental Retardation was an effort to recognize that success in achieving inclusion is dependent upon forming new coalitions of active and committed leaders at the State and local level.

That is why state delegations attending the 1995 Academy included such varied members as State Legislators, State Budget Directors, business community leaders as well as human service agency personnel, self-advocates and family members.

Such coalitions are already active in many States and local communities where people are working everyday to open new paths on the *journey to inclusion.*

On behalf of the PCMR, I sincerely hope The Journey to Inclusion, a Resource Guide for State Policymakers serves as a valuable resource in your individual journey.

Gary H. Blumenthal
Executive Director

The Journey to Inclusion

A Resource Guide for State Policymakers

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FOREWORD

The following report of the President's Committee on Mental Retardation, The Journey to Inclusion is both a compendium of information as well as a testimony to the progress toward inclusion that has been made in the field of mental retardation over the almost 30 years since the committee was established by President Lyndon B. Johnson.

The purpose of the document is to provide participants at the 1995 National Collaborative Academy on Mental Retardation (September 8 - 11, 1995) with background on the theoretical framework that governs the provision of services and supports to people with mental retardation, the best practices that the field endorses, and the changes in the form, scope and substance that mental retardation systems around the country have experienced over the past several decades.

The document also highlights the richness and diversity among the States and the range of innovation that characterizes State leadership and initiative. Clearly, services for people with mental retardation, while financed in part at the federal level, have always depended on State policies and State-level advocacy for their direction.

Most importantly, this report highlights the lives and preferences of people with mental retardation through their own words and stories. The voices of their families and the stories of their commitment to the inclusion of their family members are also given a prominent place in the narrative. Without these voices and stories, the report and the Academy would be a hollow exercise.

While the chapters that follow clearly show that the Journey to Inclusion is well launched, they also point out that too many people are still leading segregated lives in separate classrooms, sheltered jobs, special recreational settings, congregate housing and in communities where their presence and their gifts are unknown.

It is hoped that the resources in this report will help Academy participants and others create and reinforce those policy directions necessary to complete this important journey.

Val Bradley
Vice Chair
President's Committee on Mental Retardation

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Photographs were provided courtesy of the ANCOR (American Network of Community Options and Resources); Sarah Putnam, Massachusetts; Lilly M. Blase, Nebraska; the National Association of Developmental Disabilities Councils; and the Macomb-Oakland Regional Center. Special appreciation goes to Joe Dzenowagis of Macomb-Oakland for his help in transferring images of inclusion across mediums.

Finally, we wish to acknowledge the many contributions of our colleagues and their respective organizations who are participating in the National Collaborative Academy, and whose previous writings have greatly enriched this report, as well as to all the others whose works are cited in this publication. We are all indebted to their many contributions to the journey to inclusion.

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OVERVIEW

This report is designed to be a resource to the participants in the National Collaborative Academy convened by the President's Committee on Mental Retardation, as well as to all others interested in policies and programs affecting people with mental retardation. The focus of the National Collaborative Academy is on inclusion throughout the lifetime of individuals with mental retardation, and on the policies, services and supports that make inclusion a reality-the journey to inclusion.

The report begins with a discussion of the changing responses to people with mental retardation in order to provide a context for thinking about the journey to inclusion. It opens with the thoughts of people with mental retardation and their family members on the importance of inclusion, followed by an overview of trends toward inclusion in the service system and the evolution in our understanding of what is important to people with mental retardation.

Chapter II summarizes the concept of mental retardation as it relates to people's needs for services and supports, including the 1992 definition of mental retardation developed by the American Association on Mental Retardation. Information on prevalence is provided to help guide policymakers in planning for those who may require the most extensive supports for inclusion, as well as those whose needs are less intense.

Chapter III looks at how inclusion can make a difference throughout the lifespan, from early intervention with infants and toddlers with mental retardation, through the school years, into work life and participation in recreation and community connections, and on into retirement. Stories about real people with mental retardation and their families highlight each aspect of inclusion through the lifespan, supplemented by information on trends, strategies, and resources.

Inclusion in Community Housing (Chapter IV) reflects the central importance of where people live, and the issues facing individuals and policy makers on the journey to inclusion in community living. Examples of resources being used by States to finance inclusive housing, especially consumercontrolled housing, are featured, as well as trends and milestones in the shift from institutions to supported community living.

Chapter V focuses on the supports that promote inclusion-supports to individuals, to families, and to communities and systems. The chapter includes examples of effective supports at all three levels, from assistive technology to legislative initiatives at the systems level.

The final chapter emphasizes the importance of empowering and involving people with mental retardation and their families in policy making and it includes tools and resources that States can use to plan for and monitor, inclusive systems. The report finishes as it began, with the voices of self advocates, to reinforce that people with mental retardation can be our best guides on the journey.

Information on resources for the development of inclusive systems are provided in each section, and references are listed in the Appendix along with a list of the PCMR membership and national organizations involved in mental retardation. Additional information may be obtained from the President's Committee on Mental Retardation.

CHANGING RESPONSES

- WHY INCLUSION?
- WHAT PEOPLE WITH MENTAL RETARDATION ARE SAYING ABOUT INCLUSION
- WHAT FAMILIES ARE SAYING ABOUT INCLUSION MOVING FROM PROGRAMS TO INDIVIDUAL SUPPORTS NATIONAL POLICY
- SUPPORTS, STRENGTHS, CHOICES AND' INCLUSION
- TRENDS IN STATE LEADERSHIP

Message from the President on the Fifth Anniversary of the Americans with Disabilities Act

As we mark the fifth *anniversary of the Americans with Disabilities Act, I am delighted to join citizens across the country in celebration.*

With enactment of this landmark civil rights law, America became the first country in the world to make equal rights and equal opportunity a guarantee for its 49 million citizens with disabilities. Across the nation, our people began coming together to ensure equal access to the American dream.

Today, thanks to these efforts, Americans are recognizing that we all gain as citizens of a country in which everyone can participate fully. *And America is reaping the benefits of a more inclusive society. Employers have a larger pool of qualified workers. Businesses are opening doors to new customers. State and local governments are enjoying broader citizen participation. Most important, individuals are being judged not by their disabilities, but by their abilities.*

We have made great strides as a nation in fulfilling America's promise of common sense justice. Still, much remains to be done.My administration is firmly committed to the vigorous implementation and enforcement of the ADA. No longer will Americans with disabilities be kept from realizing their dreams by closed doors or narrow minds. Building partnerships between government and business and people throughout the land, we best celebrate this day by rededicating ourselves to creating a society of equal access and equal rights for all.

/s/ Bill Clinton, July 18, 1995

WHY INCLUSION?

The President's Committee on Mental Retardation (PCMR) has chosen inclusion throughout life as the theme for its National Collaborative Academies, to be held in 1995 through 1999 to reach all 50 States. This theme was selected because it resonates for people with mental retardation and families, because there is widespread interest in inclusion across the States, and because Federal, State and local policies increasingly focus on promoting inclusion and participation of people with disabilities.

People with mental retardation want to be treated equally, and they don't want to be labeled anymore. They want most of all to close down institutions and to be a part of their community.

The opposite of inclusion is exclusion. Although the majority of people with mental retardation were never institutionalized, many experienced exclusion from the schools and the social lives of their communities. As society has become more complex and services more specialized, opportunities for inclusion may actually have decreased.

Our challenge now is to consider the ways that each individual with mental retardation can be included rather than excluded, consistent with that person's unique talents, needs and choices. This approach presumes that there is no single formula for inclusion or definition of inclusion that fits every person with mental retardation. It does presume that no one should be excluded arbitrarily, on the basis of their mental retardation or some other disability label, from being part of their family and community.

WHAT PEOPLE WITH MENTAL RETARDATION ARE SAYING ABOUT INCLUSION

Tia Nelis, a self-advocate from Illinois, is co-chair of the national organization Self-Advocates Becoming Empowered and an employee of the University of Illinois at Chicago. In 1994 she told the PCMR conference on the national reform agenda about an international conference she had attended, and the two items that stood out on the self-advocates' list:

> (1) People wanted to be treated equally, and they didn't want to be labeled anymore. They wanted people to call them by their names and not by their disability, and to look at their abilities and not their disabilities.
> (2) They wanted most of all to close down institutions and to have people be a part of their community.

Ms. Nelis commented, "I have a job. I am very lucky to have a job working with people with disabilities and working with people without disabilities. Most of my friends do not have those opportunities. They work in a sheltered workshop, and they earn 79 cents every two weeks. They don't get the opportunities that I do" (PCMR, 1994a).

When representatives of the Wisconsin Council on Developmental Disabilities conducted a comprehensive statewide survey of individuals with mental retardation and other developmental disabilities, they asked each person the following question: If you had one wish, what would it be? The responses ranged from individual wishes for trips and consumer goods to personal goals in employment and having a better place to live. Although there was great variation in the answers to the question, inclusion in community living, social activities and work was a common theme throughout many of the responses, as illustrated by the following examples:

One Wish:

- To participate more with others and to be accepted by the community.
- To be together as a family.
- To go to a regular school and participate in normal activities.
- Opportunity for higher education and meaningful work.
- To visit my girlfriend every Sunday.
- Someone to go shopping with.
- To have a community living option.
- To live in an apartment and to have a job saving people's lives.
- To live in my own apartment with a friend.
- To move to better living quarters and have more money.
- To be out of a health care center living independently in a supported apartment.
- That I could get my own apartment and know how the city bus system works. • Would like to have a "real" job.
- To have a full time, good paying job.
- To have a job and earn some money.
- A job so I could make some friends, not be so isolated at my home.
- I wish I could do more things such as have a job and a better school program.
- Have a full time job and not be at a sheltered work shop.
- To get a job I like that I make enough money to support myself.
- That there was a more handicap-accessible facility to use. Whoever designed accessible bathrooms did **NOT** use a wheelchair.
- More accessible places to go.
- To be able to communicate and thus socialize more. To be able to show people what I can accomplish.
- To have a working electric wheel chair.
- To have more opportunity to play and be with other children.
- To be able to do things more with other kids, to be understood and accepted.
- That we'd live in an "understanding" society.
- That I could be an independent adult, keep my job, have friends and be able to visit my dad as often as I would like.
- To be as independent as possible and to fit into the mainstream of society (Wisconsin Council on Developmental Disabilities, 1990).

WHAT FAMILIES ARE SAYING ABOUT INCLUSION

The 1994 PCMR national agenda conference also heard from parents of individuals with mental retardation. Koquese Collins of Detroit, Michigan, talked about her son Brian, who is 11 years old and has Down Syndrome. Although he carries the label "trainably mentally impaired," his mother said it is more important to know that Brian "is an active, compassionate, and extremely friendly young man ... He is my son, a brother, a playmate, a friend, and my family. One could characterize our household as an inclusive environment that works." She talked about her hopes for Brian as follows:

My sincerest hope-a wish list, if you will-is that Brian will grow up into an adult who can live as independently as possible; he will have a job, make sound decisions, fall in love, and start his own family. I dream of the day that he will bring "Brian may never his children, my grandchildren, to visit grandma, and I can spoil them. I know this is possible because I know Brian the person, not just his disability. Brian may never be the President of the United States, but he deserves every chance at as much support available to ensure that he has the brightest future possible, so that he can become a fully active member in his community.

Craig's parents, Dawn and Don Merriman of Salina, Kansas, also talked about their hopes for their son's future, as well as some of their struggles in the past. In 1979, when Craig was born, the only comprehensive services for children with complex disabilities were in large State-run institutions. The Merrimans and others began asking why full-service delivery systems couldn't be developed in the community and why children could be covered in institutions under Medicaid regardless of their family's income, but not if they were living at home. The Merrimans have seen some improvements over Craig's lifetime, and he has been able to stay with his family and to attend local schools. They described their vision for Craig and for other children with severe disabilities:

Our dreams are for Craig to own his own home, to own his own car so that he does not have to rely on a transportation system and he can go where he chooses when he chooses, for Craig to have a sense of community, that he appreciates other people and they appreciate him, a job that he loves like we love our jobs, friends of all ages and all abilities, and that people in his community will recognize the unique talents, gifts, and characteristics of one another.

Some parents of institutionalized people with mental retardation see inclusion somewhat differently. They value the protective institutional environment as important for their relative, particularly for those who have profound or severe mental retardation and complex medical care needs. It is very understandable that families who feel their relative is happy and getting excellent care will feel uncomfortable about a total move to inclusion that might undo the choices they have made.

Bertha Atkin, parent of a woman who moved to the community after 20 years in a large State institution, understands these feelings from her own experience. She described her perspectives on community inclusion as follows:

> When the court ordered the institution closed, my husband and I led the opposition. A few years back, they said the institution was the best place for Judy. We were told that her disability was too severe for her to stay at home. Now, all of a sudden, it was "inappropriate." We were all confused, surprised and many of us were angry. Then as we saw people leaving one-by-one, we started to investigate a little further. Then we began to understand. Living in the community allows Judy to grow more than she could ever grow in the institution.
> Source: *Deinstitutionalization - From Theory to Practice. A Monograph for State Legislators* (Records, 1994).

As States and local mental retardation/developmental disability authorities develop strategies for inclusion, it is important to respect a full spectrum of feelings about inclusion and individual choice, and to support those struggling with inclusion to make the best possible choices.

MOVING FROM PROGRAMS TO INDIVIDUAL SUPPORTS

The aspirations of people with developmental disabilities to individual empowerment and community membership have brought about a shift from residential services to communitybased supports. This change, however, continues to meet resistance. To ensure inclusion for all individuals with disabilities, professionals working in the human services field need practical strategies based on a community supports paradigm.

Creating Individual Supports for People with Developmental Disabilities: A Mandate for Change at Many Levels (Bradley, Ashbaugh and Blaney, Eds., 1994)

Services to individuals with mental retardation and other developmental disabilities can be characterized in relation to the dominant approaches in various periods, and the availability of publicly financed services. The change in paradigms underlying current and emerging practices in the field of mental retardation/developmental disabilities is described by the current vice chair of the PCMF, Valerie Bradley, as follows:

> The initial metamorphosis began in the late 1960s and is frequently described as a shift from the medical model of care to the developmental model or from the custodial model to the rehabilitation model. This transition was the first inkling of. .. a paradigm shift. Only now, in the 1990s, is it possible to view the full outlines of the shift as the dust raised by a quarter century of constant turmoil is beginning to settle.
>
> This evolutionary process can be broken into three distinct stages. In the first stage, the era of institutionalization, dependence and segregation (ending roughly in the mid-1970s), the governing norms were primarily medical and the objective was to separate people who were designated sick and vulnerable from the rest of society. This era ended with the advent of the developmental model and a growing body of research showing the inadequacies of institutional care. This ushered in the second stage, the era of deinstitutionalization and community development (beginning in the mid-1970s), which was marked by the creation of group homes and sheltered workshops that were physically integrated in the community but that emphasized the provision of specialized services in socially segregated settings. The third and emerging stage is the era of community membership, which is marked by an emphasis on functional supports to enhance inclusion and quality of life as defined by physical as well as social integration (Bradley, 1994).

The changes in the approach to individuals and services across the three eras are summarized in Table 1.

Growing consensus around the paradigm of individual supports, empowerment of individuals and community membership is reflected in the increasing availability of individualized supported living arrangements, the values espoused in Federal and State legislation, and the emergence of quality assurance systems that measure outcomes related to individual choices, relationships, community participation, and the person's satisfaction with the supports and services being received.

Table 1 The Evolution in Services and Supports

Focal Questions	Era of Institutions	Era of Deinstitutionalization	Era of Community Membership
Who is the person of concern?	The patient	The client	The citizen
What is the typical setting?	An institution	A group home, workshop, special school, or classroom	A Person's home, local business, the neighborhood school
How are the services organized?	In facilities	In a continuum of options	Through a unique array of supports tailored to the individual
What is the model?	Custodial/medical	Developmental/ behavioral	Individual support
What are the services?	Care	Programs	Supports
How are services planned?	Through a plan of care	Through an individualized habilitation plan	Through a personal futures plan
Who controls the planning decision?	A professional (usually an MD)	An interdisciplinary team	The individual
What is the planning context?	Standards of professional practice	Team consensus	A circle of support
What has the highest priority?	Basic needs	Skill development, behavior management	Self-determination and relationships
What is the objective?	Control or cure	To change behavior	To change the environment and attitudes

Adapted from "The New Service Paradigm" (Bradley, 1994).

Fully implementing the new approach will not be easy. As with any other significant change in thinking, the new era in mental retardation/developmental disabilities challenges beliefs, organizational structures, relationships and policies that the field has grown comfortable with. It is also a particular challenge to extend new approaches to people whose mental retardation is more severe, or who have multiple disabilities. The words of individuals with mental retardation and families, however, are a strong reminder that we all need to work together to make implementation a reality, including facing up to the need for changes in thinking, relating, and doing. Evolutions in national policy form some of the support for these necessary changes.

NATIONAL POLICY

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 affirms the basic rights and fundamental human dignity of Americans with mental retardation. Several States have enacted legislation further defining these rights.

National policy has been transformed through prohibitions against discrimination on the basis of disability in the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990, policy goals in the Developmental Disabilities and Bill of Rights Act, education mandates in the Individuals with Disabilities Education Act, creation of the Medicaid Home and Community-Based Services waiver program, and supported work and presumptions of feasibility for vocational rehabilitation in amendments to the Rehabilitation Act.

As described in *A Journey of Renewal for All Americans: Report to the President* (PCMR, 1994b), however, great needs still exist. What matters most to people with mental retardation and their families is that which is important to all Americans: to belong to a larger community that endows its members with dignity grounded in a fundamental respect for each individual. Old service models, based on exclusion, isolation and individual "impairments" or "deficits," are still the primary resource for too many people with mental retardation and their families. New models, anchored to the values of inclusion, collaboration and individual determination, are emerging-but much more needs to be done.

SUPPORTS, STRENGTHS, CHOICES AND INCLUSION

Changes in public policy and social attitudes reflect the growing body of knowledge in mental retardation and other developmental disabilities that is beginning to shape our service systems at the local, State and national levels. The Work Group on Long-Term Care Reform at the PCMR Presidential Forum, April 1994, laid out the following description of emerging responses and challenges:

> In mapping out future long-term service and support policies, the group agreed that one of the major challenges facing the field of mental retardation and

developmental disabilities is to live simultaneously with the consequences of the past, manage the existing service system, and plan for the future. Unlike many other areas of human services policy, past decisions regarding service modalities and program placements cannot be altered easily, since the customers of the developmental disabilities service system typically require assistance that spans decades, rather than a few months or years. For example, the decision during the early years of this century to rely on large, multi-purpose residential facilities as the principal modality for meeting the ongoing service and support needs of people with lifelong disabilities continues to be a major factor in the policymaking equation, long after most consumers, parents and professionals have embraced the concept of community and familycentered services. The most important policy issue the field faces, therefore, is to find ways of accelerating the transition to a system of services that supports individuals in making meaningful choices about how they live their lives as participating, valued members of the community, while not abandoning society's obligation to people who are still being served in facilities and programs which no longer conform to contemporary views regarding "best practices."

In order to achieve such a transformation, the work group believes that it is essential to begin by articulating a vision of the future. It is the work group's belief that such a vision should include the following elements:

- The provision of services and supports tailored to the needs and aspirations of each individual, rather than a "continuum" of prefabricated long-term care program options;

- An emphasis on consumer choices either made directly or, where necessary, through a facilitator;

- The opportunity for people with lifelong disabilities to have dreams and the chance to achieve them;

- Outcome-based accountability systems that operate on all levels of the service delivery system;

- Children with disabilities should live with families;

- Independence and productivity are highly valued service outcomes for all consumers, and public policy and funding should be directed toward eliminating barriers to achieving such outcomes;

- Eligibility should be based upon the individual's needs and not labels;
People closest to those in need of supports should be empowered to help them realize their personal goals, wherever possible;

- Funding should be based on individual needs and wants, not program slots;

> •Individuals who work directly with consumers and their families should be given considerable latitude in designing and carrying out support strategies;
>
> •Emphasis should be placed on developing community partnerships in which responsibility is shared by individuals with disabilities, their families, and friends, as well as the community at large. The role of formal services should be modulated to take into account such informal, indigenous community support networks; and
>
> • Quality assurance mechanisms should be strengthened, with the emphasis on achieving meaningful individual outcomes; people with disabilities should be involved in monitoring the quality of services and supports that are provided.

The National Reform Agenda and People with Mental Retardation: Putting People First (PCMR, 1994a)

TRENDS IN STATE LEADERSHIP

The States have been largely responsible for leadership in meeting the needs of people with mental retardation and their families, within the context of Federal programs and policies. A report of the Developmental Disabilities Task Force of the National Conference of State Legislatures (NCSL) noted the many innovations that have been developed at the State and local level. These innovations include supporting people to make personal choices about where and how they live, focusing especially on supporting people in "natural" settings:

- Children growing up in a home with their family, rather than in an institution;
- Children going to a neighborhood day care center or home, instead of to a segregated program for children with disabilities;
- Children attending regular preschool and neighborhood school classes, rather than being isolated in a "special" class;
- Children and adults with disabilities participating in community activities with family and friends instead of being isolated with others who have disabilities; and
- Persons with disabilities working side by side with persons without such disabilities in a competitive job, rather than being segregated in sheltered workshops (Wright, King and the NCSL Task Force on Developmental Disabilities, 1991).

Although each State is addressing its own agenda for people with mental retardation, the context for innovation increasingly reflects values of inclusion, choice and support. These values are often found in the mission statements of State mental retardation/developmental disability service agencies, as reflected in the following examples from around the nation:

> **Alabama**: It is the mission of the Division of Mental Retardation to provide for a system of effective and efficient services to the citizens of Alabama with mental retardation and/or developmental disabilities. This system of services endorses the

> precepts that services shall be consumer and family driven; shall be provided in the least restrictive setting; shall maximize consumer and family input; shall use existing support systems; shall be outcome oriented; and shall utilize family, consumer, and employee satisfaction as major indicators of quality.
>
> **Colorado:** The mission of the Colorado Division for Developmental Disabilities is to join with others to offer the necessary supports with which all people with developmental disabilities have their rightful chance to:
>
> - Be included in Colorado community life.
> - Make increasingly responsible choices.
> - Exert greater control over their life circumstances.
> - Establish and maintain relationships and a sense of belonging.
> - Develop and exercise their competencies and talents.
> - Experience personal security and self-respect.
>
> **Connecticut**: The DMR's mission is to join with others to create the conditions under which all persons with mental retardation experience:
>
> - Presence and participation in Connecticut town life.
> - Opportunities to develop and exercise competence.
> - Opportunities to make choices in the pursuit of a personal future.
> - Good relationships with family members and friends.
> - Respect and dignity.
>
> **Kansas**: The Kansas Department of Social and Rehabilitation Services empowers individuals and families to achieve and sustain independence and to participate in the rights, responsibilities and benefits of full citizenship by creating conditions and opportunities for change, by advocating for human dignity and worth, and by providing care, safety and support in collaboration with others.
>
> **Massachusetts**: The Department of Mental Retardation is composed of people dedicated to creating, in cooperation with others, innovative and genuine opportunities for individuals with mental retardation to participate fully and meaningfully in, and contribute to, their communities as valued members.
>
> **Utah**: The mission of the Division of Services for People with Disabilities is to promote opportunities for persons with disabilities to participate fully in Utah life.

State expenditures for mental retardation/developmental disabilities services and supports have significantly increased over the past several years, considerably beyond inflation rates. The strongest area of increase has been for home- and community-based services: individual and family supports, early intervention, educational services, community residences, supported employment, and, in some States, supports for recreational activities, making friends, and retirement options.

Increases in the total public spending effort for services to people with mental retardation/developmental disabilities and, in some cases, their families, have been tracked by the Institute on Disability and Human Development, University of Illinois at Chicago since the late 1970s. From 1977 to 1992, total spending grew from $3.457 billion to $17.228 billion, a growth rate of 124% after adjusting for inflation (Braddock, Hemp, Bachelder, and Fujiura, 1995). Although increases in spending for institutional services have contributed, the major increases have been in home- and community-based services.

Looking at mental retardation/developmental disabilities spending per $1,000 of personal income reveals growth from $2.27 per $1,000 in 1977 to $3.33 per $1,000 in 1992. As illustrated in Table 2, the portion of spending for community services has increased during that time, exceeding the portion spent on large (16 person or more) congregate and institutional facilities since 1989.

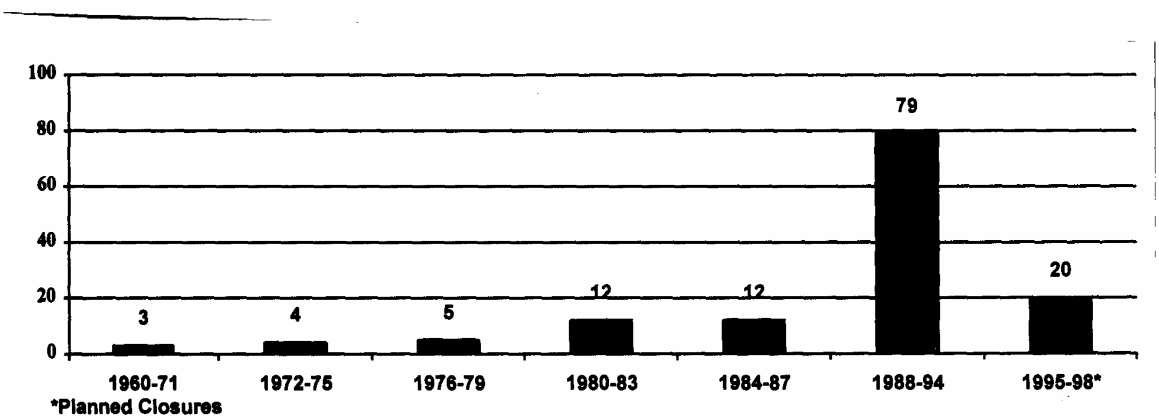
Virtually every State has reduced the population of its large public institutions overthe past 25 years. In 1967, State institutions housed 194,650 the 65,735 in State facilities on institutions over the past 25 years. June 30, 1994. In three States (New Hampshire, Rhode Island and Vermont) and the District of Columbia, the State institutions have been closed; altogether, 115 large State facilities in 32 States were closed between 1960 and 1994, with 79 of these closed between 1988 and 1994 alone. States project an additional 20 closures between 1995 and 1998 as illustrated in Figure 1 (Prouty and Lakin, 1995).

Mental Retardation/ Developmental Disabilities Spending Per $1,000 of Personal Income:
1977, 1982, 1987, and 1992
Table 2

Year	Total Spending Per $1,000 of Personal Income	Spending Per $1,000 of Personal Income for Community Services	Spending Per $1,000 of Personal Income for Care in Congregate Facilities (16 persons +)
1977	**$2.27**	**$0.57**	**$1.70**
1982	**$2.58**	**$0.86**	**$1.72**
1987	**$2.06**	**$1.36**	**$1.60**
1992	**$3.33**	**$1.90**	**$1.43**

Source: *The State of the States in Developmental Disabilities* (Braddock et al., 1995).

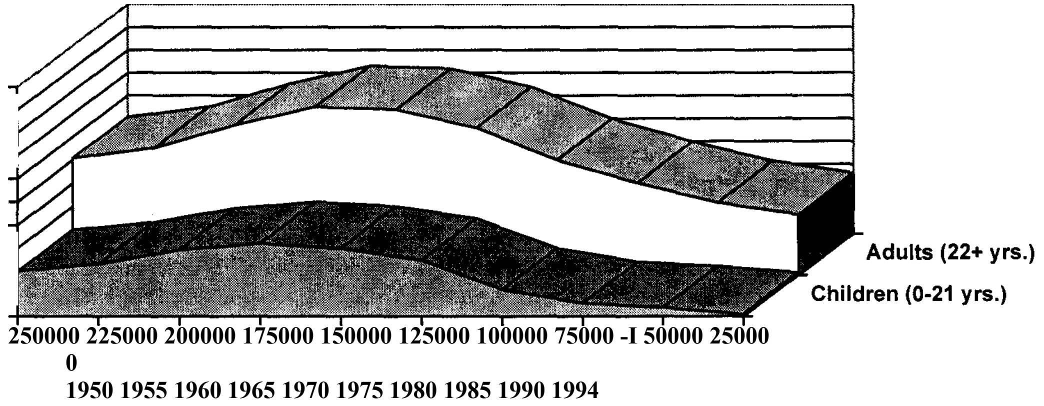
Figure 1
Numbers of Large State MR/DD Facilities and Units Closed and Planned for Closure, 1960-1998



Source: Prouty and Lakin (1995).

As more States have focused on helping children with mental retardation to live with their families or in a substitute family home, the population of children and youth in State institutions has dropped dramatically. As illustrated in Figure 2, the number of State institution residents under the age of 21 as of June 1994 was 4,001, compared to 91,600 in 1965. The drop is particularly significant for children under the age of 15, even with the national increase in children surviving with major medical care needs.

Figure 2 Total and Childhood (0-21 Years) Populations of Large State MR/DD Facilities, 1950-94



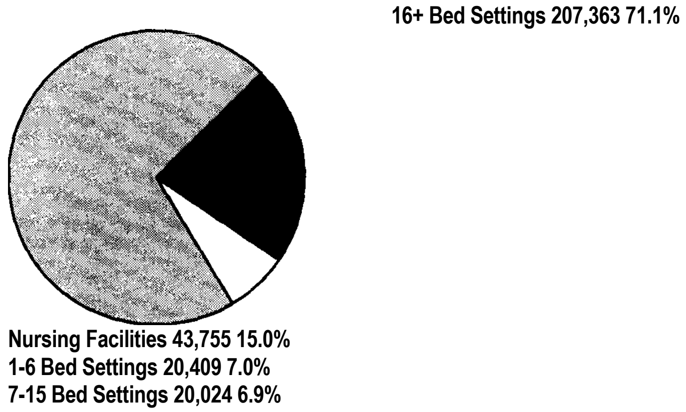
Source: Children and Youth in State MRIDD Institutions **(Lakin, 1995).**

Nearly all States have greatly expanded the availability of community residential options for people leaving the State institutions and for others, primarily adults, who do not continue to live with their families. Although some States have funded services in large private institutions and nursing homes, the strongest growth has been in the development of small privately-operated homes in the community. The number of smaller community residential service sites (i.e. settings in which 15 or fewer people with mental retardation/developmental disabilities live, excluding people living with their families) has grown from 11,008 in June 1977 to 63,654 as of June 1994. Even more remarkable has been the growth in residential settings with six or fewer residents, which have increased from 6,876 in June 1977 to 55,784 in June 1994, and have more than doubled (from 26,664) in just the seven years between June 1987 and June 1994.

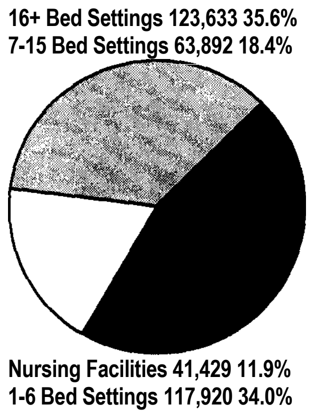
The significance of these changes to the numbers of persons with mental retardation/developmental disabilities living in residential settings of different sizes is shown in Figure 3. From 1977 to 1992, the number of individuals served in one-six bed settings rose from 20,409 (7.0% of the total number receiving residential services) to 117,920 (34.0% of the total). This number rose to 145,976 by June 1994, reflecting the growing preference for small settings that can be inclusive homes in the community of choice.

During the same period, the number served in large (16 persons or more) congregate settings declined from 207,363 (71.1%) to 123,633 (35.6%). Use of nursing home facilities for people with mental retardation also has declined, while there have been large increases in the use of residences with 7-15 participants. There are also many differences among the States in the specific configurations of residential services. Overall, however, the national trend is clearly in the direction of smaller, less institutional residential options, especially those housing six or fewer individuals.

Figure 3
Individuals Served by Size of Residential Setting:
FYs 1977 and 1992



1977 Residential Services Total: 291,551



1992 Residential Services Total: 346,874

Source: *The State of the States in Developmental Disabilities* (Braddock et al., 1995).

Nationally, the average size of residential settings for people with developmental disabilities has dropped from 22.5 people per residence in 1977 to 4.9 in 1994. There is great variety among the States, however, in the extent to which community residences have been developed and the relative emphasis on small community settings. As of June

1994, the average number of individuals per residential setting ranged from more than 12 in Virginia, Illinois, Kansas and Mississippi to less than 2 in Alaska, Hawaii, New Hampshire, and Vermont. In 1994, a majority of persons receiving residential services in settings for persons with mental retardation/developmental disabilities (excluding nursing homes) lived in settings with six or fewer residents in half (25) of all States.

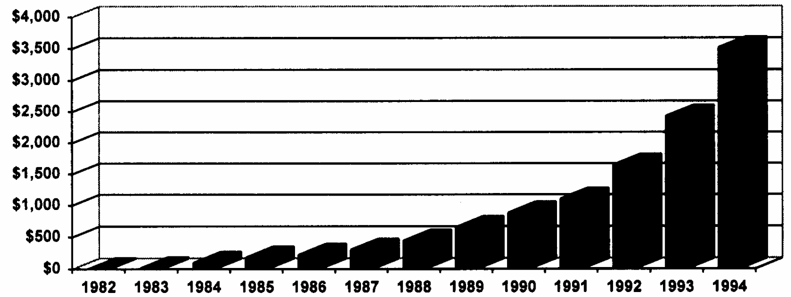
The Medicaid Home and Community Based Services Waiver

The States' expanded use of Medicaid Home and Community-Based Services (HCBS) waivers is a prime example of how States have taken a Federal policy option and used it to expand service options for people with mental retardation/developmental disabilities. Through the HCBS waiver program, States can design flexible services and supports to help people leave institutions or avoid institutional placement in the first place. The Medicaid funding for the waiver means that Federal dollars pay a minimum of 50% of waiver services, based on each State's Medicaid matching rate.

Waiver services are also usually much less costly per person than the institutional services they replace. A recent (1994) analysis of annualized the HCBS waiver costs compared with costs for placement in a Medicaid-funded Intermediate Care Facility for persons with Mental Retardation and related conditions (ICF/MR), found that waiver costs per person were 41% of ICF/MR costs. When Medicaid and related costs were added, the average cost for individuals in the HCBS waiver program was $33,444 per year, compared to $67,681 for those served through the ICF/MR program (Smith and Gettings, 1994).

States have moved rapidly over the past decade, and especially since the late 1980s, to expand their HCBS programs, as illustrated in Figure 4. Combined State and Federal spending on the HCBS waiver services is projected to reach $4.5 billion in 1995, and at least $5.5 billion by 1996 (Smith and Gettings, 1994).

Figure 4
MR/DD HCB Waiver Outlays: 1982—1994

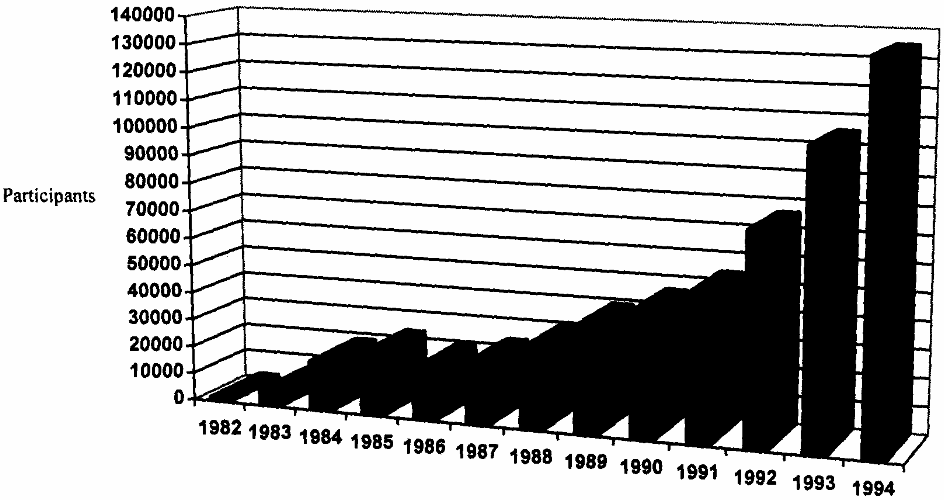


Source: *The HCB Waiver and CSLA Programs: An Update on Medicaid's Role in Supporting People with Developmental Disabilities in the Community* (Smith and Gettings, 1994).

Source: *The HCB Waiver and CSLA Programs: An Update on Medicaid's Role in Supporting People with Developmental Disabilities in the Community* (Smith and Gettings, 1994).

The number of participating States and the total number of the HCBS waivers serving people with mental retardation/developmental disabilities also has increased significantly, rising from 12 waivers in 12 States in 1982 to 80 waivers in 49 States in 1994. Figure 5 illustrates the sharp increase in participants, from 45,203 in 1990 to 134,717 in 1994. Since 1990, the annual compound growth rate in participants has been 31.4%, with the number of HCBS waiver participants almost doubling every three years (Smith and Gettings, 1994).

Figure 5
HCB Waiver Participants: 1982—1994



Source: *The HCB Waiver and CSLA Programs: An Update on Medicaid's Role in Supporting People with Developmental Disabilities in the Community* (Smith and Gettings, 1994).

Federal policy has facilitated this expansion, by removing some of the restrictions on State waiver expansion and by efforts to streamline the approval process. A 1993 survey of the States regarding their current use of the HCBS program for individuals with mental retardation/ developmental disabilities and their future waiver program plans by the National Association of State Directors of Developmental Disabilities Services, Inc. (NASDDDS) produced the following conclusions:

- States are continuing to expand their HCBS waiver programs for people with developmental disabilities at a rapid pace. In 1994, States expected to add as many participants as were being served nationwide in 1988. Although the rate of growth is likely to moderate over the near term, it appears likely that the number of the HCBS waiver participants will pass the number of ICF/MR residents in 1995 and reach 170,000 by 1996.

- State-Federal outlays for the HCBS waiver services also have grown very rapidly. Per capita spending for waiver services continues to be substantially less than spending on ICF/MR services. However, wide differences persist among the States in the extent to which they use the HCBS waiver program to support community services for people with developmental disabilities.

- Although the primary explanations for the rapid pace of expansion in the HCBS waiver services for people with developmental disabilities nationwide is the extension of services principally to individuals in the community, the program continues to play a very significant role in paying for the community placement of residents of large, State-operated facilities and, more recently, of individuals served in other types of ICFs/MR, such as larger private facilities. In addition, States have used the waiver program to help finance the community placement of nursing facility residents with developmental disabilities. Between 1991 and 1993, nearly 9,000 individuals previously served in large, State-operated facilities, other ICFs/MR, and nursing ,homes left these facilities to receive community services and supports through the HCBS waiver program. These individuals account for roughly 18% of the nationwide increase in program participants during that two year period.

- States are reconfiguring their HCBS waiver programs as well as expanding they. While States appear to be consolidating the number of programs they operate, they also have significantly expanded the number of services and supports available to program participants. The most noteworthy area of expansion is the ongoing addition of community living options. The period from 1992 - 1994 also saw a number of States adding alternative non-residential community supports to their programs as well as choosing to cover such individual supports as home modifications and assistive technology.

- State program managers expect that HCBS waiver programs will place greater emphasis on the delivery of person-centered services, and supported living and person-centered planning are taking on greater importance in State waiver programs. The waivers also continue to play an integral role in helping finance the community placement of people with developmental disabilities who are moving out of institutional settings. At the same time, they also anticipate increased difficulties in securing additional matching dollars to pay for program expansions.

The HCB Waiver and CSLA Programs: An Update on Medicaid's Role in Supporting People with Developmental Disabilities in the Community (Smith and Gettings, 1994) describes the HOBS waiver trends as well as summaries of each State's HCBS waivers as of FY 1994. The NASDDDS analysis noted the following general policy trends among the States in their HCBS waiver programs:

- The coverage of "personal supports" intended to assist people to participate more actively and regularly in community activities will become more commonplace.

- More States will over participants the option of having a "personal agent" to assist them in accessing supports and addressing day-by-day problems associated with living in the community.

- An increasing number of States will discard traditional service planning methods and adopt person-centered planning instead as their principal tool for identifying the HCBS waiver services and supports of greatest value to program participants.
- Quality assurance and enhancement systems will continue to evolve toward outcomebased approaches, as part of the overall restructuring of quality assurance systems in mental retardation/developmental disabilities services (Smith and Gettings, 1994).

NASDDDS also identified the influence of State participation in the Community Supported Living Arrangements (CSLA) program in these trends, in particular the emphasis on individual supports, the personal agent concept, and person-centered planning.

NASDDDS concluded its review of the HCBS waiver program for people with developmental disabilities as follows:

> For more than a decade, the HCB[S] waiver program has served as a powerful catalyst in shifting Medicaid financing of community services for people with developmental disabilities beyond the confines of facilities/programs and into more contemporary and satisfactory approaches to supporting people in their local communities (Smith and Gettings, 1994).

Related efforts to support individuals with mental retardation in reaching their goals are described in the rest of this resource.

The Florida Story

Independent Support Coordination is offered to participants in the State's HCBS waiver program. It replaces traditional "gatekeeper'/'service director" case management with a "personal agent" model. Independent support coordination is designed to provide people with developmental disabilities with a person-centered, streamlined, flexible, and accessible method of coordinating services and supports selected by the individual and involved family members. Goals include: (a) promoting self-advocacy and community inclusion in all life areas; (b) promoting the use of natural supports; and (c) coordinating specialized services with other programs and resources.

Support coordinators work with the person, family members and other people important to the individual in developing Individual or Family Support Plans. Coordinators work with the individual and their team in identifying and implementing the support strategies they select. In other words, coordinators serve as "personal agents" in putting the support strategy into action.

Support coordinators may not be employed by a service provider agency and may not furnish other services to the individual. They may be self-employed or work for agencies, provided that the agency does not furnish other developmental disabilities services. People with developmental disabilities select their support coordinator. In addition to meeting education and experiential requirements, support coordinators must receive at least 60 days of pre-service training under a curriculum issued by the Developmental Services Office. Support coordinators may serve no more than 35 individuals with disabilities, must accept all referrals, and must be continuously available to consumers and their families.

Adapted from Smith and Gettings, 1994.

II. MENTAL RETARDATION AND RELATED DISABILITIES

- DEFINITIONS PREVALENCE OF MENTAL RETARDATION AND
- DEVELOPMENTAL DISABILITIES
- SERVICE PLANNING IMPLICATIONS

Within the group of people diagnosed as having mental retardation there is as much variety in abilities, accomplishments and motivation as among people without mental retardation; arguably, there is more. Equally important, a substantial number of people who are identified as having mental retardation at any one time of their lives will not be so identified throughout their lives. Finally, it must also be recognized that mental retardation is a highly stigmatizing label; that is, it suggests to those labeled as well as to the people they meet in daily life a set of undesirable characteristics, which over the years have ranged from "helpless" and "childish" to "dangerous" and "uncontrollable."

Many people labeled with mental retardation and many of their allies recognize that how people are perceived by others has a strong effect on how they are treated. They want to do away with the label of mental retardation, or at least find one that is more positive. Unfortunately, the history of such efforts suggests changing language often is only a temporary remedy until the new label engenders old prejudices. "Idiotic," "imbecilic," "feebleminded and "mentally defective" are examples of precursors to the term "mentally retarded," and at least the later term implies slowness in cognitive development, (not a permanent state of deficiency). Still the search for more positive ways of distinguishing people who have abilities and potential to be a part of and contributing to their communities, while still recognizing that they need special supports to do so, is an important one. Among newer, less stigmatizing terminologies that may be used instead of mental retardation are "cognitively impaired," "intellectually challenged" and "developmentally disabled." However, because current service systems have been and remain constructed around mental retardation (and related disabilities), some attention to its definition and implications seems warranted.

DEFINITIONS

There was a time when mental retardation was defined strictly in terms of an individual's score on a standardized intelligence measure or "IQ" test. But modern definitions and diagnostic procedures also require assessment of the person's "adaptive behavior"-how well the person accomplishes the basic tasks of daily living and learning-as well as a measured IQ level, to determine the presence of mental retardation. The current definition used by the American Psychological Association, for example, categorizes individuals as having mental retardation if their IQ is below approximately 70 (statistically about 2.3% of the population) an if they also have significant deficits or impairments in adaptive behavior for their age. With standard error of measurement, a diagnosis of mental retardation is possible through an IQ of 75.

The AAMR DEFINITION

Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental retardation manifests before age 18.

The following four assumptions are essential to the application of the definition:

> 1. Valid assessment considers cultural and linguistic diversity as well as differences in communication and behavioral factors;
> 2. The existence of limitations in adaptive skills occurs within the context of community environments typical of the individual's age peers and is indexed to the person's individualized needs for supports;
> 3. Specific adaptive limitations often coexist with strengths in other adaptive skills or other personal capabilities; and
> 4. With appropriate supports over a sustained period, the life functioning of the person with mental retardation will generally improve (AAMR, 1992).

The AAMR definition is consistent with growing emphasis in the field on looking at each person as an individual, in relation to their unique strengths, desires, and needs for support, rather than focusing on deficits and labels regarding the level of mental retardation. AAMR guidelines on using the definition describe the importance of supports and their relation to inclusion (integration) as follows:

> *Appropriate supports* refers to an array of services, individuals, and settings that match the person's needs. Although mental retardation may not be of lifelong duration, it is likely that supports will be needed over an extended period of time. Thus, for many individuals, the need for supports will be lifelong. For other individuals, however, the need for supports will be intermittent. Virtually all persons with mental retardation will improve in their functioning as a result of effective supports and services. This improvement will enable them to be more independent, productive, and integrated into their community. In addition, if individuals are not improving significantly, this relative lack of improvement should be the basis for determining whether the current supports are effective and whether changes are necessary (AAMR, 1992).

The new (1992) definition of mental retardation developed and endorsed by the American Association on Mental Retardation places even greater emphasis on adaptive behavior, now called adaptive skills. The new AAMR definition also calls for a much more thorough assessment of the person's interaction with his/her environment and the need for supports within that environment *(Mental Retardation. Definition, Classification, and*

Systems of Supports, 9th Edition, AAMR, 1992). It remains to be seen whether this new system will be widely adopted, and what implications its identification will have on identifying the prevalence of mental retardation.

As noted, the terminology "developmentally disabled" is frequently used as an alternative to "mentally retarded." In its origins, however, it is a distinct concept, even if sometimes used as another term for having mental retardation. The concept of *developmental disability* moves away from a specific diagnostic label like mental retardation to a focus on severity, functioning levels, and effects of disability that originate in childhood. The Federal definition of developmental disability, as provided in the *Developmental Disabilities Assistance and Bill of Rights Act (P.L.* 103-230) is as follows:

The term "developmental disability" means a severe, chronic disability of an individual 5 years of age or older that

> (A) is attributable to a mental or physical impairment or combination mental and physical impairments;
> (B) is manifested before the individual attains age 22; (C) is likely to continue indefinitely;
> (D) results in substantial functional limitations in three of more of the following areas of major life activity
>
> - (i) self-care;
> - (ii) receptive and expressive language;
> - (iii) learning;
> - (iv) mobility;
> - (v) self-direction;
> - (vi) capacity for independent living; and
> - (vii) economic self-sufficiency; and
>
> (E) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

The Federal definition of developmental disabilities includes children and adults with a wide range of diagnoses, including mental retardation, but also chronic health problems, cerebral palsy, autism, spinal cord injury and severe head injury, so long as the condition began before age 22 and therefore affected the person's development. Amendments to the definition in 1990 added the language including very young children (birth through five years of age) who appear very likely to have developmental disabilities, based on evidence of developmental delay and relevant diagnosis. It is generally assumed that almost all people who are actively identified as having mental retardation for the purposes of receiving services other than special education could also be identified as developmentally disabled. But one of the real problems with the use of the term developmental disabilities as a diagnostic or eligibility category is that there are no standard agreed upon operational definitions of when someone has a "substantial" functional limitation.

PREVALENCE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

One reason why it is important to have some understanding of the prevalence of mental retardation and related disabilities is the importance in planning and financing services and supports. This is especially important for adults with mental retardation who need more intense formal services and supports in housing, work, leisure/recreation and other activities after they complete their education and move away from their family home. There is general consensus that about two percent of the population could be labeled as having mental retardation some time during their lifetimes based on IQ scores. In reality, many people whose IQs might be below 70, do not exhibit the difficulties in adaptive behavior. And many who exhibit difficulties in adaptive behavior at some point in their lives do not exhibit them throughout their lives. As described in the AAMR definition, mental retardation should not be viewed as a permanent condition; people can and do "cure" themselves by living relatively independent lives, especially when appropriate supports are available when needed.

People identified as having mental retardation are almost always so identified during the school years when academic problems draw attention to them. Many of these same individuals are not officially recognized as having mental retardation beyond the school years. (Grossman, 1973; PCMR, 1970) Therefore, there is a wide variation between the number of people who will sometime in their lifetimes be labeled as "mentally retarded" and the number who are at any one time being actively recognized or "treated" as having mental retardation.

Those who have examined the "active" prevalence (the percentage of the population identified at any one time) of mental retardation note that seldom is more than one percent of the population identified. This considerably lower prevalence of mental retardation reflects that mental retardation is a permanently recognized condition for only about 0.5% of the population ("the stable population of persons with mental retardation") and a "transitory status" into which falls at any one time about a quarter of the approximately 1.5% of the population that will only temporarily be identified at exhibiting mental retardation (most often exclusively during the school years).

The "Stable" Population of People with Mental Retardation

For the most part the functional characteristics and associated needs of adults falling in the profound to moderately retarded range (approximate IQ of 50-55 or below) are such that, even though some of the more capable individuals in this group may develop a range o£ important self-care and employment skills, relatively few achieve full independence from the support of family members and service providers. People with this level of impairment constitute approximately 0.4% of the population. This prevalence is based from an average finding of 0.4% in 27 epidemiological studies of communities, primarily in the United States and the United Kingdom, of which 19 were considered reasonably reliable (Abramowicz and Richardson, 1975). Because these studies were generally focused on noninstitutionalized persons in the adolescent years, it is presumed that they would represent persons in a nearly universal screening for prevalence, that is, in the school years. Adjustments of these estimates to include institutionalized persons would make 0.5% a reasonable estimate of the percentage of the total population falling in the moderately to profoundly retarded range.

There are currently a number of health, social, and demographic factors that may be affecting the prevalence of this level of disability, although it is difficult to establish the direction, if any, of the net effect. For example, in the past two decades, infant mortality has fallen sharply in the United States, particularly among high-risk premature babies, many of whom now survive with severe developmental impairments. Furthermore, advanced medical technologies are increasing the ages to which people with mental retardation are living. Other medical and public health technologies, including genetic screening, improved pre- and perinatal health and medical care, immunizations, and liberal access to abortions have probably had a general effect of lowering the incidence of moderate to profound mental retardation. In New York State, following liberalization of the abortion law, Down Syndrome births declined by 20% over a five year period (Hansen, 1978). Epidemiologically, the factors mentioned above may well have lowered the incidence of moderate to profound mental retardation while maintaining, possibly even slightly increasing, its prevalence. Demographically, this causes a trend toward a generally older population of people with moderate to profound mental retardation. Such trends have important ramifications for communities, as the primary locus of social responses to the needs of individuals with moderate to profound mental retardation will continue to shift from home and school (currently available through age 21) to a full array of much more costly adult services.

The Transitory Population of People with Mental Retardation

Many of the people who are ever identified as having mental retardation retain that label for only a limited part of their lives. The vast majority are identified as having mild mental retardation. A sizable portion of these people are only identified as having mental retardation while they are in school settings. In the 1992-1993 school year 1.4% of the school age population was reported by education officials to have mental retardation or multiple disabilities. This number has actually been decreasing in recent years (from 1.8% in 1983-1984 and 2.2% in 1978-1979), as less stigmatizing categories (especially learning disabilities) have been used to authorize and provide specialized educational services.

In the early 1970s, the substantial role that schools have historically played in creating and treating the "active" prevalence of mental retardation was shown in a seminal analysis by Tarjan et al., (1973), in which it was estimated that 75% of the people who at any one time are identified as having mental retardation are children or adolescents. These estimates have been supported by other household surveys in Baltimore, Maryland (72.5% in 1936) and Riverside, California (76% in 1973). Tarjan's analyses also demonstrated that virtually all persons ever identified as having mental retardation are identified before reaching adulthood, and that two-thirds of the persons so identified before age 21 do not retain that label in adulthood. So as schools identify fewer and fewer children and youth who in the past would have been identified as having mental retardation, two important trends can be identified. First, the proportion of people who will ever be identified as having mental retardation has decreased. Second, the proportion of children and youth among persons who are at any one time identified as having mental retardation will decrease. But even relying on somewhat aging school prevalence statistics, the combined prevalence of "active" mild retardation and stable (moderate to profound) retardation supports the estimate of only about a 0.8% to 0.9% prevalence of "active" mental retardation at any one time.

Objective Support for the 1% Prevalence Estimate

Comprehensive studies of prevalence support the 1% prevalence estimate. The Riverside, California (pop. 85,000) study in the early 1970s, combining case registries of clinical and service providing organizations (including schools) with household surveys and respondent nominations of persons outside the family believed to have mental retardation, yielded a total estimated prevalence of 1.0% when all nominated individuals were screened for clinically diagnosable mental retardation (Mercer, 1973a,b). In a second household-only survey of a controlled sample of counties in West Virginia in 1974-1976, Lindberg, (1976) studied the prevalence of multiple developmental disabilities including mental retardation. The households surveyed had a total population of over 35,000 people. Based on this survey it was estimated that 0.82% of the State's household population had mental retardation, although there were regional variations from 0.62% to 1.07%. When the prevalence of persons with mental retardation in West Virginia's residential facilities on June 30, 1977 was included, the prevalence of mental retardation was an estimated 0.88% of the State's population.

Variations in Active Prevalence by Age Groupings

Of particular importance to service systems is the varying size and severity of disability of this population at different points in the life span. Infancy and early childhood represent periods when the prevalence of <u>identified</u> mental retardation is low (less than 0.5%) but the proportion with <u>severe</u> impairments is relatively high, since most young children are not identified unless they have substantial cognitive impairments. The school years (6-21) represent a period when the identified prevalence is high (about 1.4% in figures reported to the Department of Education by school districts). But school age individuals with mild retardation constitute a dwindling majority of this population, and this majority typically does not receive specialized services outside of the school (hence the term "the 6-hour retarded child" coined by PCMR in 1970). Finally, the adult years are a period when the prevalence again decreases; returning to an average of about 0.5%, but the proportion of persons with more severe impairments is again relatively high.

National statistics are generally supportive of the surveys described above. Table 3 summarizes data from the National Health Interview Survey on persons living outside of licensed residential settings who were identified as having a major activity limitations and mental retardation, by the condition indicated as the primary cause of the limitations, along with persons in residential settings. As shown the combined noninstitutionalized and long-term care populations are estimated as 825,000 or 1.23% among persons under 18 years and 1,974,000 for all individuals. Adjustment to age 21 would yield an estimated 988,000 children and youth 21 years or younger with mental retardation and 988,000 adults. It would appear that the reduced use of the mental retardation label in schools has reduced the proportion of all people identified as having mental retardation from about 70% to about 50% over the past quarter century.

People with developmental disabilities by definition need some level of assistance in three or more areas of daily life activity. In addition to those with mental retardation, there is an additional portion of persons with developmental disabilities who also need substantial support and assistance. Because service systems for people with mental retardation and developmental disabilities have evolved out of traditional mental retardation systems, they often categorically exclude individuals with developmental disabilities not also accompanied by mental retardation, for example, people with physical disabilities without retardation. People with other developmental disabilities often have had little interest in mental retardation-oriented services because they were inconsistent with their goals, aspirations and sense of autonomy and dignity. However, as traditional service systems evolve, services are becoming more attractive to a broader range of people with developmental disabilities. As this happens, there is growing interest in understanding how many people there are those who have developmental disabilities/mental retardation. A two-year national survey will be completed in 1995 to permit estimates of a national prevalence rate for developmental disability, based on the Federal definition. This is extremely important because existing estimates are inadequate to identify the numbers of people with developmental disabilities, and the nature and extent of their needs for services and supports.

Table 3

Estimated Prevalence of Persons with Mental Retardation in the Noninstitutionalized and Institutionalized Populations of the United States As Identified for Persons with Major Activity Limitations with "Main Cause" Indicated.

	Under 18 Years		All Ages	
	Number	%Fop.	Number	% Pop.
Noninstitutionalized PopulationZ 190-419,96 estimates				
Mental Retardation	611,000	.91	1,032,000	.40
Cerebral Palsy	81,000	.12	155,000	.06
Epilepsy	65,000	.10	361,000	.14
Schizophrenia/Psychosis (evident in childhood)	20,000	.03	77,000'	.03
Total Noninstitutional	777,000	1.16	1,625,000	.63
Institutionalized Population-1994				
MR/DD Settings	48,500		311,000	
Nursing Homes [5]	500		36,000	
Psychiatric Facilities	UNK.		1,600	
Total	49,000	.07	348,600	.14
Total Est. MR Population	826,000	1.23	1,974,000	.77
1985 Population Base	67,133,000	26.03	257,900,000	100.00

*The statistics on noninstitutionalized populations are drawn from analysis of the 1983-1986 National Health Interview Survey by Mitchell LaPlante on the University of California-San Francisco, Institute of Health and Aging. These statistics represent the prevalence of mental retardation among persons for whom chronic impairments are identified to be the "main cause" of limitations in major activities (kind or amount of work, housekeeping, or schooling). Institutionalized populations represent populations of persons identified as having the conditions above within institutional populations (1986 in case of MR/DD facilities). In addition to conditions which represent the main cause of limitations in major activities, the NHIS included identification of specific conditions within general classes for 1/6 of the sample irrespective of limitations that might result. For the three major conditions causing limitations the following number of cases and prevalences were estimated for noninstitutionalized populations, irrespective of major activities limitations: mental retardation, .45%; cerebral palsy, .11%; and epilepsy, .44%.

[1] Under 18 years for non institutional population, under 21 for institutional population.

[2] From LaPlante (1990). Data on disability from the National Health Interview Survey, 1983-1986. Washington, DC: U.S. Department of Education.

[3] Populations 18 and over with limiting condition estimated from the prevalence of impairments in under 18 population because of inability to infer whether adults' condition of this type occurred in the developmental period.

° Data from Center for Residential Services and Community Living, University of Minnesota (excludes generic foster care covered in survey of noninstitutionalized populations).

[5] Data from analyses of 1985 National Nursing Home Survey by Center for Residential Services and Community Living, University of Minnesota. Includes primary diagnosis of mental retardation or cerebral palsy.

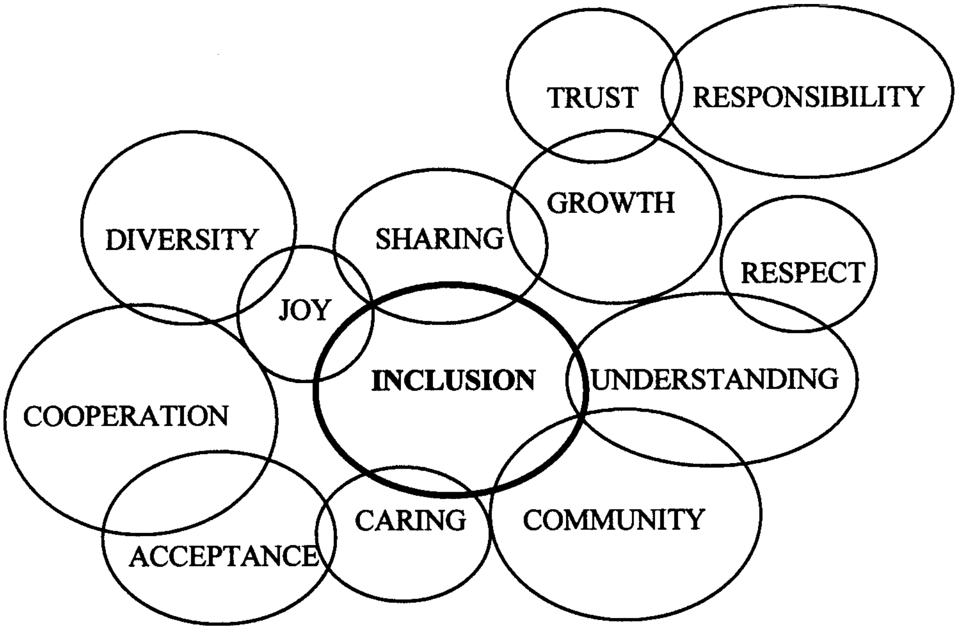
SERVICE PLANNING IMPLICATIONS

The emphasis on the more severe levels of mental retardation and related disabilities in many discussions does not mean that individuals with mild retardation may not need supports and services once they leave school, and in some cases, before entering school. Each person's (and family's) specific situation and needs are unique, as well as changing over time. People with mental retardation may need help with housing, employment, paying their bills, or marriage counseling just like anyone else. For planning purposes, however, it is generally more helpful to think in terms of the 0.5-1 % who are most likely to need a combination of informal and specialized supports, while recognizing that everyone's needs and choices will be different.

As States are moving from a mental retardation service system to a developmental disability system, some are adopting the Federal definition of developmental disabilities for service eligibility purposes (for example, Ohio), or an adaptation. The potential effect of this shift is to expand service eligibility for some individuals who have conditions other than mental retardation, and to potentially decrease eligibility for some people with mild mental retardation who do not have substantial functional limitations in three or more areas of activity. The issues around prevalence will become increasingly important. Many States will likely redefine developmental disabilities. For example, many will recognize a need to include people with mild mental retardation and few "functional limitations," but who have substantial emotional and/or behavioral problems. In considering adoption of new definitions in determining service eligibility, it is important that States have the best possible information regarding the characteristics of those who are presently being served and those *who* might be newly eligible, as well as providing assurances that individuals *who* need assistance can continue to have access to the supports they need.

III. HOW INCLUSION MAKES A DIFFERENCE

- **INCLUSION IN EARLY INTERVENTION INCLUSIVE**
- **EDUCATION TRANSITION**
- **EMPLOYMENT**
- **INCLUSIVE RECREATION AND COMMUNITY CONNECTIONS**
- **AGING AND RETIREMENT**



Inclusion is part of an overall approach to living with mental retardation, an approach that focuses more on abilities and opportunities than on disability and limitations. The PCMR National Collaborative Academies recognize the significance of inclusion throughout the lifespan of people with mental retardation and other developmental disabilities, beginning with supports for inclusion in the earliest months and years of the child's life and continuing through the school years, work and retirement.

INCLUSION IN EARLY INTERVENTION

> *Typical peers and typical settings are the right of all children needing early intervention. Staff roles and expertise are stretched and altered for the better because of learning to work in context on functional and vital skills. Good teamwork in typical settings not only addresses primary needs of children, but helps prevent secondary handicaps that derive from social exclusion* (Kjerland, 1991).

There are many reasons to make sure that early intervention services--the earlier the better-are available to children with mental retardation and other developmental disabilities, and to their parents. As a practical matter, early intervention is a cost-effective investment in children and families. Research has consistently shown that early identification and intervention reduces developmental delay, helping to prevent more severe and costly problems later on (Wright, King and the NCSL Task Force on DD, 1991).

Early intervention services are tailored to meet the needs of individual children and families, with some requiring only a Everyone benefits from few hours of support per month and others needing much more early intervention: the intensive intervention. The array of services includes screening and assessment, family training and counseling, language child, the family, the development, physical and occupational therapy, psychological services, nutrition counseling, nursing services, assistive community and society.technology, home and vehicle modifications, and a wide range of support services, such as case management/coordination support, transportation, respite services, and other supports to the family.

Key tenets of early intervention are that it is family-focused as well as child-focused.” This means that inclusion is supported right from the beginning, with home-based services and family supports that help prevent out-of-home placements. Another important tenet is that early intervention must be culturally relevant, incorporating supports and approaches in line with culture-based values, parenting practices, and communication styles.

Everyone benefits from early intervention:

Benefits to the Child:

- More skills acquired more quickly because individualized supports and training are provided;
- Less need for special education or education in segregated settings;
- Prevention of secondary disabilities;
- Supported in family participation and activities with other children; and
- Foundation for enhanced independence and productivity throughout lifetime.

Benefits to the Family:

- Skills gained by parents and other family members in implementing child's program at home;
- Reduced stress through supports and increased confidence; and
- Help with costs of special equipment, other disability-related expenses.

Benefits to Society:

- Reduced costs of special education;
- Increased productivity and contributions to society; and
- Prevention and mediation of costly secondary developmental problems and out-of-home placements.

The importance of the benefits of early intervention was emphasized at the Federal level in the enactment in 1986 of Public Law 99-457, now Part H of the Individuals with Disabilities Education Act (IDEA). This capacity-building program supports State efforts to improve their outreach and services to infants and toddlers with disabilities, developmental delays, or at risk of developmental delay.

The Promise of Part H

Part H authorizes financial assistance to the States for the following purposes:

- Develop and implement a statewide, comprehensive, coordinated, multi-disciplinary, interagency program of early intervention services for all infants and toddles with disabilities and their families;
- Facilitate coordination of payments for early intervention services from various public and private sources; and
- Enhance the State's capacity to provide quality early intervention services and expand and improve existing services.

Project EDGE: Early Intervention Pioneers

Early family-based education for infants and toddlers with Down Syndrome was developed at the University of Minnesota in the late 1960s. The five-year EDGE (Expanding Developmental Growth through Education) project supported children and their parents in play activities, followed by supported participation in a community nursery school from the age of 30 months to five years of age. At that point, children entered whatever educational programs their local school districts provided.

When the children were 11 to 14 years of age, follow-up data collection found that the children were exceeding traditional expectations for Down Syndrome. The majority were reading with comprehension at around a second grade level, with clear potential for becoming functionally literate; several were avid readers. Social adjustments were very good, and physical abilities were reflected in sports and recreational interests.

Holly Colwell was born in 1969 with Down Syndrome. She was enrolled in Project EDGE when she was six months old. Twenty years later, she had graduated from her local high school and was getting ready to attend a technical institute to continue her education. She was "mainstreamed" throughout her education, with many friends. She has a variety of interests, including figure skating. She won a gold medal at the State Winter Special Olympics and a silver medal at the International Winter Special Olympics in 1989.

Her parents feel that Project EDGE benefited Holly both academically and socially. EDGE helped parents in teaching children "how-to-do" and "how-to-grow," rather than emphasizing what the child was nnl expected to accomplish. Holly and many of the other EDGE graduates have disproved the negative predictions of the "experts" who recommended that Holly and other children with Down Syndrome be institutionalized because they would never be able to move beyond an infantile level of development. The family focus of the project also was important. Supports were brought to the home, and were tailored to each family's situation. The parents also became a built-in support system to each other. Holly's parents became a resource to new parents of Down Syndrome children throughout the area, in part to make sure that families received information on the child's potential.

Adapted from articles on Project EDGE in Impact 2(2), University of Minnesota, Summer 1989.

The Part H program emphasizes State flexibility and control, with each State designating a lead agency, an Interagency Coordinating Council, and developing a State plan. Federal funds are targeted to system building, not direct services-although some Federal dollars ~ can be used to create new services. As of December 1, 1993, the Department of Education reported that 150,000 infants and toddlers were receiving early intervention services (NEC*TAS, 1995).

Although this is a discretionary program, States accepting the fifth year of Part H Federal funding must make a commitment to implement their plan. As of 1995, all States have elected to participate in fifth year funding. Because Part H can be interpreted as establishing the State's commitment to provide the services in each child's Individual Family Support Plan (IFSP) once States accept the fifth year of Federal funding, some States had debated about relying on their own early intervention programs rather than participating in full Part H implementation. This and other issues from the State perspective are discussed in *Implementing Early Intervention Services for Infants and Toddlers with Disabilities* (Sonnier, 1991), an NCSL publication.

One of the core Part H principles is that families are assisted in obtaining services that are familyfocused and individualized. Each family's IFSP outlines specific goals, how goals will be met, and the specific services and supports needed to meet each goal.

Another core principle is that early intervention needs to take an interagency approach, recognizing that children with disabilities and their families often have needs that cut across multiple systems and agencies. States are therefore required to have an Interagency Coordinating Council and to define ways to promote interagency collaboration at the local level, as well as providing coordination support to the families.

A recent (April 1995) report submitted to the Federal Interagency Coordinating Council for Part H summarized seven areas of achievement in the eight years of Part H implementation:

1) Early intervention policies, programs and services are benefiting children with disabilities and their families. States report that their family-centered services result in:

- Better developmental and social adjustment outcomes for the child;
- Reduced stress on parents as a result of support and assistance in accessing needed services;
- Recognition of the family's role as decision maker and partner;

- Help to families in making the best choices for their children, through access to comprehensive information on community resources;
- Adaptations to individual, family and community contexts through creative, flexible and collaborative approaches;
- Children and families being valued for their unique capacities, experiences, and potential;
- Active family involvement in planning and implementation of early intervention services; and
- Potential savings in health care costs, through improved monitoring and referral to care.

2) Early intervention services are proving to have cost benefits. States that have conducted evaluation studies have identified general cost savings/cost benefits (e.g., Florida, Massachusetts and Montana), as well as reduced need for special education services (e.g., Montana and Texas), and reduced need for out-of-home placements (e.g., North Carolina).
3) Services are improved and streamlined by interagency coordination and collaboration, including at least 41 States which include local interagency coordinating councils in their Part H system.
4) State and local service system development is enhanced, including expanded outreach and child identification, new options for home- and inclusive community-based services, and the development of services which are accessible throughout the community, are culturally sensitive, and are tailored to individual family priorities.
5) More children are being identified and served through expanded services.
6) More personnel qualified to work with young children with disabilities are available to provide services, through a variety of personnel development and training strategies.
7) Legislation and funding are supporting the continuation of early intervention services. All States have authorized the operation of a comprehensive early intervention program, through State legislation, executive orders, lead agency policies, and/or interagency agreements. All States also emphasize coordination of multiple funding streams, with at least 47 States reporting that they use Medicaid to fund portions of their Part H program (NEC*TAS, 1995).

Other Federal Support for Early Intervention

The Maternal and Child Health (MCH) Block Grant is used by States to fund health services targeted to low income women and children and children with special health care needs. The amount of each State's grant is set in a formula based on low income population. States must provide $3 match for every $4 of Federal funds. The Children with Special Health Care Needs component is a resource to States in supporting early intervention services. The MCH Block Grant also emphasizes service coordination and improved access to Medicaid-funded services.

The Medicaid Early Periodic Screening, Diagnosis and Treatment (EPSDT) program entitles all low income children who meet State and Federal Medicaid eligibility criteria to services necessary to meet health needs identified through their EPSDT assessments. This includes early intervention services needed by low income children with disabilities. Medicaid must provide the health services on the child's EPSDT treatment plan even if the specific service is an optional service that the State does not otherwise include in its State Medicaid plan.

Other Federal programs supporting early intervention include the Temporary Child Care for handicapped Children and Crisis Nursery programs, the Preventive Health and Health Services Block Grant, the Social Services Block Grant, the Technology-Related Assistance for Individuals with Disabilities program, the Indian Health Service, and Migrant Health Services.

Promoting Inclusion in Early Intervention

This month our son started kindergarten. He's already one of the most popular boys in school, is learning to share, and is learning to do much more than we had dared hope. We have the [community early intervention program] to thank for much of his success.

Parent from Virginia, quoted *in Helping Our Nation's Infants and Toddlers with Disabilities and Their Families* (NEC*TAS, 1995).

Forchildren with mental retardation and other developmental disabilities, inclusion begins with family. Early intervention and support to family members-including brothers, sisters and grandparents-helps create the "environment of inclusion" that Koquese Collins talks about in describing their (Brian's) family.

In Colorado, the Special Education Services Unit is the State's lead agency for Part H. Colorado used its Part H funds in a twofold approach to empower families in making decisions for their children with disabilities and to promote availability of services that are more responsive to their needs. For example, service providers are encouraged to offer more services in homes and during evening and weekends, to involve more working parents. The State's approach is based on a belief at "if the family functions better, the child will function better" (Wright et al., 1991).

Several States developed extensive early intervention programs, in many cases pre-dating Part H." NCSL describes the Texas early childhood initiative and its Early Childhood Intervention program as models for the authors of the Part H legislation. Maine also was a national leader in early intervention and coordinated interagency services for children.

Many States have used Part H planning and implementation activities to stimulate improvements in interagency collaboration for children and families in need. In some States Part H is part of a larger initiative, such as the Ohio Families and Children First Cabinet Council.

There are several initiatives to provide supports to daycare, child care and early education programs help them feel comfortable including children with disabilities. Limited availability of special needs daycare for children with developmental disabilities often results in severe hardships to families, especially if single parents are unable to work.

> The North Dakota Developmental Disabilities Council funded the North Dakota Early Childhood Training Center to develop training modules for daycare providers on programming for children with disabilities. The training enables the providers to integrate children with special needs. Over a two-year period, 1,145 children's day care provider staff received training in 24 locations across the State. A survey evaluating the impact of the Early Childhood Integrated Training Program found that one-third of day care providers responding were serving one or more children with disabilities; one-third reported that the availability of "special needs" day care had increased as a result of the training; a majority of parents surveyed were able to access and use day care; and both parents and providers felt that day care staff were well-trained to serve children with disabilities (Zierman, 1995).
>
> Iowa schools have offered Early Childhood Special Education (ECSE) services for children from birth to age seven since 1974, and have developed a comprehensive, statewide network of ECSE services. To increase opportunities for integrated educational experiences for young children, the Iowa Bureau of Special Education developed the Least Restrictive Environment (LRE) facilitator model. LRE facilitators identify programs in their area that are interested in and able to serve children with disabilities, including Head Start, private preschool and day care programs, as well as public school kindergarten programs. LRE facilitators help in arranging for children with disabilities to enter a non-segregated program; coordinate communication between parents, community program staff and special education personnel; and provide ongoing support and assistance to the community program.

One of the most important contributions of early intervention programs is to reach out and find children with disabilities and developmental delay, so that their needs can be identified and met on a timely basis. The District of Columbia developed Project ROSE (Reaching Out for Successful Early Intervention), partially supported by the District's Developmental Disabilities Council. Project ROSE is a collaborative data collection and child-find initiative of the D.C. Department of Human Services, in partnership with birth hospitals in the city (Zierman, 1995).

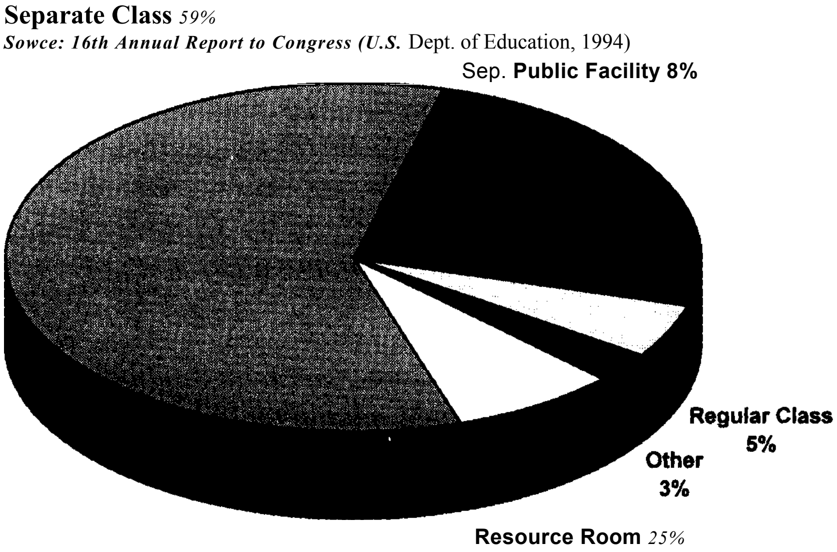
INCLUSIVE EDUCATION

> *“I do not want the `retarded corner' of the school. "* (Linda Preston, Illinois)

In its *A Journey of Renewal for All Americans: Report to the President* (PCMR 1994b), the PCMR noted that while children with mental retardation are no longer excluded from public education, they continue to be segregated. For the 1991-92 school year, for example, the U.S. Department of Education reported that only 5.0% of students with mental retardation age 6-21 were educated in regular classrooms. As illustrated in Figure 6, over 70% of the children received their education in separated classes or facilities (U.S. Department of Education, 1994).

Figure 6 Percentage of Children Age 6-21 with Mental Retardation Served in Different Education Environments, United States 1991-92 School Year.

Sowce: 16th Annual Report to Congress (U.S. Dept. of Education, 1994)



Students with mental retardation receiving inclusive education are reaping the benefits opportunities for friendships as well as enhanced expectations, as described by their parents hearings conducted by the National Council on Disability (NCD):

> IDEA [the Individuals with Disabilities Education Act] has made a difference for Maddie, a difference that translates into her attendance at our public elementary school a half block from our home with other first and second graders in her neighborhood. Her regular presence in school means that kids of all ages greet her on the playground, acknowledge her in stores, and expect that she is a part of the community. (Colorado Parent)
>
> My daughter is eleven years old. She has autism and mental retardation and up until last year ... was in self-contained classrooms. Last year we decided to attempt inclusion with lots of support through our [University Affiliated Program] and our local school district. Kara had a remarkably successful year. We saw more progress in that one year of inclusion than we saw in six or seven years of very intensive one-on-one special education. (Alaska Parent)
>
> A friend of mine has a child with Down Syndrome. It was difficult for her to have the child go into an inclusive classroom. She was very nervous and concerned about it. The first day that her Jennifer came home, she came in just bubbling and said, "Mommy, I'm a real second grader now!" That's the whole point: to let children like Jennifer know they're regular kids, too. (Margaret C. Daley)

Inclusion benefits children beyond their school years as well. A 1994 series of forums and teleconferences conducted by the President's Committee on Employment of People with Disabilities (PCEPD) described the link between inclusive education and later success as follows:

High quality education and vocational training from pre-school to post-graduate levels is the best way to ensure that people with disabilities integrate effectively into the economic marketplace and become full citizens and active, productive members of society. This can be most effectively achieved through the inclusion of people with disabilities into mainstream education...

The main aim of persons concerned with education issues and of parents, is to facilitate full integration of children with disabilities to the greatest extent possible into the classroom. Most participants stressed that integration, or "inclusion," is the best way to raise the self-esteem and self-expectations of children with disabilities, and to accustom their peers to work and live with them side by side throughout their lives. *(Operation People First. Toward A National Disability Policy,* PCEPD 1994).

Supporters of inclusive education also have noted the benefits to children without disabilities. As described by a California parent, "In every step of [my daughter's] education, there have been other parents who came to me privately and thanked me for allowing their children a first-hand human experience of the children who for so many years were relegated to special classrooms, other campuses, for separate-but not equal-education" (NCD, 1995).

The Individuals with Disabilities Education Act

In 1975, Congress enacted the Education for All Handicapped Children Act, P.L. 94-142, now Part B of IDEA, the Individuals with Disabilities Education Act. P.L. 94-142 recognized that State and local educational agencies had a duty to educate all students with disabilities, that they lacked the financial resources to do so, and that it was in the national interest for the Federal government to assist in meeting the educational needs of students with disabilities in order to assure equal protection under the law (20 USC Sec. 1400(b)(8) and (9)). The purposes were defined as follows:

- To assure that all children with disabilities receive a free and appropriate public education;
- To ensure that their rights and those of their parents and guardians were protected;
- To assist State and local agencies in providing for their education; and
- To assess and assure the effectiveness of those agencies' efforts to educate students with disabilities. (20 USC Sec. 1400(c))

This statement of purpose has been reaffirmed through reauthorizations and amendments during the last 20 years. Court decisions and regulatory clarifications have further strengthened IDEA's mandate to support individual students in inclusive education. As summarized by the National Council on Disability (1995), "The Court has made it clear that IDEA is not one of the so-called

"unfunded Federal mandates," but is a Federal grant program that is entirely justified under Congress' power and duty to implement the equal protection guarantees of the U.S. Constitution. More than that, the Court has acknowledged in the most unequivocal terms that IDEA provides Federal aid to the States to help them carry out their own legal obligations to educate all children, including those with disabilities" (NCD, 1995).

Two Massachusetts parents summarized the importance of IDEA in testimony at regional NCD hearings:

Before IDEA, the vast majority of children with disabilities had no future. IDEA has created a future with real opportunities. It must be reauthorized. As we've heard, it's a great success in human terms, but it's also a great success in cold, hard economic terms because educated children with disabilities are growing up and becoming productive adult taxpayers.

I love IDEA. It's a wonderful law. Keep it ... Strengthen the ability to monitor and enforce the laws, take out of the way the barriers that don't allow for the integration imperative to be realized, provide incentives to help teachers keep abreast of the state-of-theart technologies (instructional, as well as assistive), that are allowing our young people to achieve so much (NCD, 1995).

A recent background paper on inclusive education prepared by the Developmental Disabilities Task Force of the National Conference of State Legislatures (NCSL) summarizes the six key principle of IDEA:

1. The right of access to public education programs.
2. The individualization of services.
3. The principle of "least restrictive environment."
4. The scope of broadened services to be provided by the schools and a set procedures for determining them.
5. The general guidelines for identification of a disability.
6. The principles of primary state and local responsibilities. (NCSL, undated)

IDEA is being reauthorized in 1995, in the context of educational reform. State and local education systems are trying to improve educational outcomes for all children, including those with disabilities as well as those who are poor, educationally disadvantaged, from diverse racial and cultural backgrounds, or who have limited proficiency in the English language. A coalition of advocacy groups, including the National Parent Network on Disabilities, has urged that IDEA's protections to students with disabilities not be weakened, especially in a time of change, so that these children can continue to receive the education they are entitled to (Advocates for Children of New York, Center for Law and Education, Disability Rights Education Defense Fund, et al., 1994).

Outcomes of Inclusive Education: A Summary of Research Findings

The National Center on Educational Restructuring and Inclusion looked across a wide body of research on inclusive education, to identify outcomes and the practices associated with positive outcomes. For preschoolers, they noted conclusions through Nisbet's research summary (1994), that integration had positive effects on social competence, interactions, and some skills.

Overall, children with mild or high incidence disabilities, such as speech impairment or specific learning disabilities, were found to do as well or better in full time regular classroom than in resource room options. Classroom options also were generally more cost-effective. Children with moderate and severe disabilities in general education settings also were generally found to do as well or better than those in more segregated settings, especially in social competence. These findings were confirmed in several statewide and local district studies, as well as findings regarding the positive benefits to students without disabilities. There was also evidence of the benefits of co-teaching, i.e., collaborative teaching by a general educator and special educator with a heterogeneous group of special and general education students. Examples of positive changes were reported by school districts in California, Florida, Georgia, Indiana, Maryland, Michigan and Texas. For example, the Brevard County School District in Florida reported:

> We have seen a lot of caring and acceptance from the regular education students toward our more challenged students. They are very protective and understanding of them. The special needs students are growing tremendously. There are [students with emotional handicaps] that are excited by learning. The parents of our [students with Down Syndrome] and [students with autism] report a tremendous growth in vocabulary and communication. Students that came from a self-contained setting and exhibited a lot of anxiety about the regular classroom appear to be relaxed and comfortable with their new placement.

In summary, the research and evaluation data on inclusion indicate a strong trend toward improved student outcomes (academic, behavior, and social) for both special and general education students. As summarized from a report on inclusive education in Michigan, "When one contrasts such indications with the fact that there appears to be little, if any, evidence in research to support superior student outcomes as a result of placement in segregated settings, one must seriously question the efficacy of spending ever-increasing sums of money to maintain a dual system" (Michigan Department of Education, 1993).
Adapted from Lipsky and Gartner, 1995.

Over the past 20 years, IDEA and its predecessors have brought educational opportunities to tens of millions of students with disabilities who have received special education and related services. Currently, over five million children and youth with disabilities are receiving special education, including approximately 534,000 with mental retardation (11.5% of special education students age 6 - 21). The increases in the number of children is shown in Table 4.

Overall, there has been an increase in the number and portion of students being educated in less segregated settings. Between the 1977-78 and 1989-90 school years, for example, the portion of students with disabilities in general education public schools increased 0.5% overall, and 17% for children with orthopedic impairments. At the same time, the portion of students with mental retardation in general education public schools declined 1.5% during that period, as did the portion of students with multiple disabilities in general education public schools, which declined 5.9% (NCSL, undated).

Table 4
Students Served Under IDEA Part B and Related
Chapter 1 State Operated Programs

School Year	Total Served	Change in Total Number Served from Previous Year (%)
1976-77	3,708,588	-
1977-78	3,777,286	1.8
1978-79	3,919,073	3.8
1979-80	4,036,219	3.0
1980-81	4,177,689	3.5
1981-82	4,233,282	1.3
1982-83	4,298,327	1.5
1983-84	4,341,399	1.0
1984-85	4,363,031	0.5
1985-86	4,370,244	0.2
1986-87	4,421,601	1.2
1987-88	4,485,702	1.4
1988-89	4,568,063	1.8
1989-90	4,675,619	2.4
1990-91	4,807,441	2.8
1991-92	4,986,075	3.7
1992-93	5,170,242	3.7

Source: *Sixteenth Annual Report to Congress (U.S.* Dept. of Education, 1994).

Similarly, data available from the Department of Education on more recent trends reflects gains in inclusion for the overall population of students with disabilities from the 1998-89 school year to the 1991-1992 school year (most recent data available at the national level). As illustrated in Table 5:

- More children with disabilities are in regular classes.
- Slightly fewer children with disabilities are in separate classes and facilities.

Although there are major differences among the States, even the States with the lowest rates of inclusion are improving. The lowest percentage of students with disabilities in regular classes among the States rose from 1.08% in the 1988-89 school year to 6.23% in 1991-92, while the top inclusion percentage in regular classes rose from 79.37% to 87.41%.

Table 5

Portion of Special Education Students by Setting (%)

	All Disabilities		MR		Orth. Impmt.		Mult. Dis.	
Setting	88-89	91-92	88-89	91-92	88-89	91-92	88-89	91-92
Regular Class	30.50	34.90	5.91	5.04	29.23	32.39	7.05	6.20
Resource Room	38.99	34.90	22.42	25.44	18.58	21.00	14.03	18.05
Separate Class	24.27	23.52	58.89	59.20	33.46	34.35	46.20	47.11
Separate Facility	6.24	5.28	12.78	10.32	18.73	12.26	32.72	28.64

Source: *Thirteenth Annual Report to Congress (U.S.* Dept. of Education, *1991),* for the *1988-89* school year, and *Sixteenth Annual Report to Congress (U.S.* Dept. of Education, *1994),* for the *1991-92 school* year.

As illustrated in Table 5, however, recent gains in inclusion have been less for students with mental retardation than for students with disabilities in general. There have also been minimal gains for special education students with orthopedic impairments, and for students categorized as having multiple disabilities. Because IDEA serves many students whose disabilities may be mild (e.g., some students with specific learning disabilities-51.1 % of the total, and some with speech or language impairment 21.6 % of all special education students), the overall statistics on inclusion can be misleading regarding the inclusion of students with more significant disabilities.

At the same time, there are also great variations across the States in the inclusion of students with mental retardation, orthopedic impairments, and multiple disabilities. For example, students with mental retardation in regular classes ranged from 0.09% to 59.40% in the 1988-90 school year, and from 0.25% to 70.45% in the 1991-92 school year (U.S. Dept. of Education, 1991 and U.S. Dept. of Education, 1994, respectively). Although the general trend toward inclusion is apparent, it is also clear that there are only minimal opportunities for inclusive education in some States.

There are also significant differences among the States in the portion of students designated in special education, the portion of students within specific diagnostic categories used in the special education system, and the age range of mandatory special education availability.

Promoting Inclusive Education

The National Council on Disability and others have identified several strategies to make inclusive education work. In its report *Inclusionary Education for Students with Disabilities: Keeping the Promise* (NCD, 1994), the NCD described strategies at the local, State and Federal levels, beginning with a school district's vision that "all students are welcomed and valued learners in the schools and classes they would attend if not identified as disabled." Other strategies may be summarized as follows:

- Focus on the whole school.
- Changes in the curriculum, in particular a unitary (regular and special education) curriculum, with modifications made as needed on an individual basis.
- Grading policy changes.
- Instructional change, such as whole language and literature techniques, hands-on instruction, active rather than passive learning, multi-cultural content and processes, increased sensitivity in the approach to learners, more thematic/integrated curriculum, more in-depth instruction, more cooperative learning, and more opportunities to learn in the community.
- Creative use of resource and personnel, such pairs of regular and special education teachers sharing equally in the planning, instruction and student evaluation, and moving both consultative and direct related services into the regular education activities.
- Collaborative planning teams.
- Addressing the need for changes in relationships across all school personnel, and between the school and parents.
- Training and staff development.
- Time for team-building, planning, creating and training.
- Peer preparation on an as needed basis.
- Opportunities to celebrate accomplishments.

Anne's Story

Anne was the first student with severe mental and physical disabilities to be fully included in her neighborhood kindergarten and first grade class in the Mounds View School District [Shoreview, MN]...During the first three years of her life Anne received therapy and other programming services through the [area specialized early intervention center]. After she turned three, new legislation went into effect that required local school districts to provide programming for children with disabilities. Our school district contracted with Special District 916 to provide services to Anne at a segregated site. Although we were pleased with the programming that Anne was receiving, we found the segregated site lacking in many ways. Since none of the children in Anne's classroom talked or were ambulatory, the only verbal communication and role models for her were her teacher.

Her life was without playmates or friends. Since her pre-school experience was outside of the neighborhood setting, she did not have opportunities to make friends with other children in her neighborhood. We decided we wanted more for Anne when she entered kindergarten and elementary school. This decision began a process that spanned over one year to convince Mounds View School District officials to provide services for Anne in her neighborhood school. The process of expressing our vision for Anne resulted in a very positive team approach to beginning an inclusive education project in our district.

Anne began kindergarten and then first grade by riding to school on the same bus as her classmates and joining them full time in the regular classroom. Our pain watching the isolation of Anne's life changed to the excitement of seeing her surrounded by other children who were drawn to her uniqueness and enjoyed her friendship.

How is the integrated learning process working out in the classroom? It is benefiting all the children. For instance, since Anne uses sign language to communicate, there has been great interest from her classmates to not only learn her signs but sign language in general. Students often come up to Anne and show her the new signs they have learned. Students also have been actively involved in adapting Anne's environment to fit her needs. One day in art class Anne was having difficulty gluing paper together. A classmate came up with the idea of using a paintbrush to apply the glue. In addition, Anne's classmates have really learned the art of patience as well as tolerance. They not only wait for Anne to respond rather than answer for her, but appear to be more tolerant to the differences of other peers in class. Very seldom are negative things said about other people in the class. Along with the interaction with her peers at school, we have been pleasantly surprised to find that Anne has new friendships outside of school. She has been invited to the birthday parties of her friends, boys and girls alike. When we attend school or community functions, children come over to say hello to Anne and to introduce her to their families.

We have been amazed to see the many changes taking place in Anne. She has become more interested in communicating her needs, both verbally and with sign language. She is also more motivated to be upright and to learn to walk. We believe this increased motivation is due largely to the role models of her peers and her desire to interact with them.

These experiences have certainly convinced us of the value and naturalness of integrated programming. It is a constant challenge to facilitate this learning process and we are thankful for the enthusiasm and dedication of the professionals who have been part of Anne's team. Most of all we are very proud of Anne who plays the key role in all of these efforts. Her [ten year old] sister Marlo wrote about Anne in a way that sums up all of our sentiments: "I am thankful for my sister. I think that if my sister was not handicapped, I wouldn't be half the person I am. My parents have helped me learn more about disabilities. My sister gets into my stuff like any first grader would."

Another major strategy area is financing. The National Council on Disability found that "Most current State funding systems create barriers to inclusion by financially rewarding school districts for segregated placements" (NCD, 1994). The NCD identified Pennsylvania's approach to questions about the affordability of inclusive education. Pennsylvania uses a flat-rate allocation of dollars to districts for the education of children with disabilities, removing incentives for districts to keep students in expensive, segregated placements. As described by Dr. Douglas Kane in the NCD report (NCD, 1994):

> The Pennsylvania system basically says that we assume that 17% of the students in the school district require some kind of extra help. We assume that 1 % of the students in the district require a lot of extra help. So, we're going to give you an extra $525 for 17% of your kids; we're going to give you $7,000 for 1% of your kids. Go and do a good job. Then we also have a special fund set aside for those who really need a lot of extra help and we're going to deal with those on an individual basis.

Dr. Kane also applied the Pennsylvania funding strategy in a simulated examination of special education costs in another large State, finding that if they had used the Pennsylvania formula, State special education costs would have been almost cut in half, from $529,343,080 to $292,100,100 (NCD, 1994).

Some States also have made strides in addressing cultural diversity within special education, including efforts to avoid over-representation of cultural minority students or mis-categorizing of children and youth due to cultural differences. In Alaska, school districts have relatively low special education child counts, despite a large portion of the total student population from mixed or non-English speaking homes. The regular education program accommodates a wide range of student diversity, and disability identification proceedings respect that students' cultures, languages and life experiences are different from those assumed by Anglo-based traditional measures and procedures (NCD, 1995).

There are many organizations, programs and written resources on inclusive education. The Federal Office of Special Education Programs includes a research center on inclusive education. Statewide Systems Change projects on inclusion have been funded since 1987. The center also funds research projects that identify educational and environmental characteristics associated with effective inclusive education, and outreach projects that help States expand their capabilities to bring inclusive education to more children with disabilities. Annual Reports to Congress provide information on national and State special education statistics, including the age and number of children with mental retardation and other diagnostic categories receiving special education services and the educational settings where they are receiving services.

The National Center on Educational Restructuring and Inclusion is a major resource on programs, practices, evaluation and funding. Its goal is to promote and support educational programs where all students (i.e., both those with and without disabilities) are served effectively in inclusive settings.

Additional resources targeted to parents include the National Parent Network on Disabilities, Fiesta Educativa for Latino parents, the PACER Center and Schools Are For Everyone (SAFE).

Vermont's Efforts in Inclusive Education

Vermont has been recognized repeatedly for its strong record in inclusive education. A statewide plan for inclusion has been in place for a number of years. Approximately 85% of children with developmental disabilities are educated in regular classrooms. To help integrate the children who still remain in segregated settings, the Center for Developmental Disabilities at the University of Vermont has developed a number of programs, in collaboration with the State Department of Education:

- *The "I" Team.* Teams of specialists help the students with the most severe handicaps across the State to be educated in regular schools. The State is divided into five regions. Each has a regional education specialist, a part-time paid support parent, and an occupational or physical therapist. In addition, a core team, based at the Center for Developmental Disabilities, covers the State as needed. Assistance may be requested by the regional specialist, the educator, or parents.
- *The Homecoming Model.* This collaborative, statewide approach relies on teams to develop the support services needed to transfer students from regional special education regular and special educators comprise the team.
- *Project Wrap-Around.* This program provides intensive home- and school-based support services to families who have children at home who are at risk of being placed in an alternative residence. The program "wraps" services around the child, providing whatever is necessary to keep the child in the home and in an integrated educational setting. For example, a coordinator may provide from five to 30 hours a week of training to help parents care for their children. Other support includes respite services, support groups, marriage counseling, and substance abuse counseling-anything necessary to relieve the stress caused by caring for a child with a severe disability in the home. The school-based training includes child counseling.

Source:*What Legislators Need to Know About Mental Retardation and Developmental Disabilities* (Wright, 1990).

TRANSITION

The transition from school to the world of work and adult responsibilities is critical for all young people, and especially so for youth with mental retardation and other disabilities. Most of the opportunities associated with inclusion as adults builds on the preparation for community living and involvement, citizenship and employment that take place through the educational experience, and the transition experience in particular.

Fred's Story

Fred was born with developmental disabilities, and was in special education classes during his school years as well as some mainstream and vocational classes. His transition planning began in earnest about two years before he was to leave high school. By that time Fred had a county Developmental Disability Social Worker and a Counselor from the State Division of Rehabilitation Services (DRS). He spent part of each school day at the Secondary Technical Center of the County Technical College, working on vocational skills. The local high schools in the county bus students to the technical college for "shifts" of vocational programs. Fred received training in the Food Industry Careers program where students learn food preparation, busing, dishwashing and cleaning skills. This program provided the background for Fred's next vocational step-the McJobs Training Program.

Fred had long envied people who worked at McDonald's, his favorite eating establishment. When he was given the opportunity to go through the McJobs Training Program, a structured eight-week program for persons with special needs, he jumped at the chance. He couldn't have been prouder when he got his uniform, especially the baseball-type cap. Since he was still in school, the training was jointly funded by DRS and the State Vocational Education-Special Needs program; Fred's local high school provided transportation because this program was on Fred's [Individual Education Plan].

There were some ups and downs, but Fred made steady progress and completed his training goals. He was hired as a regular employee at McDonald's. After a few months, the manager suggested that with training on more job stations, Fred could work more hours. The McJobs job coach spent an additional two weeks at the store to provide the additional training. Fred is now working 32 hours a week at his "dream" job.

Fred's foster mother described her pride in his accomplishments, his hard work and the opportunities McDonald's has given him. She remembered that "When we got Fred, we were told that he [had severe and profound mental retardation] and would never walk, talk, or do anything. And now here is supporting himself, and he loves his job. He's a real success story!"

Adapted from Impact 5(3), Fall 1992.

The NCSL's Task Force on Developmental Disabilities placed particular emphasis on transition planning in its *Americans with Developmental Disabilities: Policy Directions for the States* (Wright et al., 1991). It describes transition planning as "a partnership involving students with disabilities, their families, school and post-school service personnel, local community representatives, employers, and neighbors." Although community employment is one outcome of effective transition planning, others include ensuring that students with disabilities graduate with the community living and other functional skills needed for adulthood.

Approximately 40,000 students with developmental disabilities exit special education programs each year. In addition to an individualized transition plan, specific mechanisms need to be in place to link individuals to community services and supports appropriate for adults. Unfortunately, far too many young adults move from the special education system, where educational and related services are required, to unemployment, idleness, lack of supports, and long waiting lists for adult services.

IDEA requires that each student have an Individual Education Plan (IEP), and that the plan address transition for all special education students by age 16, and for others as early as age 14, as appropriate. In addition, IDEA now mandates that specific transition services be provided to these students, with an emphasis on coordinated activities.

Some States and local school districts developed transition initiatives even prior to the Federal requirements. Suggested strategies for effective transition from these experiences include:

- Keeping students in some type of educational setting.
- Improving competence in basic skills.
- Improving competence in the vocational and community living skills needed for success in adult life.
- Developing a transition plan with long term goals.
- Building self awareness, self determination and self-advocacy skills.
- Building post-school support need to meet goals (Thompson, 1992).

Minnesota passed legislation in 1986 requiring a transition initiative and creating a state-funded Interagency Office on Transition Services in the Department of Education. The office staffs the State Transition Interagency Committee (STIC), which sets policy and facilitates coordination among local and state agencies. STIC includes representatives from the Departments of Education, Human Services, and Jobs and Training; the community colleges; and parent/advocacy groups. The legislation also requires that each student's IEP must address transition needs by grade nine or age 14.

Teresa's story

Last year, Teresa graduated from her local high school. She had received special education *and* related *support* services since elementary *school.* At age *13,* Teresa started participating in school-sponsored training activities in the community with her teacher and a small group of other students. She learned to shop at a grocery store, take a bus, and order from fast-food restaurants. When she reached age 14, Teresa spent at least two hours during each school day in community-based job training. In school, she had trained in occupations such as food service, domestic home cleaning, and clerical and custodial assistance. When she was ready to leave school, Teresa knew she wanted to be a clerical worker. She already knew how to run a copy machine and felt confident that she could do the job. The transition program was able to match her with an employer, and she moved directly from school to an office job. Now Teresa works 20 hours a week and takes the bus to work, a 30-minute ride. "I'm so glad she was able to get a job so she won't forget all the things she learned in school," says her mother. "It's amazing, really, what she can do. I'm proud of her, but more importantly, she's proud of herself."

Source: Americans with Developmental Disabilities: Policy Directions for the States (Wright et al., 1991).

In 1991, Minnesota was awarded a five-year statewide Systems Change grant by the U.S. Department of Education, to improve transition services for youth with disabilities. The project's focus includes collaboration with youth and their families as primary partners, with an integral part in planning and decision-making. Community Transition Interagency Committees have been formed, to promote collaborative transition efforts at the local level. Project activities include:

- State-level policy development and planning, including community forums and other activities to obtain broad input.
- Consumer and family participation in the transition planning process. Professional development and training.
- Demonstration projects and related technical assistance to Community Transition Interagency Committees.
- Information exchange, including a quarterly newsletter, *What's Working in Transition.*

In the early 1990s, Maine developed an innovative voucher system to fund transition services for individuals with mental retardation between the ages of 20 and 26 who were exiting the public school system and living at home. Up to $12,000 per year, paid for by the State's Bureau of Mental Retardation, was available for services such as evaluation, job placement, counseling and follow-up, job coaching, supported employment, transportation, respite care, recreational and leisure activities, and post-secondary education. The services must be defined in an individually-designed transition program, and must not be available through other funding sources.

"Suggestions for legislators" on transition are provided in the NCSL's *Americans with Developmental Disabilities: Policy Directions for the States* (Wright et al., 1991). Additional information on effective transition is available from the National Transition Implementation Institute (NTII), funded by the U.S. Department of Education. The NTII is a collaborative venture of the Institute on Community Integration of the University of Minnesota, the University of Vermont, Colorado State University, University of Illinois at UrbanaChampaign, and the University of Arkansas, as well as a national network of Regional Resource Centers, various Federal and State agencies, and consumer, advocacy and education organizations. The NTII is assisting Minnesota and other systems change grantees in improving their State transition policies and services. The feature issue of

Impact (5(3) Fall 1992) on transition summarizing the Minnesota systems change project described above also lists resources on transition.

EMPLOYMENT

It has long been recognized that having a job contributes to a person's self esteem and how society defines an individual's worth. People with disabilities are the most unemployed and under-employed group of Americans. A recent Harris poll found that 69% of working-age individuals with disabilities are unemployed, despite the fact that most people with disabilities want to work and to be as economically self-sufficient as possible. With appropriate training, job opportunities and supports, people with mental retardation and other disabilities are often model employees, miss fewer work days than other employees, and have less turnover.

Traditional employment and adult services for people with mental retardation were based on a continuum model. Individuals were placed in adult day activity centers and sheltered workshops, with the idea that they would progress from adult activity to sheltered employment and on to community employment, with sufficient training. For most people, however, the activity center or sheltered workshop became the permanent "job placement."

More recently, supported employment has emerged as a new approach to moving people into jobs in regular settings. Supported employment looks at individual skills, interests and aptitudes, and matches them with an appropriate job. A job coach works closely with the individual, the employer and others who are part of the person's life to help get the employment experience off to a good start. Supports provided by the job coach and others, including co-workers, include training in the work to be performed, worksite or job modifications, assistive technology, and counseling. The job coach also supports the employer, supervisors and co-workers, to solve problems that may arise. Especially if the person has severe disabilities, the job coach may work side-by-side for an extended period before cutting back on the hands-on support. Gradually, however, the job coach is less involved as the supported employee gains in skills and confidence.

Mike's Story

Mike is a 34-year-old data entry clerk with a county personnel board in Alabama. An employment specialist helped Mike assess his personal interests and vocational skills and find his current position. Because he has severe disabilities as a result of cerebral palsy, Mike benefits from several assistive technology devices to perform the demands of his job and to live independently. At work, Mike uses a modular work station system and an augmentative communication device that generates printed speech through a computer. Using a head pointer, Mike can type, operate a computer, dial a telephone, turn pages, and operate his television, VCR, microwave oven, and other home appliances. For mobility, he either pushes a manual wheelchair with one foot or uses a power wheelchair which he operates with his chin and mouth.

Mike's lifestyle today is dramatically different from his 15 years in a nursing home, which he entered at age 15 because he felt that he overburdened his mother. He needed assistance with mobility, feeding, dressing, bathing, toileting and other daily activities. The nursing home was the only place considered appropriate within the service system for Mike during those years. Fortunately, he was able to relocate to a transition living center, where he took classes in personal and community living skills, personal care attendant hiring, and basic computer skills. Since his employment, Mike has moved to his own apartment and uses part of his wages, supplemented with State and Federal benefits, to pay for his personal attendant.

Adapted from *Americans with Developmental Disabilities: Policy Directions for the States* **(Wright et al., 1991).**

Katherine's Story

Katherine describes herself as 25 years old, living in a group home, and having mental retardation. She has worked at Wendy's as a dining room attendant/hostess for 2 1/2 years, where she has been Employee of the Month. She and her job coach looked for a job she would be interested in, explained the supported employment program to the people at Wendy's, and helped Katherine learn how to do her work. As Katherine explains, "She stayed with me and did the job along beside me. Little by little, as I learned how to do the job myself, she would step aside and watch me and make. sure I knew how to do it. Finally, I could do the job all by myself, so she left. She hasn't left me by myself though. She comes back every so often for my evaluation. If Wendy's feels I need to add more to my list of jobs, she will help train me to learn how to do it."

Katherine works four hours a day, five days a week. She is using her earnings to pay rent, groceries, bills, clothing and gifts for others. She saved enough to buy her own bedroom furniture, a TV and stereo/CD/tape player. Her enthusiasm for her job is contagious:
I love my job coach! She gives me life! If I didn't have my job coach, I wouldn't have found work. I wouldn't have been so well trained, and Wendy's wouldn't have such a great hostess. I would still be at home. I wouldn't have my own money. I wouldn't have my friends at Wendy's. I wouldn't have a place to go and help out every day. Wendy's needs me! I'm a valuable person to them! The customers love me and are like family to me.

Katherine's mother also is enthusiastic about her daughter's job and the positive changes in her life. When Katherine finished her high school at age 22, she had a diploma but no job skills and no job opportunities. She was at home, mostly watching television, with no challenges or projects and no money of her own. In combination with a move to a group home, Katherine began working with the job coach who helped her find and get the job at Wendy's. Her mother's pride mirrors Katherine's:

Katherine loves her job. She has a purpose. She has a reason to get up each day. She has a place to go. She has people who need her. She earns her own money and uses it to support herself. She takes great pride in that ... and so do I. She likes being like her older brothers and sisters-working, living on her own.

Source: Conversion: The Time is NOW! (RRTCNCU, 1994).

At the Federal level, there is policy to support increased opportunities for employment. The Rehabilitation Act provides grants to States for supported employment services, and places special emphasis on serving persons with severe disabilities. The Americans with Disabilities Act (ADA) prohibits job discrimination on the basis of disability, and requires reasonable accommodations for employees with disabilities. A recent study found that job opportunities and income levels had increased significantly for some people with mental retardation since the passage of ADA. Average monthly income rose from $63 per month in 1990 to $387.50 per month in 1993, above the inflation rate. Not surprisingly, increased earnings were associated with greater independence and life satisfaction (Blanck, 1995, summarized in News and Notes 8(2), March/April 1995). Work incentive programs administered by the Social Security Administration make it possible for people receiving disability benefits-Supplemental Security Income (SSI) and Social Security Disability Income (SSDI)

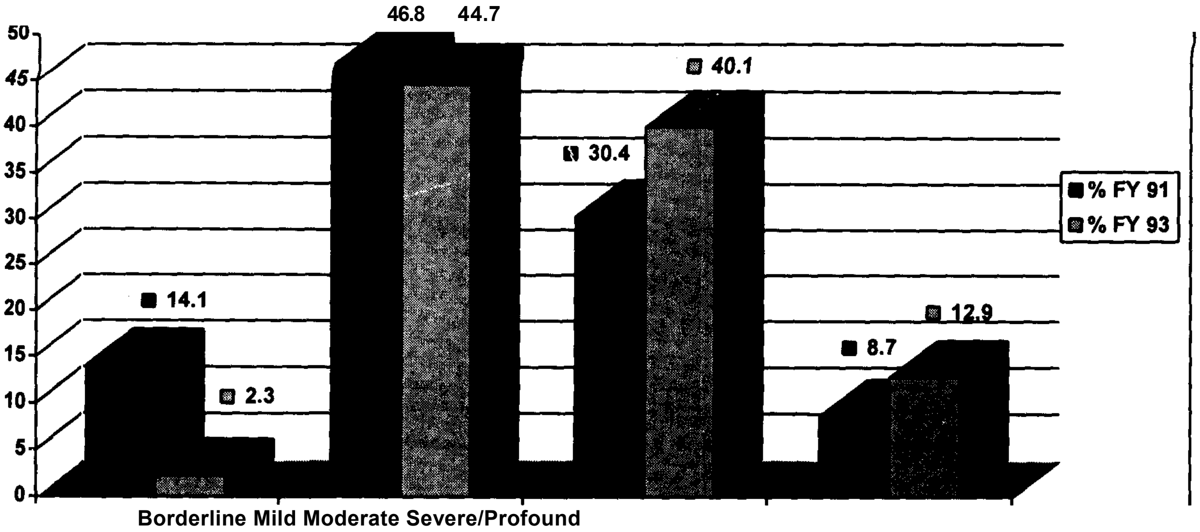
-to transition gradually into employment without losing the safety net of income support and related eligibility to Medicaid (SSI recipients) or Medicare (SSDI beneficiaries).

PCMR has charted the unemployment of individuals with mental retardation since its beginning. In its 1967 Report to the President, PCMR estimated that the potential annual earnings lost because of unnecessary unemployment among people with mental retardation ran into the billions of dollars. In 1983, the PCMR report noted that hundreds of thousands of employable people with mental retardation were unemployed because of misconceptions and low expectations. Although there have been some advances, the 1994 PCMR report indicates that unemployment rates among adults with mental retardation exceed 70%; 70% of persons served in day and employment programs are served in segregated programs; and 80 cents of every State dollar and 90 cents of every Federal dollar continue to support segregated rehabilitation and employment services (PCMR, 1994b).

Trends

Supported employment has grown rapidly over the past decade. Data compiled by the Rehabilitation Research and Training Center on Supported Employment at Virginia Commonwealth University (RRTCNCU) indicate that supported employment has grown nationally from under 10,000 participants in 1986 to 105,380 participants in 1993. People with mental retardation continue to be the primary consumers of supported employment services-approximately 70% of the total. Although most of these individuals are people with mild or moderate mental retardation, there has been an increase in the portion with mental retardation at the severe or profound level, rising to nearly 13% of supported employees with mental retardation in 1993 (RRTC/VCU, 1995).
Figure 7

Supported Employees with Mental Retardation as Their Primary Disability: FY 91 vs FY 93



Source: Prelimininary Comparison of National Supported Employment Data for Fiscal Years 1991-1993 (RTCNCU, 1095).

An earlier survey, conducted by the Training and Research Institute for People with Disabilities at the Children's Hospital in Boston, compared findings from agencies in 20 States for 1986 and 1991, as well as projections for the future. As shown in Table 6, the portion of individuals in competitive employment and supported employment increased significantly from 1986 to 1991, while the portion in facility-based work declined. The researchers noted, however, that the <u>number</u> of individuals in facility-based work increased, commenting that "we appear to be adding integrated employment as a service component rather than replacing segregated services with integrated ones" (McGaughey, 1993). It was also noted that the portion of individuals with mental retardation and other developmental disabilities in competitive and supported employment is lower than in the facility-based work supported by the agencies in the survey. Overall, however, the agencies planned major increases in the numbers served in integrated employment, and a slight decrease in those receiving facility-based employment services (McGaughey,1993).

Although the majority of State resources continue to support segregated employment and adult services, there has been a significant increase in expenditures for supported employment services by State developmental disabilities agencies. These agencies typically finance the long term supported employment services for individuals with mental retardation, while funds for the initial period (up to 18 months) may come from the State vocational rehabilitation agency.

Based on data from 42 States, growth in supported employment spending by State developmental disabilities agencies grew more than threefold from 1988 to 1992, rising from $62 million to $220 million. Similarly, the number of individuals being supported rose from approximately 14,000 in 1988 to 58,000 in 1992 (Braddock et al., 1995). There were also substantial differences among States regarding the level of expenditures, with large programs funded by developmental disabilities agencies in 16 States accounting for about 75% of the supported employment resources (Braddock et al., 1995).

There also has been considerable growth in the use of Social Security work incentives among SSI and SSDI beneficiaries with disabilities. At the same time, these programs are reaching a relatively small portion of individuals receiving disability benefits. There are also significant differences among the States regarding the extent to which work incentives are being used. The 1619 work incentive program helps SSI recipients with mental retardation and other disabilities to retain a portion of their SSI benefits (1619(a)) and to stay eligible for Medicaid even if their earnings exceed what is allowable to continue receiving a cash benefit (1619(b)). As of June 1988, there was a total of 32,556 participants in the 1619 program. This had risen to 69,087 by June 1995 (SSA, 1995).

Table 6 Changes in Employment Services: 1986 -1991

Type of Employment	1991 Survey Mean	1986 Survey Mean
Competitive Employment		
- Percentage of agencies offering	**70%**	**67%**
- Percentage of consumers in competitive employment	**18%**	**16%**
Supported Employment		
- Percentage of agencies offering	**90%**	**42%**
- Percentage of consumers in supported employment	**29%**	**7%**
Facility-based Work		
- Percentage of agencies offering	**90%**	**90%**
- Percentage of consumers in facility-based work	**51%**	**77%**

Source: "National Trends in Day and Employment Services" (McGaughey, 1993).

There are major differences across the States in the rate of 1619 participation among SSI recipients. Some States (for example, Texas) have enacted legislation mandating relevant service agencies to provide access to information on work incentives. Data provided by the Social Security Administration in the *Quarterly Report on SSI Disabled Workers and Work Incentive Programs* includes information on each State's level of participation. These data should be reviewed in relation to the State's profile of SSI recipient demographics, including the portion who are working age, the availability of State Supplementation Payments (SSP), and the interaction between SSI and SSDI benefits.

For the most part, however, there are very few States which could not increase the 1619 program participation rates of adults with mental retardation.

Making Community Employment Work

The Washington Division of Developmental Disabilities has encouraged its county service systems to develop job programs in community employment settings with opportunities for inclusion. As of 1991, 1,400 of the 3,440 people receiving vocational program services were in supported employment. The initiative was supported by a grant from OSERS, with long range goals of changing the way unions and businesses think about people with disabilities, and of looking beyond entry-level and high turnover to greater opportunities for better-paying and more challenging jobs.

An OSERS systems change grant in Maryland 1985-1990 led to conversion of approximately 50% of day program positions to supported employment. Maryland coupled project activities with a policy of targeting 85% of all expansion money to supported employment. As the program entered its fifth year, approximately 1,100 people with disabilities had supported jobs with 268 employers, including Marriott Hotels, Pizza Hut, Radio Shack, J.C. Penney, Red Lobster, and Ramada Inns. Earnings averaged $3.68 per hour, with supported employees working an average of 29.7 hours per month (Wright et al., 1991).

In West Virginia the Developmental Disabilities Planning Council funded Community Access, Inc., a supported employment agency that places people with severe disabilities in jobs in the community. Placements during the first year included a full-time position in the State Department of Highways, one in an auto parts store, and several other non-traditional jobs. The Council also funded two projects to convert facility-based work programs to community employment, providing day program staff with extensive training in supported employment and personal futures planning to help tailor employment options to individual interests and strengths. In addition, the program includes opportunities for volunteer work, with individuals now volunteering at the Salvation Army, a nursing home, and a VA hospital (Zierman, 1995).

The Wood County Board of Mental Retardation/Developmental Disabilities in Bowling Green, Ohio, provides comprehensive services to individuals with developmental disabilities. In 1985 the Board began Wood Lane, a community employment services program, to provide an alternative to sheltered workshops. Services include a career development group, occupational work sampling, work evaluation, short term transition sites, a mobile work crew, work enclaves in community job settings, job development, training, habilitation services, case management, psychological services, follow-along services, and employee support options. The program is funded by a variety of Federal, State and local sources, including education Chapter 1 funds for student transition training, the State vocational rehabilitation agency, ,and the Private Industry Council. Most of the individuals have been placed in individual placements and are working with coworkers without disabilities, allowing them to use the natural supports of the employment setting.

Terri's Story

When Terri was 17 years old, she was having difficulty finding services to meet her needs. She had no previous vocational experience, limited verbal communication skills, autistic-like behaviors, and did not like being in school. She was referred to Wood Lane for job exposure opportunities.

The support plan for Terri was to expand her repertoire of work skills and appropriate behaviors slowly by demanding slightly more of her at each successive job site. Through a series of five transitional work experiences, Terri continued to make great strides. Work became the focal point of her day. She proved herself to be a competent worker as well as increasing her personal living skills. She also learned to use an electronic communication device with the help of her job coach.

Now Terri is 21, and has recently celebrated her one year anniversary as a sorter for a local mail service. She has learned to pack her lunch, use public transportation, and even to adjust her routine at home to meet fluctuations in her work schedule. Her goal now is to maintain employment and to move into a more independent living arrangement.
Adapted from Fulk and Slusser, 1993.

The Rehabilitation Research and Training Center at Virginia Commonwealth University focuses on supported employment. In surveying States regarding their move to supported employment and the conversion of segregated (sheltered) employment to supported community employment, researchers identified three States with above average percentages of conversion: Michigan (42.7%), New Hampshire (27.5%), and Vermont (32.6%). Through discussions with representatives in these States, they identified characteristics which seem to promote successful expansion and conversion to supported employment:

- Demonstrated commitment to the value of community integrated employment, regardless of the degree and type of disability. States are demonstrating commitment through incentive grants for conversion, through funding strategies that reimburse fairly for services and allow for resources to follow the individual.
- Leadership demonstrated by a continuing investment in building consensus around the importance of community integrated employment services among direct service staff, board members, and consumers.
- Cooperation, including close State/local cooperation in using resources such as the Medicaid Home and Community Based Services (HCBS) waiver.

The VCU Center also reported on information from Florida on their use of the Medicaid HCBS waiver to expand supported employment. Florida's policy of appropriating funds specifically for supported employment and performance objectives for conversion ran into problems when State

Developmental Services funds were reduced. Supported employment was not included as a billable service under the State's existing HCBS waiver, further reducing resources available. A new expanded HCBS waiver has been approved, however, which focuses on independent support coordination, with waiver funds now following the individual. This means that when people leave a facility-based work program, the dollars go with them to supported employment. Implementation of the new approach broadens the concept of conversion to include a variety of transition activities, including start-up funding, flexible requirements for using current funding during transition, relaxing of monitoring standards during transition, and targeted development funds or incentives (Allen, 1994).

Resources

There are a wide array of resources that can help States and agencies to enhance community employment opportunities for individuals with mental retardation. The Fall 1993 issue of Impact listed several organizational and print resources, including the President's Committee on Employment of People with Disabilities Information Line: (800) 232-9675 and (202) 376-6205, for TDD. The PCEPD also sponsors the Job Accommodations Network (JAN), a resource to employers and employment service programs on how reasonable accommodations can be made to enable people with disabilities to work in competitive employment. State Developmental Disabilities Councils also add a resource in promoting community employment.

Information on reasonable accommodations also is part of the technical assistance available through the Disability Business Technical Assistance Centers (DBTACs) in each Federal region. The DBTACs receive Federal grants to promote compliance with the Americans with Disabilities Act through education and technical assistance to the business community and to individuals with disabilities. The RRTC at Virginia Commonwealth University was funded in October 1993 for a third, fiveyear period by the National Institute on Disability and Rehabilitation Research to provide research, training and leadership on supported employment for individuals with the most severe disabilities.

Resources on Social Security work incentive programs have been developed in several States, often supported by the State Developmental Disabilities Planning Council. Nationally, a Robert Wood Johnson Foundation project has worked with 12 States on expanding access to work incentives. Considerable resource information on work incentive expansion strategies is available from Allen Jensen at the Intergovernmental Health Policy Project, the George Washington University in Washington, DC. The Social Security Administration also has published information summarizing the features of the various work incentive programs.

INCLUSIVE RECREATION AND COMMUNITY CONNECTIONS

Leisure, recreation, friendships and community connections are as important to people with mental retardation as they are to everyone. An essay on integrated community recreation by Schleien and Rynders (1989) summarized this as follows:

> Leisure and recreation activities are an important part of American life. They promote physical health, social interaction, skills development, and self-esteem. Unfortunately, these activities have historically received relatively low priority in programs for persons with developmental disabilities. This long-standing neglect is distressing because appropriate participation in leisure/recreation activities is associated with development of collateral skills important in daily life, such as independent living and work skills. The possession of these skills can play an important role in the successful community adjustment of individuals with disabilities.
>
> Individuals with disabilities often form negative self-concepts and low expectations for themselves as a results of society's devaluation of their contributions ... Participation in community based integrated leisure/recreation activities offers a natural setting for overcoming these problems through fostering competence, autonomy, and confidence, as well as improved social interactions with peers who do not have disabilities...
>
> [Innovative leisure/recreation] programs provide evidence that individuals with disabilities not only benefit greatly from community recreation, but also that their presence in integrated programs makes an important contribution to the experiences of participants who do not have disabilities. It's through integrated leisure/recreation activities that many of the ideals implied by the concepts of normalization and least restrictive environment can be realized (Schleien and Rynders, 1989).

Although opportunities for community leisure and recreation seem to be increasing, especially for children in inclusive education, many people with mental retardation and other developmental disabilities express a need for these activities and for the connections they bring. Findings from the person-to-person National Consumer Survey of people with developmental disabilities include:

- 55% of individuals (all ages) expressed a need for recreation and leisure services and supports.
- Less participation in ordinary community living activities such as going to a food store or supermarket and going to the movies than people with less severe disabilities.
- Adults much more apt to feel very lonely or remote from other people than adults in the general public, as well as less likely to have visited or even to know the names of the families living close to them (Jaskulski and Metzler, 1990).

Emily's Story

Emily is a 16-year-old girl with mental retardation. She is vivacious and enjoys socializing tremendously. In June 1990, she joined a Girl Scout troop that meets near her home. Before her first meeting, she had already read the entire handbook and identified the badges she wanted to earn. Within two months, she earned two badges: pet care and toddler tending.

When Emily's enthusiasm and sometimes unpredictable behavior disconcerted some of the other Scouts, the troop leader tactfully explained about Emily's disability. It relieved the other girls to know that there was a reason for her behavior. She began making friends within the troop and spending time with them outside of Scouting. She also enjoyed numerous troop activities, including writing letters to members of the Armed Services during the Persian Gulf War, selling Girl Scout cookies, and attending a sleepover with other Scouts at the local science museum. She also has been nominated for a national Scouting experience, providing further opportunities to broaden her horizons.

Emily's adventures in Girl Scouting are complemented by her broadening horizons in other activities. She has begun volunteering at a local hospital one afternoon a week where she helps out in the marketing office and delivers beverages to patients. On hospital days Emily is quick to come home from school, get her hospital ID, and get on her way. Her mother is proud of her growing maturity and optimistic about her transition into employment, based on her success in Scouting and volunteer work.
Adapted from Friendships and Community Associations (Reidy, 1993).

Friendships and community connections for people with developmental disabilities go beyond physical integration through living in the community to actually being of the community. No matter how severe their disability, people benefit from having friends who know and care about them as individuals. Like everyone else, people with mental retardation value friendships because of the intimacy and affection, companionship, support and help in feeling important and valued. People with disabilities also indicate that their friendships with nondisabled community members are very important, both directly and indirectly. There is also considerable evidence of positive growth and changes in behavior when people who have difficulty speaking or expressing themselves have a chance to interact with community members (Amado, 1993).

Recreation, friendships and community connections have received increasing attention over the past several years. "Circles of friends" and related efforts to help people with developmental disabilities build and maintain friendships and caring relationships with community members have been developed by numerous service agencies. Special Olympics and other specialized recreational programs have been augmented by expanded opportunities in most communities for some degree of integrated recreation. At the national level, implementation of the ADA is reducing barriers for people with disabilities at Despite these trends, however, much more needs to be retardation are supported in making friends, having private as well as public recreation sites. done to see that people with mental community connections, and enjoying integrated recreation and leisure.

Building Friendships and Community Connections

One of the leaders in the field of friendships and community connections, Angela Novak Amado, recently summarized several projects that have developed effective strategies for helping people with disabilities to meet and form friendships with other community members and to be more fully included in their communities (Amado, 1993). In the Friends Project, for example, 23 individuals with various levels of developmental disability were assisted in having more friendships with persons without disabilities and to be more fully included in their communities. Agency staff working with these individuals were helped to become "community connectors," and agency practices were modified to be more supportive of relationship and community connection building. Each consumer was supported through a "focus group" to design and follow up on individually tailored strategies. Funded by the Minnesota Developmental Disabilities Planning Council, the project also has produced a "how to" manual: *Friends. A Manual for Connecting Persons with Disabilities and Community Members* (Amado et al., 1990). Similar approaches were used in Chicago, IL; Louisville, KY; Powell River, BC (Canada); and various communities in western Massachusetts.

Amado stresses three basic principles associated with the success of these projects:

- Act as if almost anything can happen.
- Start small-one-to-one.
- Plan and implement the program based on a capacity-based view of the individual (Amado, 1993).

The coordinator of the western Massachusetts project also has summarized the experience of successful programs through emphasis on integration into recreational and leisure activities, religious congregations, the development of personal relationships with and without disabilities, and through such routine activities as becoming regular visitors at libraries, bakeries, coffee shops, and other public places (Reidy, 1993).

A neighborhood association in Illinois sponsors a Community Building Project designed to invite community members to include people with disabilities in their everyday lives-to go to church, a ball game, or dinner together. Many people with disabilities spend most of their time with other people with disabilities in programs set up for "them." The Community Building Project tries to change the "them" to "us," recognizing also that people with disabilities have much to offer community life. The project is a commitment to the inclusion of people with disabilities in everyday life within a particular community. People who join a Community Building group develop a relationship with a person with disabilities and help him or her be an active part of the community. The key to community building is making connections and building relationships through family, friends, neighbors, small businesses, places of worship, associations, libraries and clubs. People with developmental disabilities are becoming active members of their communities, assuming responsibilities, and making lasting friendships through the Community Building Project.

In Oregon, Polk Community Living (PCL) provides community-based services to adults with mental retardation and other disabilities. The agency is committed to providing the services necessary for people to become "totally integrated," of which helping people meet and develop relationships with community members is an important part. They have found the following approaches to be effective:

- **Meeting others through common interests**: Staff spend a lot of time learning about each person's interests and using interests as the context for helping people to develop friends and acquaintances.

- **Support to make it happen**: Once activity interests have been determined, staff provide whatever supports are necessary to make them happen. Sometimes this results in an individual's signing up for a class or joining an organization. Some of the best relationships have developed through participation in civic organizations or adult education classes.

- **Supporting established relationships**: Prior to people's receipt of PCL services, the agency tries to learn all about them and the people who are involved in their lives. Once they are in their new community residence, the agency believes it has the responsibility to help the individual maintain these relationships. They follow through on this commitment with resources, including transportation, support to consumers in entertaining family and friends, and letting people know about upcoming events.

- **Using staff as a model**: Staff play one of the biggest roles in the development of friendships. Staff are encouraged to develop personal relationships with the people they support. The agency has found that community members are often afraid of or don't know how to interact with people with developmental disabilities, so staff behavior becomes a model that other community members follow. Some people also have made community connections as a spin-off from relationships with staff. It is not unusual for someone to become acquainted with a staff member's family and friends, and some of these contacts have developed into lasting relationships (Paradigm Systems, Inc., 1992).

Friendships and Community Connections between People with and without Developmental Disabilities (Amado, 1993) presents several descriptions of successes in supporting friendships, connections and other inclusive activities, as well as an extensive bibliography. The *Impact* series from the Institute on Community Integration, University of Minnesota, includes feature issues on integrated leisure and recreation (Volume 2(3), Fall, 1989) and on integrated outdoor education/adventure (Volume 4(4), Winter, 1991-92). Both of these issues include examples of inclusive recreation and resource information. An issue on challenging behavior (Volume 4(1), Spring, 1991) includes information on how relationships and community connections have been effective in reaching and supporting individuals with challenging behavior in ways that greatly increase their inclusion. Organizational resources include TASH, The Association for individuals with Severe Handicaps, and the Arc/US. Both groups have developed resource information on inclusive recreation and leisure activities.

Robert's Story

Learning basketball skills from the other young adults who regularly play at the local community center, going out to dinner, visiting the science museum, and playing soccer are some of the activities that Robert now enjoys. This was not always the case. Because of challenging behaviors, he rarely had the opportunity to engage in integrated social and recreational activities prior to reaching adulthood. As a result, he was rarely exposed to peers without disabilities except for other children in the foster family with whom he had lived since infancy. He had few interests common to young adults his age. He also had minimal communication skills, further isolating him from peers and the community, and likely contributing to his having challenging behaviors.

During his final year of school, Robert participated in a Community Service Training Program. He worked closely with two facilitators whose responsibility was to promote development of the social skills Robert needed to be able to interact with young men his own age.

Working with Robert was difficult at first because of his challenging behavior and his poor communication skills. The facilitators soon found, however, that Robert was attempting to communicate with others and express his preferences in the best manner in which he know how.

As Robert and facilitators got to know each other, his positive responses to people and activities increased. His communication skills improved dramatically and he significantly reduced his challenging behaviors. He interacts with other young adults and engages in a variety of community activities. The communication skills which Robert's teachers thought he couldn't learn are now used everyday. With a combination of oral speech and signing, he initiates and respond to others to indicate his likes and dislikes and becomes involved in more social conversations.

After 18 months, his new social and communication skills allowed Robert to make friends with a group of young adults at his local community center. These experiences have set Robert on a path to initiate social relationships, building a network of others he can rely on. These skills will also help him in supported employment and supported community living in the future.

Adapted from "At Home in the Community," Impact 4(1), Spring 1991.

AGING AND RETIREMENT

People with mental retardation are living longer, along with everyone else who has benefited from improved nutrition and medical care. Although life expectancy continues to be shorter for individuals with severe and profound levels of mental retardation who are non-ambulatory, the vast majority of people with mental retardation now have lifespans nearly the same as individuals without mental retardation (Eyman and Borthwick-Duffy, 1994). Regardless of their choice to retire or to keep on working or participating in daily program activities, they need services and supports that address their move into being "senior citizens."

Jan's Story

Jan is 59 years old. She lived in a large State mental retardation facility from the age of 14 until the age of 55, when she and her best friend wrote the Governor asking for help to move into the community. Now she and her friend share an apartment in a small city near where Jan lived as a child. They get along with support from their case manager and community living support staff, who help them with shopping, cooking and meal planning, money management, and keeping track of the benefits they are entitled to. Jan is not interested in working at this point in her life. She spent two years at a sheltered workshop when she first moved into the community, but requested the opportunity to retire.

Adapted from Jaskulski, 1994b.

General demographic trends in aging, coupled with social trends of adult children living with parents, caring for elderly parents, and single-parent families, are converging with longer lifespans for people with mental retardation. It is increasingly common for family members "to have lifelong rather than time-limited responsibility for a relative with retardation, for caregivers to have more than one family member dependent on them at the same time, and for caregivers to have less marital support" (Seltzer and Krauss, 1994). Recognizing the need for supports as individuals with mental retardation age and involved family members become unable to provide care is an important component in the journey to inclusion, especially for those who have always been included in the family and community.

States and local service systems are providing supports through senior centers and other programs funded by the Older Americans Act, through Medicaid HCBS waivers and Social Services Block Grant programs, and collaboration between mental retardation/developmental disabilities and aging services at the State and community level.

Moving into retirement can be problematic for older adults with mental retardation, especially those who have not worked in competitive or community employment. Although the availability of retirement preparation and support is increasing, many older individuals with mental retardation continue in sheltered employment and adult activity programs beyond their mid-50s to mid-60s when most workers leave the workplace (Sterns and Sutton, 1993). Some service programs have run into problems with regulations that are interpreted as requiring people to participate in work-related activities, even if they are past retirement age. Older individuals with mental retardation also may not be familiar with activities and supports that would be an alternative to continuing in the daily programs they have been attending.

There are indications, however, that States are developing strategies specifically to meet the needs of the growing numbers of older adults with mental retardation. A survey in the mid-1980s, for example, identified 327 community-based programs targeted to this population in 40 States (Seltzer and Krauss, 1987). The survey also found that several supplemental retirement programs had developed, primarily since around 1980. These programs provide part-time day programs for elderly people with mental retardation and serve as retirement options, with a primary focus on recreation rather than employment or vocational activities. At the time of the survey in 1984, 30 programs were identified in 15 States, serving an average of just under 20 people (Seltzer and Krauss, 1987).

Including older adults with mental retardation in generic aging service programs requires attention to individual support needs as well as supports needed by both the mental retardation and aging service systems. Although collaboration between the aging and mental retardation/developmental disabilities systems is still limited, examples are increasing. Collaborative activities include shared training opportunities, supporting participation of older adults with mental retardation in community senior centers and activities, coordinated assessments of support needs, and pooling resources. Examples of approaches in supporting collaboration include the following:

Teaming to Promote Inclusive and Appropriate Aging Experiences for Persons with Developmental Disabilities is a two-year initiative funded by the Federal Administration on Aging, being carried out jointly by the Hawaii Developmental Disabilities Council, the State Executive Office on Aging, and the University of Hawaii/UAP. The project focuses on collaboration among agencies serving aging persons, direct care staff, community members, family members of aging individuals, and aging people with and without developmental disabilities. Teams have been established to focus on three areas: inclusion in generic seniors programs; day care programs and services; and supports for family caregivers (Zierman, 1995).

The North Carolina Developmental Disabilities Council provided funding to the Developmental Disabilities Training Institute to develop a statewide interagency training program. The *Training Approach to Improving Community Services for Older Citizens is* cross-training representatives of developmental disabilities and aging networks on supporting older persons with developmental disabilities. Central to this initiative is a model training curriculum which has been piloted in four sites, with two additional sites planned. The result of the training is an environment in which professionals work together to improve access to generic aging services and supports for older adults with developmental disabilities. The project also is helping local communities to explore innovative and individualized approaches for including older adults with developmental disabilities in generic aging services (Zierman, 1995).

Bill's Story

Bill was one of the first people to receive services from Comprehend, Inc., a program created in 1985 to serve people with mental retardation/developmental disabilities, age 55 and older. The program focuses on providing opportunities for choices of social, recreational, residential and economic services available in the community.

At the time he joined the program, Bill was 64 years old and living alone on his Social Security income. He had mild mental retardation and multiple medical problems, including a coronary pacemaker. He was unable to read or write other than his name. Bill had lived all his life in the same town and worked as a laborer at local businesses for many years. In retirement, he spent his leisure time aimlessly wandering the business district and making spontaneous visits to offices and stores. He was a lonely man, well received by everyone, but considered a "likeable nuisance."

As a first step in the Comprehend program, Bill received support in identifying his needs and improving his living situation. Comprehend helped him to move into a three-person home within walking distance of the business area, including support in personal care and financial guidance. Bill paid off debts he had accumulated with local stores and learned better management of his personal funds, an area that had caused problems for him in the past. His case manager provided transportation for his medical care, and also encouraged him to attend senior citizen centers three days per week. Bill became involved as a helper at the senior center and was there for nearly every event.

As a result of the support available through the Comprehend program, Bill found a more productive and socially valued place in his community. His wandering around the town decreased to a minimal level, he contributed to the operation of the senior center, he dated, and he made new friends who accepted him for what he had to offer.
Adapted from Arnold, 1993.

In Nebraska the Developmental Disabilities Council funded the Eastern Nebraska Office on Aging to enhance services to older adults with developmental disabilities and to older caregivers of adult children with developmental disabilities. The *Mainstream: Eldercare for the Older Adult with Developmental Disabilities* project encouraged inclusion of elderly persons with developmental disabilities in regular senior programs. Specialized services, including a case manager, were provided; 145 individuals received aging program services, including participation at a multi-purpose senior center, home delivered meals, and homemaker services. An innovative aspect of the program is the inclusion of five volunteers with developmental disabilities, all over age 60. They provided 1,226 hours of volunteer service to the Omaha community during 1994 as Senior Companions and Foster Grandparents. The project also improved the Office on Aging's assessment of elderly individuals' long term care needs, taking into account an individual's cognitive level. There is also a "how to" manual available for replication of the approaches that were successful in promoting inclusion (Zierman, 1995).

Irving's Story

Irving has a clear idea about what older persons with developmental disabilities deserve: "I believe that everyone should be challenged to the best of their ability level." That is certainly what is happening for Irving. At the age of 54 he works at the job he has held for the past 19 years, lives in his own home, and is improving the world for persons with disabilities through his self-advocacy activities.

The motivation for Irving's self advocacy is his vision for people with disabilities: for people to feel comfortable making decisions for themselves, and secure in the knowledge that people are listening to them. He was the first self-advocate to be on the national Arc Board of Directors, and he has been on several other boards and advisory councils. Irving received the Citizenship Award from the Arc in recognition of his "overcoming obstacles toward achieving success as a leader and contributing member of the community." He is also involved with the selfadvocacy group People First.

Irving attended the signing of the Americans with Disabilities Act with a friend who was excited that it would help immediately. Irving was more excited, however, for the children who will benefit from the ADA in the years ahead. "When I was young, parents never knew what was out there. Today the situation is better. The public doesn't try to hide the situation."

Irving feels fortunate to have had opportunities for personal fulfillment and to make a difference in the world. He's working through his advocacy to ensure that all people with mental retardation and other disabilities have those same opportunities.
Adapted from Kloos, 1993.

Respect for individual choices and preferences are an essential component of designing programs for older people with mental retardation and other developmental disabilities. Just as people without mental retardation, some people choose retirement while others prefer to keep on working, of to part-time employment. Some individuals may need help in exploring retirement options, and support in moving into new activities. Prospects are improving, however, for older people with mental retardation to be included in activities of their choice.

The *Person Centered Later Life Planning Project* has been developed by the Rehabilitation and Research Training Center Consortium on Aging and Developmental Disabilities, based at the

Institute on Disability and Human Development, University of Illinois at Chicago. Although the project also works with family members and program staff, the focus is on training older individuals with mental retardation and other developmental disabilities to examine later life options and to guide their own support planning process. Exploration of new experiences in leisure activities and opportunities to participate in community activities help participants make informed choices about retirement and aging. In addition, several participants have developed new interests and abilities (Heck, Heller, Factor et al., 1993).

George's Story

Several times a week, George, a man in his mid-forties, spends his evenings at the local Knights of Columbus (K of C) Hall near his home. Weekly, he helps with the bingo games. He likes to work in the kitchen preparing the meal they serve on bingo nights. Sometimes George shares a meal with fellow Knights. Other times, George attends by himself and visits with other members. He has rarely missed a meeting. He also marches in the annual Saint Patrick's Day parade, and participates actively in all fund-raising activities.

George has been a Knight since 1988. He is a Third Degree Knight, a very respectable position to hold with the organization, as Fourth Degree is the highest level. He also recently sponsored another man to join the organization.

George's involvement with members is not limited to his time at the K of C Hall. Other members have invited George to their homes, and he has reciprocated. In 1990, when it came time for him to move to a new apartment, several of his friends from the Knights came over to help.

George's contribution to the organization is significant. The Grand Knight commented on his helpfulness: "George is always willing to help out with any project." In fact, he was commended in a recent issue of their newsletter for selling a large number of raffle tickets. He works tirelessly at bingo games, and he recently worked 12 hours straight at the summer picnic.

Up until a few years ago, George, diagnosed with mental retardation, spent most of his life living in a State institution. He then lived in a community residence for several years before moving into a staffed apartment with a roommate. During the day, he works at a sheltered workshop. Before joining the Knights, most of his free time was either spent watching television or riding his bicycle up and down the street near his house. He had few interests and fewer friends outside his service program.

Although George is not a talkative man, his "before" and "after" photographs, along with testimonies from staff and friends, highlight the change in his personality. One photo, taken the night of his initiation into the Knights, shows George with a serious, almost fearful, expression on his face. A recent photo, taken at the K of C Hall, shows him relaxed, smiling, with a warm twinkle in his blue eyes. Another photo shows George proudly wearing his K of C pin on his lapel. Other members describe George as being very shy when he first joined. They say he is much more outgoing now, and participates in the joking and bantering that is part of the atmosphere.

When George is asked about what he enjoys about being a member, he says, "I like that they ask me to help. I like joking around with them; we joke about my cat." For George, his initiation into the Knights of Columbus has also been a true initiation into community life.

Source: "Friendships and Community Associations" (Reidy, 1993).

IV. INCLUSION IN COMMUNITY HOUSING

- ASPECTS' OF COMMUNITY LIVING
- SUPPORTED COMMUNITY LIVING
- TRENDS IN FINANCING AND HUMAN RESOURCES
- SUMMARY

One Man's Walk Through Modern History of Residential Services

by Kevin Otley

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

When I moved into a group home, I had to follow all of the rules. I had to go to bed at a certain time, and when I was in bed, I had to be asleep; that was that. I lived with two other guys. We were being watched all the time, 24 hours a day, seven days a week. Two years ago I got married. My wife and I moved into our own apartment. Now that I have my own place, I make the decisions. I have my own keys. I can let myself out, and let myself back in.

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

Reprinted from *The Guidebook on Consumer-Controlled Housing (1995),* Fields and Lakin (1995).

With remarkable brevity and clarity Kevin Otley describes the evolution in housing and related support services for persons with mental retardation and developmental disabilities. He identifies three major phases in this evolution: institutions, supervised community living, and supported community living. He also captures well the experiences that many people associate with each phase. While we should probably let well enough alone (Mr. Otley pretty much says it all), this chapter outlines some of the concepts, accomplishments, challenges, and future directions in community housing and related support services.

ASPECTS OF COMMUNITY LIVING

Most definitions of community focus on aspects of mutuality and reciprocity, as reflected in shared interests, interpersonal relationships, interdependent roles and involvements, and common expectations. Similarly, the goals of community living for people with mental retardation and other developmental disabilities are linked to how people define a quality of life within their respective communities. For the purposes of this overview, six broad aspects of satisfying community living are considered: 1) presence in the community; 2) health, safety, and basic comfort; 3) personal growth and development; 4) social relationships; 5) valued community participation; and 6) personal self-determination.

Community Presence

Community presence refers simply to the opportunity for people to have physical presence in the community. This might go without note if it still were not being denied to so many people.

Out of Institutions and into the Community

In recent years people with mental retardation clearly have had substantially increased access to community living. In 1967, State institutions housed 194,650 individuals with mental retardation and related developmental disabilities; in June 1994, they housed 65,735 people. Along with the "deinstitutionalization" has come tremendous growth in community services. In June 1977 only 20,409 (8.2%) of the 247,796 individuals receiving residential services outside their natural or adoptive homes from State-licensed or State-operated residential services were in places of six or fewer residents. Seventeen years later in 1994, 145,976 (47.0%) of the 310,911 individuals receiving residential services were in places with six or fewer residents. Conversely, in 1977 83.6% of persons receiving residential services lived in MR/DD institutions of 16 or more residents as compared with 34.6% in 1994.

Another indicator of changing patterns of residential care is the average number of people living in each residential setting in which people with mental retardation receive residential services. That average decreased from 22.5 residents in 1977 to 4.9 residents in 1994.

Broad Indicators flnlers1a1e Variability

There has been great variation in the extent to which people living in various States are provided the opportunity to live in community settings. As Table 7 shows, the range of variability among States is as follows:

- Average size of residential settings, from 1.3 to 20.7 individuals;
- Percentage of people living in seifings of 1S or fewer residents, from 19.0% to 100.0%; and
- Percentage of those in places with six or fewer residents, from 4.7% to 100.0% (Prouty and Lakin, 1995).

Community Services for People with Severe Impairments

Individuals with severe developmental, behavioral, and health disabilities are living in the community all through *the United States, and their numbers are growing rapidly. But providing adequately supported access to community* services for people with significant medical and behavioral needs still presents challenges, and as a result community services for people with the most severe disabilities have been slower to develop. This discrimination and delay have caused a situation in which it is estimated that over 80% of the people who are living in public and private residential institutions and nursing homes are people with severe intellectual, medical and behavioral disabilities, despite the evidence that community living is working well for others with severe and complex conditions. On June 30, 1994 nearly two-thirds (65.5%) of State institution residents were reported to have profound mental retardation. Similar patterns exist for persons with medical or behavioral impairments. There are many examples of successful community housing and support services for persons with severe disabilities, and these services are growing rapidly. There is also well-documented evidence of the developmental benefits of community living (Larson and Lakin, 1989). Despite these factors, institutional placement still prevails for people with severe disabilities in many States. Denial of access to community living benefits amounts to systematic discrimination, yet continues to be an all too common practice.

Health, Safety and Basic Comfort

One of the important concerns in community living, especially in States that have developed commitments to community membership for everyone, has been basic health, safety, and comfort *needs.*

Table 7 Summary Statistics on the Size of Residential Settings on June 30, 1994

Total Settings	Total Residents	Average Residents/Setting	Percent in Settings with 1-15 Res.	Percent in Setting with 1-6 Res.
AL 212	2,182	10.3	47.7%	16.5%
AK 303	576	1.9	93.4%	81.3%
AZ 1,503e	5,229	3.5	96.8%	90.5%
AR 348e	2,172	6.2	33.6%	19.8%
7,232*	42701	5.9	72.9%°	65.2%
CO 1,474*	3,876	2.6	89.2%	72.6%
CT 1,698	5,571	3.3	75.9%	66.2%
DE 199	705	3.5	54.6%	54.6%
DC 227	1,084	4.8	100.0%	66.5%
1,143	9,107	8.0	56.3%	36.1
GA 734	3,639	5.0	42.3%°	42.3%
HI 830	1,118	1.3	91.4%	90.8%
ID 505	1,665	3.3	79.8%	49.5%
IL 1,042	15,768	15.1	35.4%	4.7%
IN '1,689	7,626 "	4.5	69.5°1°	32'.9%
IA 1,544*	5,839	3.8	66.6%°	34.4%
KS 233	3,002	12.9	50.8%	19.5%
KY 1,064	2,705	2.5	57.0%	50.0%
LA 1,003	7,953*	7.9	47.1%	38.5%
481	1,553	3.2	82.8%	63.0%
MD 1,223	4,483	3.7	77.4%°	77.4%
MA 1887	8,324	4.4	74.5%	64.0%
MI 2,247e	9,130	4.1	95.5%	95.5%
MN 2,591e*	10,256e*	4.0	78.9%	60.3%
231	2,836 "	12.3	25,1% "	14.4%°
MO 1,116	6,218	5.6	61.9%	38.3%
MT 690	1,472	2.1	88.9%	52.9%
NE 323	1,694	5.2	59.5%	47.2%
NV 240	608	2.5	75.3%	75.3%
2,137e	3,348e	1.6	98.4%	91:2°1°
NJ 1,306	9,930	7.6	44.7%	44.7%
NM 210*	1,130*	5.4	67.7%	43.6%
NY 6,100*	30,938	5.1	82.4%	25.1%
NC 756	6,893	9.1	57.4%	47.1%
595	1,854	"	87.8^{6}/o	59:0%`
OH 2,257	13,312	5.9	54.5%	34.1%°
OK 811	3,838	4.7	41.2%	34.7%
OR 991	3,803	3.8	83.5%	68.9%
PA 4,219	14,998	3.6	59.2%	53.6%
324	1,290'	4.0	96.7%	72.2%
SC 898	4,686	5.2	57.4%	26.6%
SD 500e	1,769	3.5	80.2%	41.2%
TN 538	4,248	7.9	54.6%	17.0%
TX 1,207	13,742	11.4	36.4%	29.3%
UT 534	2,163	4.1	57.8%	43.4^{6}/6
VT 566	770	1.4	100.0%	100.0%
VA 155	3,207	20.7	19.0%	7.0%
WA 1,726	6,675	3.9	75.5%	63.9%
WV 405*	1,214*	3.0	78.7%	43.7%
3,066'`	11,248	3.7	67'.2%	58.4°,6
WY 341	763	2.2	79.6%	71.2%
U.S. Total 63,654	310,911	4.9	65.4%	47.0%

e indicates estimate * indicates 1993 data

Access to Appropriate Medical Care

As people with mental retardation test and extend their abilities to live as independently as possible in their communities, they must be assured of appropriate attention to their health and wellness. National and State studies have shown that persons with mental retardation in community residential settings almost universally receive medical and dental services at least annually (Hill et al., 1989). Care providers and family members overwhelmingly report satisfaction with services received; even the community, medical and dental services for persons with very extensive health care needs generally receive positive reviews (Lakin, Burwell, Hayden and Jackson, 1992).

The general satisfaction with the adequacy of available medical services is perhaps not surprising, since they are similar to those used by the increasingly older, more often disabled "general public." But problems exist. Increasingly people who use Medicaid report problems in obtaining medical care and related services. People with modest incomes that exclude them from qualifying for Medicaid are frequently without health insurance or excluded from private insurance because of pre-existing condition exclusions, high premiums and copayments, or are provided benefit packages that limit specific benefits they need. People from rural areas who need specialized medical services often have difficulty accessing them. In a number of States managed care enrollments of Medicaid recipients, including those with developmental disabilities, are being developed. Rhode Island has proposed a particularly innovative approach that would bundle both service users and service providers into a single managed care buyer pool.

Providing for Basic Safety and Well-Being

Assuring safety and well-being of people in community housing is increasingly challenging for several reasons. First, there are more and more community living arrangements: community residential services were provided in almost 64,000 different sites in 1994, an increase from 11,000 in 1977. Second, there is increasing development of, living arrangements with less than full time supervision, which permits people to enjoy their greatest possible liberty, but reduces monitoring of their well-being. Third, "caseloads" for service coordinators/case managers are often too large for careful attention to people's lives (i.e., often 50 or more), and most State licensing and certification programs provide for only annual surveys.

Assuring safety in an increasingly dispersed service delivery system, especially when coupled with emphasis on individual preference and choice, requires new ways of thinking about "quality assurance" and related quality enhancement activities. As noted in the previous chapter, supports to individuals in establishing and maintaining ongoing mutual relationships, involvement, and commitments among people with mental retardation, their families and friends, neighbors, advocates and others, are gaining in importance. These relationships further enhance individual safety and well-being, by increasing the circle of people who know and care about each person in community living.

Guaranteeing Basic Rights

To paraphrase Martin Luther King Jr., people with mental retardation have the same rights as other citizens, they are just waiting for those rights to be recognized. Societal attitudes towards persons with mental retardation hinder recognition of their basic rights. Certainly the low expectations of the "qualifications" of citizens with mental retardation represents one of the most substantial barriers to benefiting fully from the Americans with Disabilities Act. A critically important protection for the rights of people derives from being accepted and valued as full members of the society. Such acceptance is fostered by opportunities to fulfill valued roles in their community as neighbors, coworkers, purchasers of goods, community volunteers, and friends.

Equal Opportunities for Children to Grow Up in a Family

For children in this culture the basic right to live in a family is generally recognized. The national commitment to this right is reflected in the policy of permanency planning, outlined in the Adoption Assistance and Child Welfare Act of 1980. This law requires States to make an effort to prevent out-of-home placements through support and services to natural families. Plans are developed to return the child home as soon as possible when out-of-home placement is unavoidable, and to secure adoption or permanent foster family placement when returning home is no longer viable. Through family supports and the guarantee of a free appropriate education in the community where children live, this country has made great strides in reducing the number of children and youth with mental retardation living outside natural or adoptive homes (from about 91,000 in 1977 to 48,500 in 1988). But while permanency planning is a guarantee for children and youth in child welfare/social service systems, it is not mandated for children and youth whose services are funded by Medicaid, education and other programs serving children and youth with mental retardation. Therefore, significant moral challenges in guaranteeing equal protections for typical family living for all children and youth remain.

Freedom from Discrimination on the Basis of Severity of Disability

Basic protection should mean freedom from discrimination in opportunity for community living based on the severity of disability, in standards for guardianship which frequently deny people control over the most basic aspects of their lives, and in freedom from repressive and punitive environments. New promises of programmatic access (not merely physical access) to activities sponsored by public funds under the Americans with Disabilities Act offer tremendous opportunities to reduce discrimination in access to community activities. It also provides significant challenges in developing the training and technical assistance co-involvements needed to help community agencies meet their new responsibilities. Reconsideration and reform of guardianship laws is another area in which efforts are being made to end discrimination and to give adults with mental retardation control over their own lives, which have often been unnecessarily handed to others or to the State.

Progress has been made in recognizing the rights of people with challenging behavior to enjoy less restricted, less punitively controlled lives in the community. As services to individuals with challenging behavior become increasingly dispersed across community settings, some States (e.g., California, Minnesota, Vermont) are moving to establish, expand, and integrate ongoing training, behavioral support, and crisis response services for families and community agencies to avoid (re)institutionalization.

Opportunity for Personal Growth and Development

All people need to learn new skills that add to their competence, and that fulfill their interests. Research consistently shows that the functional skills of living in our society are better developed through community living than in institutions. In fact, 18 studies conducted between 1976 and functional 1988 comparing the development of functional skills by people moving from institutional to community living All develop better through showed positive gains for the people moving to the community (Larson and Lakin, 1989). The most obvious explanation of this outcome is that learning is an interactive process involving both the individual and his/her environment. An individual learns the skills of the society by participating in it.

Increasingly the focus of personal growth and related supports is shifting from "professional" opinions about what is best for people, to what people need to know and do to fulfill their personal goals and desires. Personalized individual planning approaches such as those of Mount and Zwernik (1989), O'Brien and Lyle (1988), and Smull and Harrison (1992), as well as heightened sensitivity to people's desires, are being used to identify and realize personally valued outcomes in areas like housing, social relationships, recreation/leisure activities, and other components of daily life. As a result, substantial evidence has been produced in recent years of people' with mental retardation achieving levels of independence, inclusion and self-determination that were rare 10 to 15 years ago.

Social Relationships

Social relationships are a key to personally satisfying lives for all people, with family relationships often being the most important. For adults with mental retardation there are especially compelling reasons to promote sustained family involvement. Frequently family involvement entails more than the typical support and nurturance of families, by providing important protections, monitoring and individual advocacy by family members (Lutfiyya, 1991). And while family involvement in the lives of persons living in the community is notably higher than for persons in institutions (Hill et al., 1989), many families express dissatisfaction with the quality of communication between support service providers and family and the extent to which the family involvement is facilitated.

Social relationships with people other than family members are as important for persons with mental retardation as for others. Like most people, individuals with mental retardation derive most of their social relationships from people *who* share their residence, work place, and day program with them. Despite the improved opportunities for relationships in the community, most non-family social relationships for persons with mental retardation are with paid staff (Hayden et al., 1992). For example, Minnesota's HCBS waiver service recipients are actively engaged in recreation and leisure activities, but only about 5% of them participated in these activities during a one-month period with people other than family members, other people in their residential or day programs, or paid staff members (Lakin et al., 1992). Indeed, many people in community settings appear as isolated as their counterparts who live in institutions (Bercovici, 1983).

As described in the previous chapter, people have begun to document experiences of individuals and agencies demonstrating effective methods of promoting and sustaining meaningful social relationships (also see Taylor and Bogdan, 1989). Efforts to establish sustained interactions over prolonged periods, such as Minnesota's "Friends Project" (Amado, 1992), appear particularly important, given evidence that programs of simply pairing people for peer interaction ("buddy programs") tend to have limited lasting effects (Hirsch and DuBois, 1989).

Valued Participation

Nothing is more important to people than being valued community members, as part of normal variety of individuals *who* make up and contribute to a community. When there have been years of segregation and discrimination, recognition of people's full citizenship often requires proactive involvements. Actively using the resources and venues of community life (schools, libraries. parks, restaurants, stores, etc.) is an important way of communicating membership. Employmer is another important expression of membership, since in our society work is the most command probably most consistently valued, way for adults to contribute to their communities.

Other culturally valued roles are being assumed by people with mental retardation. For example, the involvement of people in the selection, purchase/rent arrangement and/or maintenance of their own homes not only engages them in a valued social role, but increases their skills in areas that are basic to increase independent living and maximum control over their own homes. It also makes the person, not an agency, the one paying for the housing and contributing to the local economy. People with mental retardation are increasingly visible not only as workers and householders, but as consumers of goods and services, volunteers, representatives on boards and committees, spokespersons and political activists, participants in community organizations and recreation/leisure activities and so forth. These efforts contribute substantially to the valuing of people with mental retardation by others in their communities.

Personal Autonomy and Self-Determination

Self-determination and "empowerment" are increasingly recognized as important goals and aspects of daily life for people with mental retardation. These terms subsume a wide variety of skills and opportunities in the areas of independence, self-expression, choice-making, problem solving, self-management, and self-representation. Supporting and enhancing self-determination is an essential part of providing the opportunities for people to benefit fully from community life. Recent efforts to educate parents, policy makers, professionals, and others about the importance of self-advocacy to empower people to gain control over their personal lives and to be the primary agents in insuring quality in their daily lives and services is a growing force. More and more local, State, and national self-advocacy organizations are organizing self-advocates to increase the opportunities for these organizations to develop local, State and national chapters. Hundreds of State and local "People First" or similar organizations are operating across the United States. Without question these organizations have created more pervasive general expectations that people with mental retardation must have a significant role in making not only the personal decisions in their lives, but also the policy decisions that affect their lives.

SUPPORTED COMMUNITY LIVING

In recent years these various components of a rich and rewarding community lifestyle have been brought together in a new approach to services called "supported community living." This new concept of community living is having major effects on the goals and desired outcomes of services for people with mental retardation. Many of basic principles, challenges and experiences of supported living are described in IMPACT: *Feature Issue on Supported Living* (1995). In the supported living concept, human services are viewed as means for supporting the unique desires, abilities, circumstances, and needs of each individual. Supported community living includes several basic premises, including the following:

- All people need and deserve a home of their own where they can be themselves, choose to do what they want, be with whom they choose to be;

- Funding for housing should be separated from the funding for services so that they can change one without changing the other;

- The natural supports and relationships available to people through family, community and friends should be sustained and fostered;

- Services should be planned around and support each individual's personal preferences and desired lifestyle;

- People should have a choice in the services they receive and from whom they receive them;

- Services should be deliverable in different ways to different people in different places, including recognition of cultural differences;

- Service providers should find less intrusive ways to bring services and supports into people's homes and be more sensitive and respectful of being in another person's home; and

- Service providers need to adjust to a "market" in which "clients" become "customers" and revenues to an agency are determined by demand for specific services by the "customers" rather than a total number of people who are "awarded" to an agency to be provided comprehensive care (Adapted from Impact 8(3), Sept. 1995).

Each of these premises implies significant changes from the traditional facility-based service delivery system. But this new expectation of how things could be and should be is steadily becoming how things will be in the future as States like Alaska, California, Michigan and Rhode Island made significant policy shifts and system reforms to honor the basic right of people to shape their own lives and destinies.

Jim's Story

The Alaska Developmental Disabilities Services program works closely with individuals with mental retardation, families and community members to help people stay in their communities. These efforts include people like Jim, who live in remote Alaskan Native villages. Jim was going to have to leave because his family and the village couldn't deal with him. He was having a hard time getting along with others, and people were teasing him and he was teasing others. He had some major hygiene issues and was extremely overweight. He also has a severe seizure disorder.

State staff worked with Jim, his brother, and the village council to solve problems and to find him the supports he needed. Service dollars were used to purchase custom clothes that were tailored to fit him. The village council helped him to get regular baths at the health clinic. Someone was hired to spend time with him during the day, to help him learn how to deal with other people criticizing him, and also how to have conversations with people that were polite. Someone also is helping him cook, and he is in the process of learning how to cook for himself.

Jim lives in a cabin next to his brother's. He was helped to get a fuel oil stove that was safe and could heat the cabin, as well as insulated windows to reduce the fuel bills. His brother got the materials, with the freight fees donated, and did the installation.
Getting all these supports has taken a lot of heat off the family, and the community looks at Jim in a much more positive way. He looks very good and is happy being able to socialize without being teased. All of these supports were needed to keep him in his home community.
Adapted from Anderson and Gross, undated.

Because supported living is a set of principles more than a type of program, it is difficult to count how many people may be receiving services in a manner that equates to supported living. It is probably the case that thorough analysis of people's lifestyles would find that "supported living" in its ideal is enjoyed by a relatively small fraction of adults with mental retardation. As one indicator, only about 42,600 people were reported to be living in homes that they rent or own in their own names in June 1994, or only about 12% of all residential and nursing service recipients with mental retardation. But that was an increase of 25% over the previous year as supported living more and more becomes the standard against which the quality of community housing and supports is evaluated. Indeed, in this role the supported living concept is continuously contributing to the personalization of community services, whether in people's own homes, in foster homes, in group homes and even in some institutional settings. The supported living concept is causing heightened attention to basic aspects of the quality of life, including:

- Control over one's own home or personal space;
- Freedom to shape one's daily life;
- Choice in services, service providers and service goals;
- Autonomy from formal service systems through opportunities to exercise independence and to use informal natural supports and generic community services as available; and
- Opportunities and support in building and sustaining meaningful, enjoyable relationships with other community members.

TRENDS IN FINANCING AND HUMAN RESOURCES

Systems for people with mental retardation are undergoing a continuing evolution from residential services primarily in large congregate settings, to one in which people live in typical community housing with varying levels of staff support. This transformation often puts traditional service systems, their funding, their monitoring and other existing practices in considerable disharmony with what people need for the lifestyles they want. These conflicts are often evident in the nature, amounts and conditions of available financing for housing and services.

Key Funding Programs and Issues

Until 1971, there was essentially no Federal participation in the financing of housing and related services. Most people lived with their families or in State institutions which were generally underfunded, with State only revenues. As has been well documented, these institutions typically housed people in overcrowded settings which generally violated their most basic civil rights. The Federal government entered the picture in a significant way in 1971 when it provided States the opportunity to cost-share certain residential services that meet specific standards of quality (as quality was then defined).

Medicaid Long-Term Care Services

Intermediate Care Facilities for Persons with Mental Retardation and Related Conditions(ICF/MR). The first Federal program targeted to residential services for people with mental retardation was the Medicaid ICF/MR program, initially authorized in 1971. Almost half (45%) of all persons with mental retardation who are receiving services while living outside their family homes currently reside in this congregate care setting (four or more residents). Under the current (1995) Medicaid program, the Federal government pays from 50%-80% (depending on a State's per capita income) of facility costs for ICFs/MR that comply with highly detailed administrative, environmental, personnel, treatment and rights requirements.

Ten Reasons Why People Should Rent or Own Their Own Homes

All across the United States more and more people with developmental disabilities rent or purchase their own homes. The common thread in this "consumer-controlled housing" is that the people have the homes they want with the services and other supports they need brought to them, not them being forced to live in the "homes" of their services. Thus they are able to live life more on their own terms. They can become the "kings and queens of their own castles," no longer just guests in places that are owned by or rented and controlled by the agencies that provide needed services. There are at least ten very significant advantages to people who live in consumer-controlled housing:

1. Permanency: The risk is reduced that other people will decide one must move from one's own home. People who live in their own homes are free to choose new service providers or even to reject service providers without also losing their homes.
2. Community Inclusion: People who control their own housing have greater choice in living near people and places that support their participation in the community.
3. Freedom: People who live in homes they control make their own rules. The basic right to privacy desired by all human beings is more easily met in one's own home. The place where one can *"be* oneself' is more easily achieved in one's own home.
4. Respect: A home of one's own is a typical and important achievement of American adults. It gives the owner or leaseholder a valued social role. Both owners and renters contribute to the local economy.
5. Responsibility: A home of one's own makes an individual responsible for a number of economic and domestic activities. Responding to these responsibilities helps people to grow in social competence, both in actual terms, and as they are seen by others in their community.
6. Economic gain: People who buy their own homes have found that careful purchase and long-term residence can yield an equity build-up that increases an owner's financial resources. Those who rent often can choose housing and housing arrangements at costs that free funds for other economic decisions.
7. Location: People who choose their own homes can live where it is most convenient to their jobs, families, friends, stores, transportation, and so forth. They can live close to places they enjoy and thus be able to participate more frequently and with less dependence on others.
8. Choice: To most people, the prospect of spending their whole lives with strangers whom they have had no voice in selecting is dismal at best. Yet this is the typical experience of persons with developmental disabilities. Controlling one's home includes controlling not only where one lives but, also, with whom.

9. <u>Self-Determination</u>: People should have a right to control as much of their lives as possible. Few areas are more basic and unambiguous in self-determination than selecting the housing one wants within one's resource limits.
10. <u>Independence</u>: People who live in their own homes can exercise independence in seeking a new service provider. In contrast, people who live in buildings owned by a service-provider agency must weigh the loss of home, neighborhood, and proximity to friends against seeking services from another individual or agency (Adapted from Fields and Lakin, 1995).

The total population of ICFs/MR in June 1994 was 142,118, compared with 140,752 in 1982. Although most (88.6%) ICFs/MR are relatively small (i.e., have 15 or fewer residents), the great majority of ICF/MR residents still live in large facilities. In 1994, 66.0% of ICF/MR residents lived in facilities with more than 16 residents. Virtually all units in State institutions for persons with mental retardation are certified as ICFs/MR (96% of State institution residents live in ICF/MR units). Only 23.3% of people living in community settings with 15 or fewer residents and only 13.4% of people living in settings with 6 or fewer residents live in ICFs/MR.

ICF/MR care is expensive. In 1994, the average annual cost (Federal and State combined) to the Medicaid program of an ICF/MR recipient was about $65,000, with the average costs of large public ICFs/MR reaching $82,300 per year. Total ICF/MR expenditures have grown from $3.6 billion in FY 1982 to $5.9 billion in FY 1988, and to $9.2 billion in FY 1994. ICF/MR care brings substantial Federal reimbursements back to the States ($5.3 billion in Fiscal Year 1994), although the "return" varies remarkably from State to State due to great variation in State use of the ICF/MR program as well as differences in Federal matching rates.

As a congregate care program, the ICF/MR program is considerably out of step with the evolving approaches to community housing and services. Not only is it an institution dominated program in an era committed to community services, it is also a program that provides little flexibility to respond to individual differences and preferences. The program often is interpreted as requiring people to live in congregate care homes while receiving an essentially identical set of services, regardless of personal needs or desires, as well as having incentives for non-work day activities. The ICF/MR program also has hundreds of regulatory requirements, almost none of which is related to understanding and responding to people's personal preferences and goals.

Despite its lack of congruence with the evolving goals of community services, the number of ICF/MR residents grew slowly (on average of 0.5% per year) from 1982 to 1993, with total expenditures growing at about 10% per year. In Fiscal Year 1994, ICF/MR enrollments decreased (by 5,800) for the first time in program history, while program expenditures remained essentially unchanged from Fiscal Year 1993 at $9.2 billion. One year does not make a trend, but it seems reasonable to expect that the program's inconsistency with the evolving goals of community housing and supports will result in continuing decline in utilization.

Medicaid Home and Community Based Services (HCBS). The Medicaid Home and Community Based Services (HCBS) waiver has been a highly popular alternative to the institutional orientation of the ICF/MR program. Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35) established the option for States to provide Medicaid HCBS to people with mental retardation and related conditions. This program allows "waiving" certain Medicaid requirements and allows States to finance "non-institutional" services for Medicaid-eligible individuals who, in the absence of alternative services, would remain in or might be placed in a Medicaid institution (i.e., a Nursing Facility or an ICF/MR). Non-institutional services that can be provided under the HCBS program include case management, personal care services, adult day health services, habilitation services, respite care, or any other service that a State can show will lead to stable or decreased costs for Medicaid funded long-term care. Although not allowed to use HCBS reimbursements to pay for room and board, virtually all States offering HCBS to people with mental retardation do provide services to people in their homes under the categories of personal care, habilitation, and homemaker services, while in most instances using cash assistance from other Social Security Act programs (e.g., SSI) to fund the room and board portion of the residential program. Given both its flexibility and its potential for promoting the goal of community based care and habilitation, the HCBS program has generally *been* of great assistance to States in providing community services.

In the more than a decade between enactment of the Medicaid HCBS program in August 1981 and June 1994, 50 States chose to provide Home and Community Based Services. The number of HCBS program participants grew from 1,381 on June 30, 1982, to 22,689 on June 30, 1987, to 62,462 on June 30, 1992, to 122,075 on June 30, 1994. Approximately 3.0 billion dollars was expended on the HCBS program in Fiscal Year 1994, up from $1.6 billion just two years earlier. As noted above, the average expenditure per recipient of about $28,500 (with adjustments from partial year participants) was less than 50% of the average ICF/MR cost. In June 1994, based on statistics on 61.3% of HCBS recipients, it was estimated that about 23.8% lived with their natural family, 51.5% lived in housing owned or rented by the agency providing services to them, 13.6% lived in "foster" home arrangements, 23.8% lived in homes that they themselves owned or rented (8%) and 1 % in other types of arrangements.

Medicaid Community Supported Living Arrangements. In 1990 Congress amended the social Security Act to allow up to eight States to provide Community Supported Living Arrangements (CSLA) to Medicaid-eligible people with developmental disabilities. Separate from, but in many ways similar to the Medicaid HCBS program, CSLA provides greater flexibility in service provision, permits specific targeting of services to eligible groups and geographic areas within a State, does not require demonstration of ICF/MR or nursing home level-of-care need for eligibility and allows each State to develop its own quality assurance plan within defined Federal standards. Total cost of the CSLA program was capped on an annual basis in each of the program's five years and at a five year total of 100 million. Proposals from the eight States selected to provide CSLA (California, Colorado, Florida, Illinois, Maryland, Michigan, Rhode Island, and Wisconsin) varied in target populations, projected numbers of recipients, services to be included, per recipient costs, and in other aspects. The CSLA program offered participating States the potential to enhance quality of services by integrating a number of programmatic elements which consumers, advocates, providers and other professionals have long argued are necessary to such an effort, including variety and personalization of services, choice of services and vendors and consumer involvement in "quality assurance". In general, program development as defined by the number of individuals served was considerably slower than States had originally projected, reflecting the complex challenges in creating "systems" that can administer the supported living ideal. But at the end of the 5-year pilot project about 4,000 people were being served. These pioneers have provided a wealth of learning about how to design and implement supported living programs, and this learning is now being transferred to HCBS programs in the eight participating States as well as with other States sharing their ideals.

Medicaid Nursing Facilities (NF). As of June 30, 1994 an estimated 36,200 persons with mental retardation were living in Medicaid NFs. This number has been steadily declining in recent years, influenced in part by the 1987 Omnibus Budget Reconciliation Act which stipulated that States must screen persons with mental retardation in nursing homes for the appropriateness of their placement. States were required to submit "Alternative Disposition Plans" regarding the findings of those reviews. Medicaid HCBS financing is available to the individuals leaving nursing homes, as well as institutional ICF/MR placements. Between June 1989 and June 1994, the number of nursing home residents with a primary diagnosis of mental retardation decreased by 6,500 (or 15.2%).

Other Medicaid Services. In addition to the specific programs for people with mental retardation described above, Medicaid finances medical services, personal care services and other "generic" services used by people with mental retardation who live in community settings. For example, most service recipients with mental retardation have a designated case manager/service coordinator, which may be a Medicaid-financed service through a Medicaid targeted case management program or an HCBS service, or may be a State and local funded service. Most ICF/MR and HCBS recipients also receive transportation services (e.g., to and from their day activities), which may be provided by a residential, day activity, an independent provider, or by using public transportation. For ICF/MR residents transportation costs are generally included within the per diem rate for the day or residential program. For Medicaid HCBS recipients, transportation is sometimes an independent service in a State's HCBS program and paid for as such, or imbedded in per diem rates for residential or day programs.

The Rhode Island Story

In 1994 Rhode Island officials submitted an innovative five-year research and demonstration proposal to the Federal Health Care Financing Administration (HCFA) that will test the applicability of a capitated managed care model for acute and long term care services for people with developmental disabilities. Entitled CHOICES (Citizenship, Health, Opportunities, Interdependence, Choices, Environments, Supports), the waiver will combine current Medicaid and other State funding streams into a single, coherent system in order to promote more streamlined and cost-efficient service delivery as well as accelerate the transition of Rhode Island's current delivery system from one which is provider driven to one that is more consumer driven.

Rhode Island's CHOICES initiative lays out a five-year plan to test a new framework for employing State and Federal dollars in tandem to pay for consumer-driven community services and supports. CHOICES breaks out of the mode of "facility-based" funding methods by emphasizing individually-based capitation payment methods, coupled with a high level of flexibility and consumer empowerment in selecting and obtaining services and supports.

Over the five-year time frame covered by the waiver, Rhode Island officials estimate that StateFederal Medicaid outlays for long term supports and acute care services for adults with developmental disabilities will be $97 million lower than would be the case if the current system were continued. These savings are expected to arise from the application of managed care principles, improved and streamlined service delivery, and the exercise of consumer choice.
Source: "Choices: Rhode Island Proposes to Revamp State and Federal Funding to Promote Consumer-Driven Services," Community *Services Reporter, April 1994.*

Other Programs

There are two primary payment sources of support for non-Medicaid services for people with mental retardation: (1) individual SSI/SSP benefits and Medicaid State plan services; and (2) State and local MR/DD agency funds (including funds originating with the Federal Social Security Block Grant).

Social Security/ Medicaid. The great majority of individuals with mental retardation living in non-ICF/MR living arrangements are adults with little or no private income. They are therefore eligible for Supplemental Security Income (SSI). The Federal SSI benefit level in 1995 is about $450 per month. Many states further supplement the Federal SSI benefit with State supplementation payments (SSP) for people in various categories, which vary from State to State. As result of their SSI eligibility they are also eligible for Medicaid and their State’s Medicaid State Plan services. Medicaid services include 12 “mandatory” services, including physician services, inpatient and outpatient hospital services, laboratory services, home health services, Nursing Facility services, and others. At the State’s option, the vast majority of States also offer dental services, physical services, optometrist services, eyeglasses, prescribed drugs and speech and language services, and other services of substantial benefit.

The room and board of non-ICF/MR housing, including that of HCBS and CSLA recipients, is usually financed through SSI/SSP income. Adults with employment income also must contribute part of their earnings in most programs. Conceptually, payment of SSI/SSP income by residents to residential providers is generally perceived as a tenant/landlord relationship, in which the SSI/SSP payment is considered a "rent check" to cover the costs of room and board. In many cases, the residential provider is the "representative payee" for the resident, so that the SSI/SSP is sent directly to the provider. Concerns have been raised about this practice in that SSI/SSP is a payment for basic necessities to an individual with disabilities, not a residential prepayment program in which people's money is controlled by other people, with individuals unable to influence how their money is spent. Treatment of SSP also influences access to the 1619 work incentive program.

State Financing. State mental retardation/developmental disabilities agencies are the primary payment source for non-Medicaid services. These funds are made available from State revenues and certain Federal flow through programs, most notably the Social Services Block Grant (SSBG). Analysts of the potential effects of Medicaid block grants have examined the history of continual decreases in the amounts and significance of the SSBG in the lives of people with mental retardation. Following consolidation of Social Security Title XX into the SSBG, States experienced decreases in SSBG funding from 8% to 20% over the next three years, with even greater real dollar decreases. These coincided with significant growth in the use of the ICF/MR option to fund community housing and supports. Although the SSBG still provides about $600 million for community services in 1995, it represents barely a tenth of the $6 billion that States spend for ICF/MR, HCBS, CSLA and NF Medicaid match in total, and less than a quarter of State match for ICF/MR and HCBS community services.

Other sources of State funds also contribute to a wide range of housing and community supports. Among these are many State and local housing authority administered benefits that may be tapped to assist the financing of a residence. The most beneficial of these for individuals with mental retardation has been the HUD Section 9 subsidies and vouchers. Although a number of other HUD programs have assisted service providers in financing group homes, such programs are increasingly viewed as out of step with the goals of people who aspire to have their own homes, not to live in a home owned by their service provider.

State Initiatives in Consumer Controlled Housing

Several States have developed programs to help people with mental retardation and other developmental disabilities move into individualized housing under their control, either as home owners or as tenants. *A Guidebook on Consumer Controlled Housing* (Fields and Lakin, 1995) describes the following State initiatives:

Michigan's State Housing Development Authority is currently operating the MI Home (More Independence through Home) program to assist nonprofit agencies to acquire oneto four-unit residential properties for rental by people with disabilities. One goal of the MI Home project is to make rental housing affordable to people with modest incomes, with rent set at a maximum of 30% of each individual's income. Prospective tenants are primarily those with a history of residence in an institution or adult foster home. Funding is through the Federal HOPE Program administered by the Department of Housing and Urban Development.

The State of Rhode Island has made $600,000 available for home ownership by people with development disabilities in a one-year demonstration project, the Mortgage Program for Persons with Developmental Disabilities. Staff from the Rhode Island Housing Mortgage Finance Corporation are available to help consumers in searching for property. Staffs from the Department of Mental Health, Mental Retardation and Hospitals evaluate properties relative to needed community service, structural condition and maintenance needs. There is also a home buyer counseling component, through the purchase process and following. New and existing single family homes and condominiums requiring minimal maintenance are eligible for purchase. Funds for the demonstration project have been made available through a State bond issue.

The New Hampshire Home of Your Own demonstration has been implemented through a collaborative initiative of the State Mental Health and Developmental Services Department, the New Hampshire Housing Finance Agency, the University of New Hampshire's Institute on Disability/UAP, the Developmental Disabilities Council and the State's Disability Rights Center. The Housing Finance Administration set aside $1.5 million of its standard first time buyer program especially for people with developmental disabilities. The agency also budgeted an additional $100,000 for down payments and closing costs, which was matched by the Mental Health and Developmental Services Department. These funds are made available to participants as grant-like second mortgages. Federal funds from the HOPE Program also are being used for down payments, closing costs, necessary general repairs, and accessibility modifications.

Financing has been structured through an unconventional use of the individuals' HOBS Medicaid waiver dollars. The Housing Finance Agency originates the mortgages.

Ohio's Community Capital Assistance project purchases housing for people with developmental disabilities *who* require supportive living services. Individuals take an active role in selecting the type and location of the housing, *who* their roommates will be, and how the home is furnished. Existing properties are acquired with the help of local real estate brokers. The County Board of Mental Retardation/Developmental Disabilities is responsible to select or set up the local nonprofit organizations, such as a local Arc chapter, to assist consumers in their selections. When properties are sold, the proceeds must be reinvested in other acceptable housing. By 1994, 144 properties had been acquired, providing housing to 370 people. Total value of these properties was $9 million, with State participation valued at $6.5 million. The program is operated by the Ohio Department of Mental Retardation/Developmental Disabilities, using funds raised by the Ohio Public Facilities Commission.

Additional information on strategies to promote consumer-controlled housing, from the community to the State systems level, is available from the National Home of Your Own (HOYO) Alliance, a technical assistance center at the University of New Hampshire Institute on Disability/UAP. The Alliance works with State coalitions of housing finance and disability organizations to develop pilot projects of home ownership and control. A *Guidebook on Consumer Controlled Housing* (Fields and Lakin, 1995) provides information on additional State and local strategies, as well as guidance to individuals and family members on home ownership and control.

Major Related Challenges Limiting Access to Services

Large numbers of people with mental retardation are currently being denied community services. In 1993 reports from 41 States yielded a national estimate of 56,300 persons with mental retardation currently waiting for community residential services, in addition 1Q people waiting to move from institutions to the community (Prouty and Lakin, 1995). The most serious problems with respect to access to services and other programs appear to be for adult children who have remained at home beyond the age that most family members typically leave to reside in the community.Two periods are notable: 1) early adulthood at the time when children typically leave the family home and when special education entitlements end; and 2) as aged parents are no longer able to care for a middle-aged child who has spent much of his/her adulthood living in the family home.

There are a number of resource factors contributing to limited access to community services. First, as noted earlier, institutional costs have continued to rise steadily (although recently stabilized) despite steadily decreasing populations. The inability to reduce institutional costs significantly, even as populations are decreased is a major factor in the rapid increase in institution closures noted in Chapter I. In addition, some States face similar problems as they try to rid themselves of the group homes and private institutions that were capitalized as part of the first generation of community services development. These factors are compounded in many States by general constraints in State revenues and competing budget priorities.

The quality of community experiences of people with mental retardation is largely dependent on their receiving personal support and instruction. Informal support from family, friends and neighbors is extremely helpful, but some people require substantial support from paid individuals. Clearly the recruitment, training, and retention of these community support personnel will be a great challenge in the next decade. Annual staff turnover among the over 150,000 full-time equivalent direct care staff in community residential settings averages 55%75% nationwide. Only a small minority have had any specialized training prior to employment, and yet work in an increasingly dispersed social services system with much greater personal responsibility and less direct supervision than in similar roles in institutions. And still their wages remain only about 75% of their institution counterparts. Most of these individuals are young, a demographic segment which will experience a 20% decrease in size over the next decade. Obviously there is a substantial need for the development and improvement of systematic and proactive approaches to personnel recruitment, training and retention for such roles. These efforts must be system-wide, creating efforts that increase the potential pools of support providers.

***Redefining/Redesigning Quality Assurance to Reflect New Standards* of *Excellence*.** Finally, as community service goals and financing are redefined, an important related policy issue concerns the development of new definitions of quality and related systems of quality assurance. The ICF/MR program evolved as a heavily-regulated program to respond to the abuses found in many large institutions. Although less regulated, the HCBS programs in some States look more like "son of ICF/MR" than a system to protect people's rights and fulfillment of their personal goals. On the journey to inclusion, however, the pendulum is swinging back to less-regulated, less controlled systems of care. People with mental retardation are gaining more control over where and how they choose to live. States and local governments and provider agencies have begun to experiment with new approaches to quality, assurance and enhancement (see, for example, Blake, Prouty, and Lakin, 1993). The Accreditation Council on Services for People with Disabilities has totally redesigned its accreditation process around outcome objectives and indicators based on the value of services to the recipients (Accreditation Council, 1993). There is strong support for these new approaches, tempered by recognition that publicly financed programs must also protect people's health and safety. Careful definition, program development, and evaluation of quality and quality assurance that balances choice and self-determination with reasonable attention to health and safety will receive growing focus in the near future.

SUMMARY

Major changes have taken place in community housing and related services for people with mental retardation throughout the last decade. These changes include:

- A shift from serving individuals in larger facilities to serving individuals in the community

- Increased emphasis on individually tailored services, leading to greater diversity in the places where people live and in how they spend their time;

- Continuing efforts by States to secure Federal Medicaid cost-sharing of community services outside of ICFs/MR, in particular through the Medicaid HCBS program;

- More creative financing of community service programs, drawing upon multiple funding sources to meet the specific needs of individuals for housing, personal assistance, vocational opportunities, medical services and specifically designed supports;

- Improving efficiency, including institutional closures to free up resources for the tens of thousands of unserved individuals; and

- Reinventing the definitions and measures of quality and the procedures of quality assurance to reflect the goals of community living.

V. SUPPORTS FOR INCLUSION

•SUPPORTS TO INDIVIDUALS
•SUPPORTS TO FAMILIES
•SUPPORTS TO COMMUNITIES AND SYSTEMS"

Bev's and Art's Story

Bev and Art have been married for four and one-half years. Both work full time, and in their spare time they enjoy going for walks, visiting friends, going to the movies, or going out for dinner. Occasionally they attend city council meetings and offer their opinions on issues.

Bev and Art both have mental retardation. Art also has epilepsy, for which he takes daily medication. They met and fell in love in a group home. Now they live in a comfortable, onebedroom apartment. Art does not read, so the push-button telephone and his daily epilepsy medication are color *coded. Initially, the newlyweds* received daily assistance from a service provider in a semi-independent living program, but now it's only every other day, or about eight hours per week. Art reports that he likes to wake up to a clock radio instead of a staff person yelling at him. In a group home, he could not leave unless a staff person accompanied him; now he goes out whenever he wishes. Both Bev and Art agree that they prefer living with each other, rather than with 13 strangers (Wright et al., 1991).

Making inclusion a reality for people with mental retardation throughout their lives requires the availability of supports, on three levels:

> 1) **Supports to individuals**, to help each person reach his or her goals and to be included in desired activities.
>
> 2) **Supports to families and friends**, to provide them with the assistance they need in their love and concern for the individual with mental retardation, and in their efforts to support that person.
>
> 3) **Supports to communities and systems**, to help schools, community resources, businesses, and governmental systems in planning and implementing strategies for inclusion.

As illustrated in the examples of inclusive early intervention through aging and retirement, inclusion doesn't "just happen." When people with mental retardation and other developmental disabilities are meaningfully included, it is the result of plans, policies, and programs that are designed to support inclusion.

SUPPORTS TO INDIVIDUALS

Flexible and Individualized Supports

With individualized and flexible supports, all natural environments can be open to people with disabilities, including persons with severe disabilities. These supports are critical to facilitating social integration. Documented best practices in the field have shown that individuals with developmental disabilities, when provided with supports, can be fellow classmates, good neighbors, contributing coworkers, and involved citizens (Bradley, 1994).

Individual supports associated with inclusion include the following:

- *Communication support,* including assistive devices, interpreters for people with deafness, caring individuals who understand and encourage people's unique forms of communication, and communication therapies.

- *Mobility support,* including individually tailored wheelchairs, accessible transportation, mobility training, and access to transportation for recreation and leisure activities as well as for school or work.
- *Counseling and training support,* based on individual needs for support in enhancing skills in such areas as community living, personal care, and interpersonal relations.

- *Educational support,* including educational and related services provided as part of student's Individual Educational Plan (IEP) through IDEA, such as adaptations of curriculum and assignments, supplementary learning opportunities, and specialized therapies provided at school so children can go to the same school as the other children in their neighborhood.

- *Personal assistance services,* often provided by a personal care attendant whose help in getting dressed, cleaned up and out of the house can make the difference between isolation and inclusion.

- *Community connection support,* including supports through circles of friends, personal friendship building strategies, and uniquely designed supports to community involvement in religious, cultural, recreational and civic activities.

- *Employment supports,* including job exploration, supported employment, and opportunities for productive activities.

- *Environmental modifications* at home, school, work, and throughout the community as needed to eliminate barriers to inclusion.

- *Advocacy support,* including support of self-advocacy efforts as well as access to personal and legal advocacy.

Cutting across all the possible supports for inclusion is person-centered planning and coordination support: learning about each person's unique talents, goals, preferences, and idiosyncrasies as well as his or her disabilities; working with the individual -and involved family members and friends, as appropriate-to plan ways to reach personal goals in approaches that make the best possible sense for that individual; to empower people with disabilities to have real control over their lives, through listening, providing information and training, and supporting the achievement of personal goals; and by checking up periodically to make sure that supports are still working, with the ability to help arrange for modifications as needs change over time.

Planning and coordination support is the "glue" that holds services and supports together. Planning support that focuses on inclusion is often associated with *personal futures planning,* or similar planning models that start with what's important to the individual rather than what a team of professionals think is important. Personal futures planning:

- Is based on a positive view of people with disabilities, rather than seeing them as having "defects" and impairments to be "fixed;"

- Is comprised of goals that anticipate that positive changes, activities, and experiences will increase, rather than focusing on decreasing specific negative behaviors;

- Uses ideas and possibilities for community sites and settings, and for valued roles in those settings; and

- Includes goals that are important to the individual even if some of them seem outlandish, unrealistic, and impractical or require major changes in existing patterns (adapted from Mount, 1994).

An individualized support plan lays out the specific supports, strategies, and milestones for reaching the goals in the personal futures plan or equivalent.

Trends and Resources for Individual Supports

There is growing emphasis on supports to individuals throughout the field of mental retardation and of disabilities in general. The new definition of mental retardation adopted by the AAMR (1992) incorporates the concept of supports as an integral component of the assessment process, along with the concept of five valued accomplishments: 1) community presence; 2) choice, autonomy, and control; 3) competence, including the opportunity to express one's gifts and capacities; 4) respect and having a valued place in one's community; and 5) community participation/network of personal relationships (Luckasson and Spitalnick, 1994). As developed by the AAMR, supports relate to these desired accomplishments as follows:

Supports refer to an array, not a continuum, of services, individuals, and settings that match the person's needs... [and] should be matched in the context of the person's desires. Supports are resources and strategies that promote the interests and causes of individuals ... that enable them to secure access to resources, information and relationships as part of inclusive work and living environments and that result in enhanced interdependence, productivity, community inclusion, and satisfaction. Support resources are individual resources, skills, and competencies and the ability and opportunity to make choices, manage money, manage information, and the like. These resources are also other people, whether family, friends, coworkers, people one lives with, mentors, or neighbors. Technology might also be a form of support resource and includes assistive devices, job or living accommodations, or even behavioral technology. Another support resource encompasses habilitation services that may be needed if the other naturally occurring resources are either not available or not sufficient to assist the person in a desired living, working or school environment. Clearly, these services, whether provided by a specialized disability agency or a generic service agency, are a subset of supports (Luckasson and Spitalnick, 1994).

Although rhetoric about moving to a supports focus is not always accompanied by real changes in the service system, there are growing signs that supports are becoming central to designing new approaches and revamping existing programs:

- Early intervention services through IDEA Part H require Individual Family Support Plans.

- States have expanded the use of Medicaid optional services to finance supports to individuals, including personal care/personal assistance services, rehabilitative services, coordination and related support through the targeted case management option, and prosthetic devices.

- Trends in the Medicaid HCBS waiver reflect the expanded availability of supports such as case management, personal assistance, environmental modifications and adaptive devices when States renew their waivers, as well as significant growth in the number of individuals covered.

- Supported living and supported employment continue to grow, as described in the previous chapters.

- The Technology-Related Assistance for Individuals with Disabilities was reauthorized in 1994, continuing a program of grants to States to increase coordinated access to assistive technology, as well as information and assistance to individuals provided by the National Institute on Disability and Rehabilitation Research (NIDRR).

Assistive technology has special importance for inclusion, as it removes communication and accessibility barriers that keep people isolated. Bob Williams, the current Commissioner of the Administration on Developmental Disabilities (ADD), uses a

"Liberator," a communication device that allows him to speak through his computer. He relies on the Liberator in managing a more than $122 million Federal agency, as well as to organize and communicate information in other activities. He is helping ADD to collaborate with NIDRR and other Federal agencies to promote access to assistive technology, including training, ongoing support, and opportunities for self-instruction, as well as hardware and software (Williams, 1995).

In Ohio, the Developmental Disabilities Council brought together a coalition to improve and expand personal assistance services. The Coordinating and Expanding Personal Assistance Services project supports consensus building on an advocacy action plan that is supported by funding agencies as well as consumers and advocates. The project works closely with a program funded by ADD, administered by United Cerebral Palsy Associations, Inc., to train 30 people with disabilities to advocate for personal assistance services (Zierman, 1995).

The Maine Developmental Disabilities Council supported the Maine Meeting Place, an on-line service to link people with developmental disabilities and family members with each other and with the service system. A keyboard and a small box linking the keyboard with the phone line and the television is all that is needed; a computer is not required. During the first year the network expanded to 1,500, including many people in rural areas, and tens of thousands of messages have been placed on the board. The project has demonstrated that people can communicate using low-cost ($25-$75) low-tech equipment obtainable on the surplus electronic market, and that desire for information and assistance overcomes people's fears of technology (Zierman, 1995).

Melvin's Story

Melvin is a 52 year old man with cerebral palsy and mild mental retardation. He is unable to walk and has only limited use of his upper extremities, making him dependent on others for most of his daily care. Melvin has difficulty articulating words clearly, but he cheerfully manages to make himself understood.

Melvin grew up in a close family, with seven brothers and sisters. All of his family took part in his care, but his mother was the primary caregiver who pushed his wheelchair, bathed and toileted him, and put him to bed. Melvin lived with his mother until she died from a heart attack in 1985. After her death, he lived for a short time with one of his brothers, but after less than a year the brother became ill and Melvin had no choice but to move into a nursing home.

In the nursing home, Melvin's independence was severely curtailed. He couldn't shower or use the toilet when he chose. There was no one to push his wheelchair, so Melvin spent a lot of time sitting in the day room or the hallway. After a few years his wheelchair broke, and rather than pursue proper replacement, the nursing home loaned him one that didn't fit him well. The nursing home did not encourage independent mobility, and after a while Melvin's upper extremity function decreased to the point that he could no longer feed himself or turn on his radio. He had a few friends in the nursing home, but there was not much for them to do.

In 1991, Melvin was selected for Illinois' CILA (Community Integrated Living Arrangements) program. In preparation for community placement, he was referred to the Assistive Technology Unit at the University of Illinois at Chicago for seating and wheeled mobility, augmentative communication, environmental controls, and any other equipment that might increase his independence. Through the assistive technology support, Melvin was fitted with a head-controlled power wheelchair while he was still in the nursing home. His new mobility immediately made him more optimistic. He was no longer dependent on others to move him around, and he didn't have to sit in one place all day long. He gained additional independence through assistive devices that enabled him to feed himself again, to use the toilet without assistance, and to control lights, his radio, television and a fan.

In October 1994, Melvin finally moved into his community residence. He lives with two other men and an aide who helps them with activities of daily living, shops and cooks, and provides transportation. Melvin loves his new home. He is beginning to feel like a home owner and takes pride in paying his bills and share of the rent. The best part of the new residence is the opportunity it offers for self-determination. Now Melvin can visit his family whenever he wants. He can decide for himself whether to go to work or take off a day. If he wants to go the park, baseball game, or a show, he goes by himself using his new wheelchair. As Melvin sums up his new situation, "I can go anywhere and I can do anything."
Adapted from Mendelson, 1995.

United Cerebral Palsy Associations, Inc. has worked with its local affiliates and private foundations to create TECH TOTS Libraries across the country. TECH TOTS Libraries are parent-run centers with toys and equipment that can be borrowed by families with infants and young children with disabilities, to use at home. Trained Parent Coordinators are available to help other parents and their children choose toys and equipment, learn how to get the most out of using the items, and compare notes with other families (Gradel and McMeekin, 1995).

SUPPORTS TO FAMILIES

The term [family support] is best defined as an array of practical supports that are determined by individual family needs. Ideally, family support is flexible, focuses on the entire family, changes as family needs change, encourages families to use natural community supports, and provides a convenient and central access to services and resources.
Source: Family Support *Services in the United States. An End of Decade Status Report* (Knoll et al., 1990)

Families want to keep their children with developmental disabilities at home. Home families need various supports and services to strengthen them as primary caregivers; to prevent inappropriate out-of-home placements and maintain family unity; and to reunite families with members who have been placed out of the home, whenever possible. Families and their family members with disabilities benefit most from access to a flexible array of supports that can be used on an as-needed basis, including:

- Respite care
- Help with special disability-related expenses
- Training and counseling
- Home and vehicle modifications
- Peer support
- Information and coordination support
- Advocacy

Although most family support programs focus on families with children with disabilities, many adults with mental retardation still have parents as their primary caregivers. The National Consumer Survey found, for example, that this was the case for 71% of adults with mental retardation aged 18-21 years, 41% of those 22-34 years, 28% of individuals 35-49 years of age, and 13% of those aged 50-64 years. The portion of adults with cerebral palsy still cared for by their parents in these age groups was even higher (Knapp, 1994).

The Human Services Research Institute (HSRI), a leader in research and technical assistance on family support, summarizes information on families and their need for support as follows:

> No two children or families are exactly alike. Each has unique needs, strengths, capabilities, and preferences. Many families, however, find that the "ordinary" challenges faced by others can become "extraordinary" when providing care to a child at home with disabilities. Families who provide care at home must learn how to implement specialized care routines while attending to normal family functions. Because of the added pressure, these families can face a variety of challenges over and above the normal responsibilities associated with raising a child.

Available research suggests that the difficulties actually experienced by individual families are related to multiple factors including the seriousness of the family member's disability, the presence of challenging behavior, family characteristics, specific parenting patterns, the family's capacity for coping with adversity, and the availability of community support services. As a result, though not all families who provide care at home have extraordinary problems, all are more "at risk" for having difficulties than families without members with disabilities (Agosta and Melda, 1995).

Most family supports are financed with State funds. A national survey in 1992 (Melda and Agosta, 1992) identified a total of 69 programs in 46 States, with 27 States expending $1 million or more on family supports. States reported that a total of nearly 199,000 families received family support services, based on the last year for which data were available. Based on data for 66 programs in 43 States:

- 38 programs were funded with 100% State dollars
- 11 programs were funded with 75-99% State dollars
- 17 programs were funded with less than 75% State dollars

The 38 programs funded with 100% State funds alone represented more than $79 million in State funds (Melda and Agosta, 1992).

Family supports promote inclusion in particular by helping families avoid out-of-home placements, and by supporting community connections. Although providing care at home to a child with disabilities brings many challenges, most families reject out-of-home placements (Agosta and Melda, 1995).

Family supports make sense from a broader public policy perspective as well as for the families involved. A recent analysis of family costs in caring for their adult son or daughter with mental retardation or related disabilities noted that "Out-of-pocket expenditures devoted to home-based care represent demands not placed upon public resources ... The marginal costs of supplementing and encouraging family-based care may represent a far more efficient use of limited service resources than the outright purchase of additional out-of-home capacity ... Family-based care of adults with [mental retardation/developmental disabilities] may be central to the national portrait of services for both demographic and economic reasons" (Fujiura, Roccoforte and Braddock, 1994).

Aaron's Story

Aaron was born prematurely with cerebral palsy and sensory impairments. He needs a tracheotomy tube to help him breathe; a gastrointestinal tube to help him eat; and other extensive medical, health, and social supports. Aaron's mother, father and brother want him to live with them at home. Because no single funding source is flexible enough to meet all of Aaron's and his family's unique needs, the family uses a combination of private, local, State and Federal resources.

Private health insurance covers medical and dental care, hospitalization, some medicines, Aaron's special food formula, his wheelchair, and some other equipment. Aaron is eligible for some Medicaid waiver program home-based services and equipment that the family's private insurance does not cover, such as a home health aide to be with him after school. The State's Family Support Program allowance of $250 per month covers physical therapy at home, with his parents assisting, and other special needs, such as the wheelchair lift on the family van. Aaron and his family also receive supportive home care under their State's Community Options Program and respite care through the county developmental disabilities agency. Aaron now attends a typical class in a regular neighborhood school, with supports for both himself and his teacher. Even though it's complicated, the funding puzzle helps ensure that Aaron lives at home and not in an institution, which could cost more than $50,000 annually, and that he and his family get the quality services they need.

Adapted from Wright et al., 1991.

The National Conference of State Legislatures suggests the following points to consider in developing policy for family support programs:

- Assistance with at-home care enhances a family's capacity to provide care and improves the quality of life for the entire family, including the member with a disability.

- Responsive family support programs provide a wide array of support services for families, whether they are biological, foster, or adoptive families. Families' needs vary, and each family should be encouraged to select those services that are most appropriate to build upon its strengths and to meet its needs.

- Support services should be available to families from the onset of the disability and should be designed to reach out to families.

- Access to family support services should be timely and convenient for families.

- As the person with a disability reaches adulthood, the focus of support programs should shift to choices for the individual, whether he or she lives with the family or is in another community setting.

- The public sector cannot be counted on to meet all family needs. Support services should build on the framework found in the family, the neighborhood, and the community. Employers and private health insurance carriers also should be called on to provide support.

- Families should be allowed to control resources, making the system less "provider driven" and more "consumer-driven."

- Children with disabilities benefit most from training in natural settings where they can learn independent living and work skills that will enable them to live in the community once they become adults or choose to live away from the family home.

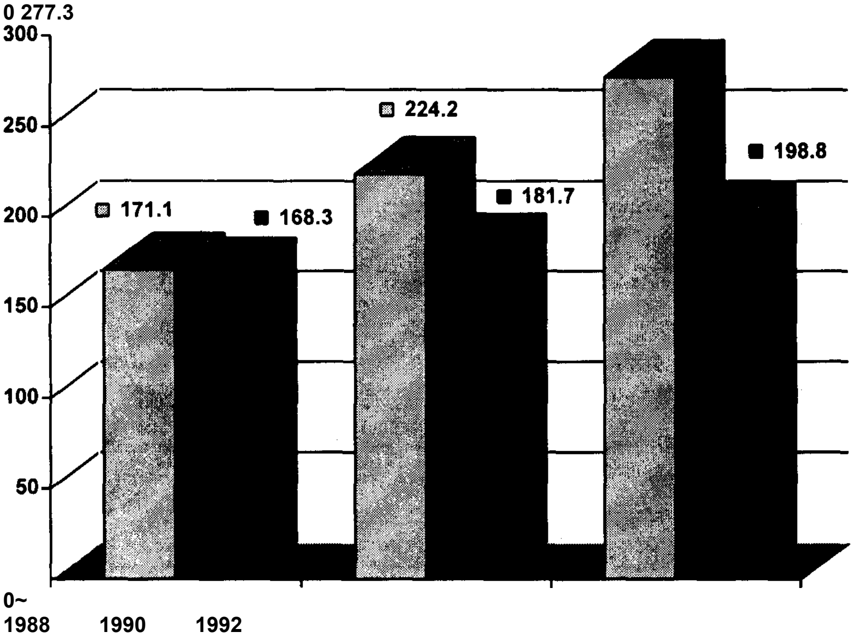
- Strengthening the family structure may be less costly to the State than funding expensive alternative residential options (Wright et al., 1991).

Trends and Resources for Family Supports

> *"You have no idea what it takes to raise an autistic child with mental retardation. It is not easy. We do it because we love our child, not for the SSI check."*
>
> Parent, quoted in The Arc (1995).

Family support resources and numbers of families receiving supports continue to increase as more and more States make a commitment to helping families that include children with disabilities. Between 1988 and 1992, for example, family support expenditures increased from $157.9 million to $279.4 million, and the number of families increased from 168,300 to 193,800, as illustrated in Figure 8.

Figure 8 Trends in Family Support



Source: Supporting Families (Bauer, 1994).

- Spending (in $millions)
- Families Served (in thousands)

A recent (1995) national survey suggests that all States provide at least some supports to families with a child with disabilities, although many reach only a small number of families (Agosta and Melda, in preparation).

The ultimate flexibility in supporting families is being achieved through subsidy and voucher programs. These approaches are often favored because of the diversity in family needs, the opportunity for families to purchase less expensive informal supports, and the simplicity in administration. As of 1995, over 25 States have implemented some type of cash assistance program to help meet family needs (Agosta and Melda, 1995). HSRI has conducted extensive reviews of these programs and their effects on families. Comments from parents receiving cash subsidies in three such programs include the following:

- Illinois:
  - The program helped us to buy the equipment we needed to help our child develop.
  - Our family member was able to get high quality hearing aids that we would not have been able to afford.

- Iowa:
  - It is the only program that has been willing to help us financially and recognize our needs.

- The extra money helps us to keep our child at home.

•Louisiana:
- Having a child who is quadriplegic is very expensive. money helps us get through everyday living.
- It enables me to afford to keep my daughter at home.

Although most family support programs are funded primarily with State dollars, resources also are available through the Medicaid program, in particular the HCBS waiver program. States are offering respite care, case management/coordination support and home- and community-based services through their HCBS waiver programs:

> •The New Mexico HCBS waiver covers respite, homemaker, personal care, psychosocial services, private duty nursing, physical therapy and case management for children with disabilities.
>
> •The Maryland HCBS waiver covers case management, private duty nursing, and durable medial equipment and supplies.
>
> •The Texas HCBS waiver funds respite care.

The waiver also can be used to expand Medicaid eligibility to children with disabilities and their families. In addition, Medicaid Model 50/200 waivers are being used to cover family supports and specialized services to individuals who would otherwise be in a hospital or institution. States with the TEFRA Medicaid eligibility option can finance family supports and services with combined Federal/State Medicaid dollars by ignoring parental income when determining a child's eligibility for Medicaid services, if the child would otherwise be institutionalized (Bauer, 1994).

Families also receive flexible support through the Federal Supplemental Security Income (SSI) program. Low income children with disabilities are eligible to receive cash payments adjusted to family income level, as well as possible State supplementation in 27 States (Agosta and Melda, 1995). As the Social Security Administration has revised childhood disability determination to respond to a Supreme Court ruling on procedures used in the past, the number of children with disabilities receiving SSI benefits has risen from 296,000 in 1989 to 847,000 as of June 1994. A significant portion of new awards have gone to low income children with mental retardation. SSI also makes the child eligible for Medicaid, a major benefit in making services affordable. As summarized by the parent of a child receiving SSI in a recent survey:

If *my son loses any-services, I* will not be able to care for him and then he may be institutionalized. I have no future right now. I pray that I may someday soon be able to work and get insurance and that I will be able to take care of my son. But he needs SSI now (The Are, 1995).

Virtually every State has success stories to share in family support strategies, while acknowledging that more needs to be done. State Developmental Disabilities Planning Councils have been active in several States to demonstrate the benefits of family support programs and to support family focused policies:

> The Idaho Developmental Disabilities Council sponsored a successful demonstration of family support services. The Family Support Initiative provided a forum for families and professionals to define a comprehensive, family-directed and community-centered system of support services to meet the unique needs of families all over the State. Public awareness activities and the Family Support Network have heightened understanding among policy makers and the general public of the need for family support, and legislation has been readied for introduction with endorsements from key organizations. Idaho's system is expanding to strengthen the role of the family and reunite and/or retain the family unit through flexible policies, information, and financial and personal support (Zierman, 1995).

The Minnesota Story

When a class action lawsuit forced Minnesota to deinstitutionalize services for children with developmental disabilities, the State redefined its public policy to conform with the philosophy that all children, regardless of disability, have a right to grow up in a family home and that families need support in their efforts to care for their children with disabilities.

In the ten years (1980-1990) that the Disability Law Center collected data on the effects of deinstitutionalization, the number of children residing in Minnesota regional treatment centers (State institutions) dropped from 245 children to only three. The number of children living in private ICFs/MR dropped from 585 to 161; 127 children were placed in an alternative living arrangement through some type of Medicaid HCBS waiver. The total number of children living in alternative out-of-home arrangements decreased from 830 in 1980 to 291 in 1990. In addition, more than 1,800 Minnesota children and their families were receiving necessary supports in the community through the State's Family Subsidy program, Medicaid HCBS waiver services for inhome supports, and aggressive use of the TEFRA option.

The State also realized significant cost savings through the deinstitutionalization and family support initiative. Although overall expenditures increased 20 percent, the number of children with developmental disabilities and families being supported increased by 240 percent.

(Adapted from Bauer, 1994).

Family support legislation was enacted in Louisiana following broad-based advocacy and consensus building, actively supported by the Louisiana Developmental Disabilities Council. In 1994 the Legislature appropriated $1.4 million for family support subsidies, reaching 500 additional families of children with severe disabilities. Families receive a cash subsidy of $258 per month to help offset the extraordinary costs of carrying for some children at home and to reduce the need for institutionalization. Louisiana also adopted the Medicaid TEFRA option, bridging the service needs for many children who would otherwise not be eligible for Medicaid while living at home (Zierman, 1995).

The Michigan Developmental Disabilities Council joined with the Association for Retarded Citizens (now The Arc) and other advocacy groups to support passage of the Family Support Subsidy Act in 1983. A primary rationale for the legislation was the need for children with disabilities to remain with their families, coupled with the hope that the State would realize cost savings by preventing out-of-home placements. Michigan has been successful in reducing institutional populations, and has virtually no children in its remaining State institutions. The Michigan program provides direct cash subsidies of approximately $225 per month to families of children with severe disabilities who would otherwise require expensive institutional care. Families with taxable incomes above $60,000 are not eligible. Officials believe the program is cost-effective. The average cost of the subsidy per child per day is $7.50, compared to $200 or more per day for institutional care (Wright, 1990).

Wisconsin's family support program began in 1984 as a demonstration project funded by the Developmental Disabilities Council, followed by legislation to make it a statewide program in 1985. The program is noted for its flexibility and family/consumer orientation. Families of children with severe disabilities are eligible for up to $3,000 worth of services annually, regardless of their income. The program pays for services and supports tailored to the unique needs of each child and family. Families can choose services such as child care, counseling, architectural modifications, unreimbursed medical and dental expenses, nutritional supplements, clothing, special equipment and supplies, homemaker services, in-home nursing, in-home training, respite care, and vehicle modifications. The program is administered at the county level, where staff work with families to encourage creative use of community resources. The program requires that 90 percent of the family support funds allocated to the counties be spent for services (Wright, 1990).

The NCSL Task Force on Developmental Disabilities has developed the following recommendations to State Legislatures on family support:

1. Create and fund family support programs for those families who provide care at home for their children with developmental disabilities, adhering to the following guiding principles:

- The program should support the family rather than the service provider;

- All children, regardless of disability, have the right to grow up with a family, biological or otherwise, and need enduring relationships with adults;

- The role families pay in providing care at home must be recognized and supported so that family members are enabled and empowered to make informed decisions; and

- The means for supporting family efforts should build on existing support networks and natural sources of support within the community and should be culturally sensitive.

2. Provide flexible programs to meet the needs of individual families, recognizing that their needs change over time.

3. Require coordination of all family support-related activities undertaken by State agencies, such as departments of developmental disabilities, education, human resources, public welfare, and mental health.

4. Use all public and private sector resources available to families, including government agencies, private employers and private health insurers.

5. Ensure adequate training for persons who provide family support.

6. Design all family support initiatives to promote the integration of persons with disabilities into the community.

7. Monitor the quality and effectiveness of all service programs through systematic reviews, which should include input from consumer families.

8. Define family support as a benefit program that is not included as income for purposes of State taxation.

9. Provide independent living and work training to youth with disabilities to facilitate transition into adulthood and to promote independence (Wright et al., 1991).

SUPPORTS TO COMMUNITIES AND SYSTEMS

As defined in the Developmental Disabilities Assistance and Bill of Rights Act, community supports are activities, services, supports, and other assistance which help communities respond to the needs of individuals with developmental disabilities and their families, develop local networks of informal supports and make communities accessible and better able to offer their resources and opportunities to people with developmental disabilities (Zierman, 1995). Communities and systems need to be supported in making inclusion a reality for people with mental retardation and other developmental disabilities, just as individuals and families need supports. Supporting inclusion means providing supports to:

- Day care centers and schools,
- Employers and co-workers,
- Businesses and services,
- Governmental agencies,
- Religious and civic organizations, and
- Media.

People who are familiar with the benefits of inclusion and who are used to participating in activities that include people with mental retardation/developmental disabilities may not yet be in the majority in all communities and settings. Those concerned about inclusion need to acknowledge that some community members, especially adults, may not feel comfortable in interactions with people with disabilities. They may be unsure how to relate to someone with mental retardation through lack of experience, and may be afraid of doing something wrong or inappropriate. Without losing sight of the expectation of inclusion and the commitment to reject discrimination, support and encouragement can be offered, with confrontation as the last resort.

People with developmental disabilities have long been the object of negative attitudes and stereotypes. They have been pitied, shunned, and seen as having little to contribute to their communities. These beliefs have been perpetuated by the segregation and isolation of people with developmental disabilities. Fortunately, there are indications that attitudes may be changing, at least regarding disability in general. As people with disabilities, their families and friends have demanded to be included in the mainstream, the public has seen that people with disabilities are valuable friends, neighbors, classmates and co-workers. A 1991 Harris poll of the general public found that half of those surveyed knew someone with a disability. Of those individuals, more than half had a friend with a disability, one-fourth had a family member with a disability, and one-fifth a co-worker with a disability. In addition:

- 92% of those surveyed believe that society will benefit economically if people with disabilities are assimilated into the workforce, and

- 82% see the employment of people with disabilities as a "boost" to the nation, not a "threat" to others' jobs (Zierman, 1995).

Public awareness and education activities are a mayor support to communities -in promoting inclusion and in combating the negative attitudes of the past.

Supporting communities and systems also encompasses infrastructure development, including funding initiatives, curriculum development, training programs, and ongoing quality enhancement activities. In Nebraska, the Legislature and Governor agreed in 1995 on a Blue Print for Action, calling for $27 million in new funding for community services and supports to people with mental retardation and other developmental disabilities over the next biennium. The plan will be used to implement the State's Developmental Disabilities Services Act of 1991 (LB 830). The act broadened eligibility to include individuals with developmental disabilities other than mental retardation, established an entitlement to developmental disability services following graduation from special education, reformed systems for coordination support (case management) and quality assurance, and provided for overall enhancement of the community service system. Implementation was deferred from July 1993 to July 1995 due to State budget constraints.

Nebraska's *Blue Print for Action* was enacted to reduce waiting lists for community-based services and to fund services under the entitlements in the Developmental Disabilities Services Act. New funds of $27 million earmarked for service expansion, funded through a combination of increased Federal funds in an expanded Medicaid HOBS waiver program, fees paid by service recipients, and other sources. State general revenue sources reflect only about 10 percent of the new money. The additional resources will be used to:

- Meet the needs of an expected 370 youth who will be transitioning out of special education programs over the next two years;
- Extend service coordination to an additional 1,255 individuals;
- Purchase services and supports for over 1,000 people with developmental disabilities currently on waiting lists; and
- Establish outreach and intensive training services to meet the needs of people going through behaviorally-related crises.

The plan also calls for cost-sharing on a sliding scale, with fees being paid by individuals and families of those receiving services (NCSL, 1995).

Trends and Resources in Supports to Communities and Systems

The Americans with Disabilities Act (ADA) challenges businesses, employers, communities, and public agencies to break down barriers to inclusion. Since July 26, 1994, all provisions of the ADA have been in effect. Title I of the ADA prohibits discrimination in employment in all businesses and programs with 15 or more employees, and requires reasonable accommodations in hiring, training and promoting people with disabilities. Other sections of the ADA address access to services and employment in State and local government; require accessible public accommodation in, stores, hotels, commercial operations and recreation and cultural activities; and mandate equal access in telecommunications for individuals with hearing and/or speech impairments. Accessibility and non-discrimination under the ADA includes people with mental retardation.

Many State Developmental Disabilities Councils and other advocacy organizations have worked with Federally funded resources to promote compliance with ADA, to inform people with disabilities about their rights under ADA, and to provide consultation on cost-effective compliance. ADA compliance also is supported in each Federal region by a Disability and Business Technical Assistance Center (DBTAC).

The Indiana Story

The Indiana Developmental Disabilities Council actively promotes the month of March as Disabilities Awareness Month, focusing on grass roots participation in consciousness-raising activities through statewide media coverage. Seventeen different information packets were offered in the 1994 campaign, including: Editorials, Art Contest, Awareness in the Classroom, IndiciaBank Receipts Campaign, Library Display and Story Hour, Mayoral Proclamation, Print Media Public Service Announcement (PSA), Radio Breakfasts, Radio PSA, Recognition Awards, and Special Events-Working with Local Clergy. Orders for nearly 3,900 packets were filled. The Council also widely distributed its *Awareness Activities* booklet and Interacting with People *with Disabilities* brochure.

The private sector joined the Council in these efforts. The cost of printing the posters and bookmarks on disability was covered by Ameritech. Eight Indianapolis-area grocery stores, banks and utility companies agreed to participate in the campaign and use the Disabilities Awareness Month logo. A news release announcing Disabilities Awareness Month was sent to every daily and weekly newspaper in the State. Three million logo impressions were created.

The annual campaign has grown from year to year. In 1994, 33 newspapers participated, up from 20 in 1993, and orders for materials also increased. The total number of impressions measured for 1994 was over 3 million, compared to 2.5 million the previous year. An estimated two million more people were reached through television and radio PSAs, newsletters, mail stuffers, grocery bags, posters, and brochures.

The Indiana Developmental Disabilities Council also collaborated with the Calumet County Boy Scouts of America to develop and distribute Scoutvideo93. The video is a training resource for adult and youth Scout leaders on disabilities awareness and effective techniques for including youth with disabilities in Scouting. It has been distributed to Scout leaders throughout Indiana, and is available to Scouting leadership nationwide (Zierman, 1995).

The Pacific Disability Business Technical Assistance Center (Pacific DBTAC) is one of ten centers set up around the nation through the funding of a five year grant from the National Institute on Disability and Rehabilitation Research. The Pacific DBTAC serves Federal Region IX, which includes Arizona, California, Hawaii, Nevada and the Pacific Basin. Its purpose is to promote compliance with the ADA by building a partnership between the disability and business communities in order to promote full and unrestricted participation in society for persons with disabilities through education and technical assistance.

The Center operates a toll-free 800 technical assistance hotline, conducts region-wide dissemination of ADA-related materials, coordinates and conducts regional conferences, individual state training workshops, and local trainings and presentations. Pacific, DBTAC also maintains a technical assistance library, publishes a newsletter and coordinates the provision of on-site technical assistance (Jones, 1995).

Supporting Rural Communities in Alaska

HOPE Cottages, one of Alaska's mental retardation service provider agencies, developed Community Resource Teams to help people remain in their home communities. The purpose of the Community Resource Teams is to allow local communities to develop and control developmental disability services that are desired by the community. HOPE started this concept about seven years ago, as a result of requests for services by rural communities where there were generally no or only a few services. These teams were started so that local communities could make decisions about what services were needed, and to be involved in planning and managing those services. There are three Community Resource Teams: Dillingham, Unalaska, and Kodiak.

In Dillingham, the CRT is made up of parents, family members and individuals with disabilities. This group, in cooperation with HOPE, responded to a Request for Proposal from the State, and received funding for several services, including natural home supports, foster care/shared care, employment and residential supports. They were able to help one man return home to his family after living many years in an institution and a temporary placement in Fairbanks. He is now living in his own apartment in his home community and sees his family often. In Unalaska, respite and home care services have been established through a CRT. In Kodiak, public meetings were being held to determine what services the community wants and to establish a CRT.

The agency's preference is that each of these CRTs will become part of a local organization and that HOPE's involvement will only be in assistance in getting started, or to provide technical assistance later on an as needed basis.
Adapted from Anderson and Gross, undated.

Compliance resource information for States, communities, employers, and individuals with disabilities is available through several Federal agencies and programs, including the Civil Rights Division of the Department of Justice, the Department of Transportation, the President's Committee on Employment of People with Disabilities, the Equal Employment Opportunities Commission, the Architectural and Transportation Barriers Compliance Board, and the National Institute on Disability and Rehabilitation Research (NIDRR). Technical assistance on ADA compliance is available through NIDRR on (800) 949-4232. The Arc's Access ADA Initiative, funded by the Department of Justice, focuses specifically on the application of the ADA to people with mental retardation and other cognitive disabilities. The Americans with Disabilities Act. Developmental Disabilities Councils Implementation Activities (Musheno, 1994), available through the National Association of Developmental Disabilities Councils, provides additional information on resources and strategies to promote inclusion through ADA compliance.

Legislative committees and task forces have played a major role in developing supports to systems and communities. In Utah, for example, a Legislative Task Force for Persons with Handicaps challenged the State agency, the Utah Division of Services for People with Disabilities (DSPD), to focus more clearly on people's quality of life. The DSPD worked with the HSRI to develop a new quality assurance system. They formed the Quality Assurance Academy of developmental disability stakeholders, including two members of the Utah Legislature, to design their approach. The Academy began by defining choice, community membership, individualization, and opportunities for full participation in Utah life as the value base. The State developed standards that emphasize internal provider quality assurance systems. This is coupled with external assessments of developmental disability services based on four standards:

1) Personal growth and development of individuals served;
2) Consumer participation in his/her own individual program plan;
3) Consumer participation in Utah life; and 4) The provider's own quality assurance plan.

At the same time, Utah has shifted the focus of its program survey process from paper and process compliance to observing the quality of real world outcomes for the individuals receiving services, including consumer satisfaction surveys. DSPD also is expanding its technical assistance activities, to help providers enhance the quality of developmental disability services being provided (Jaskulski, 1994a).

The Kansas Story

The Kansas Developmental Disabilities Reform Act signed on June 6, 1995, culminates three years of consensus building on State policy. The Act states that it will be the policy of the State to assist people who have developmental disabilities to have:

- Services and supports which allow people opportunities of their choosing to increase their independence and productivity, as well as integration and inclusion in the community;
- Access to a range of appropriate services and supports; and
- The same dignity and respect as people who do not have a developmental disability.

The Developmental Disabilities Reform Act also creates a single point of entry in each region. The current community mental retardation centers are being re-designated as Community Developmental Disabilities Organizations to serve that function. They will be responsible for determining eligibility as well as serving or arranging for services as needed by individuals with developmental disabilities in the area, within the limit of legislative appropriations.

State Developmental Disabilities Councils are a significant resource to States in public education and consensus building activities. Many Councils also have directly supported infrastructure enhancements, including the development of training curricula for service system personnel, research on financing options, and designing reforms to quality assurance systems:

> The Louisiana Developmental Disabilities Council provides staff support to the Louisiana Coalition for Inclusive Education, and the Council's Assistant Director serves as the Cochairperson. Several Council members are also Coalition members. In its three year existence, the coalition has been successful

in moving inclusive education to a major State agenda item. The Louisiana Human Development Center, a Developmental Disabilities University Affiliated Program, was funded by the State Department of Education to establish and operate the Louisiana Clearinghouse and Technical Assistance Project on Inclusive Education. The Program in Severe Disabilities at the University of New Orleans joined with the State Department of Education to obtain a Federal systems change grant in inclusive education. Both projects provide training and technical assistance to school systems. The two universities and the Department of Education are all members of the coalition. The Developmental Disabilities Council expands access to the resources on inclusive education by providing funds to reimburse local school systems for travel expenses and substitute teachers for faculty to attend workshops on inclusive education and to visit schools where inclusive education is working (Zierman, 1995).

The Texas Developmental Disabilities Council produced *The ABC's of Inclusive Child Care,* a videotape about three children with disabilities in regular child care settings. Also featured are two child care center directors, two teachers, a teacher's aide, two parents and two case service coordinators. The video uses imagery and story-telling to convey that children with disabilities who are included learn to develop the relationships that will benefit them throughout their education and on into employment and adult responsibilities. The Council has distributed over 700 copies of the videotape and continues to respond to requests (Zierman, 1995).

In Kentucky, emergency response personnel do not receive any standardized training in disability-related issues. Graduates of emergency training programs had difficulty recognizing specific disabilities and in interacting with persons with speech, hearing or other limitations. Contact often was frustrating for both the responding personnel (fire, police, and emergency medical staff) and individuals with disabilities. People with disabilities sometimes were arrested as a result of misperception and misunderstanding by the responding officers. The Kentucky Developmental Disabilities Council developed "Project Aware" to address these issues, providing training to over 1,000 police, fire and emergency medical staff. The project has led to discussions on how to incorporate this training in the standard curriculum for all emergency response personnel (Zierman, 1995).

Another source of support to communities and systems has been the increasing opportunity for interaction between people with and without disabilities, and the related visibility of individuals with disabilities in the media. Children without disabilities are increasingly able to have classmates with disabilities, who are also their friends and playmates. A young man with Down Syndrome starring in the television series "Life Goes On" brought home the message of the capabilities of people with mental retardation, in real life as well as in the fictional descriptions of his accomplishments. Although barriers of attitude and segregation are a long way from being torn down, there is much reason to be optimistic for the future.

VI. DEVELOPING POLICY FOR INCLUSION

•EMPOWERMENT AND INVOLVEMENT
•PLANNING THE JOURNEY TO INCLUSION
•RESOURCES FOR INCLUSION STRATEGIES

The passage of the Americans of Disabilities Act signals a national policy that dependency, charity and welfare for people with disabilities are vestiges of the past. The emphasis now is on empowering people with disabilities with self-sufficiency, independence and the ability to make their own choices. **Evan Kemp (1990).**

Policy makers at all levels of government are looking at ways to promote inclusion of people with mental retardation and other disabilities, as community members, co-workers and neighbors. Planning for inclusion encompasses the frank assessment of current policies that affect inclusion, identifying barriers to inclusion, and building consensus on policies and strategies to make inclusion a reality. One of the most powerful resources to policy makers in the journey to inclusion is the empowerment and involvement of individuals with mental retardation/developmental disabilities and their families. Their active participation ensures that services and supports are cost effective responses to the **customer's** needs, as well as reflecting the values of those most affected.

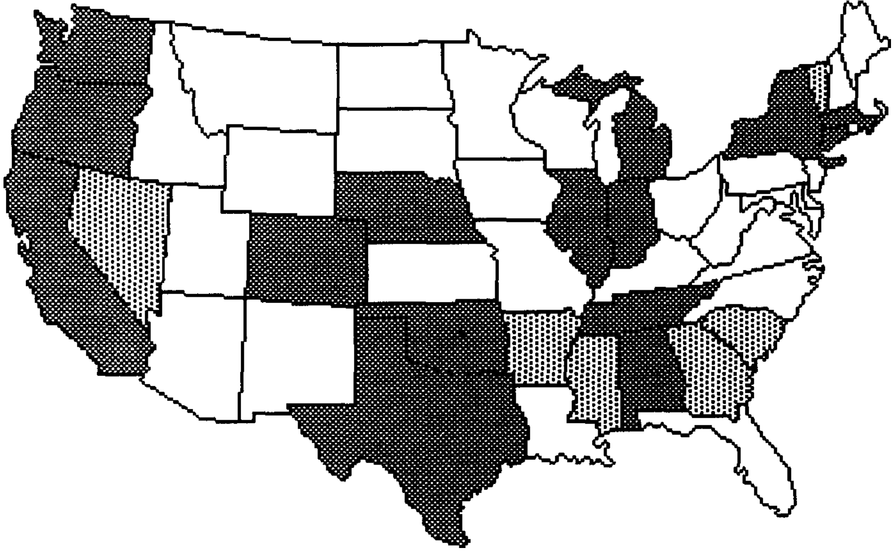
People with mental retardation and their families are increasingly involved in making decisions about their lives, in determining the services they need, and in shaping the policies that affect their access to supports. Although much more progress is needed, involvement is increasing at local, State and national levels.

Some of the most exciting activity in empowering and involving individuals with mental retardation is in self-advocacy. Over the past 20 years, self advocacy groups have formed from the community to the national level. People First, the first such group, began in Oregon in 1973, and grew rapidly throughout that State and beyond. A 1984 study identified 152 self-advocacy groups in the United States and British Columbia, the site of the conference attended by people with mental retardation from Oregon that inspired what became the first People First group (Browning, Thorin and Rhoades, 1984). The 1990 Self-Advocacy Directory (Association for Retarded Citizens [the Arc], 1990) listed 380 groups in the U.S. By 1994, a survey conducted by People First of Illinois and the University of Illinois at Chicago identified a total of 505 active self-advocacy groups in 43 States, with groups in formation in two additional States (Longhurst, 1994). Although most self-advocacy organizations are local groups, the survey identified 15 States with statewide self-advocacy organizations directed by people with developmental disabilities, as illustrated in Figure 9. Three additional States were reported to be in the process of developing statewide organizations (Longhurst, 1994).

Figure 9

State Self-Advocacy Organizations, 1994

States with Self-Advocacy Groups and a State Organization
States without Self-Advocacy Groups
States with Self-Advocacy Groups but Not a State Organization



Source: Longhurst, N., *1994. The Self-Advocacy Movement by People with Developmental Disabilities. A Demographic Study and Directory of Self-Advocacy Groups in the United States.* **Washington, DC: American Association on Mental Retardation.**

Self-advocates also have formed a national umbrella organization, Self-Advocates Becoming Empowered. The definition of self-advocacy adopted by this group is as follows:

Self-Advocacy is teaching people with a disability how to advocate for themselves and to learn how to speak out for what they believe in. It teaches us how to make decisions and choices that affect our lives so that we can become more independent. It also teaches us about our rights, but along with learning our rights, we learn our responsibilities (Hayden and Shoultz, 1991).

There is evidence that growth in self-advocacy organizations is continuing. The most recent directory, the Self-Advocacy Groups 1995 Directory for North America, lists over 700 groups in the U.S. as well as additional groups in Canada (University of Minnesota, 1995). This directory was originally compiled by the University of Minnesota with support from the Kennedy Foundation, and is now maintained by Self-Advocates Becoming Empowered.

Individuals with mental retardation also are increasing their opportunities for self-determination. Policy makers and program managers who are listening to consumers are beginning to meet the challenge of supporting self-determination without abrogating their responsibilities to keep vulnerable people as safe and healthy as possible.

TJ.'s Story

When I was 8 years old, I went to a State institution for 11 years in the State of Connecticut, and the name was The Training School. There was another State institution there, and it was closed by Brian Lensink and Charlie Garroway and a lot of other people who fought to close the institution.

What I understand about empowerment is that we are people first. We want people to look at us as a person but not as a label. That is happening at the PCMR. I like the PC but not the MR. The truth is the President's Committee is very important, but MR not, because that is a label that we are always going to have on people, and we don't want that label anymore. Certainly, you people have the control. You are experts. You are experts in your field, but I am an expert too, in my own field. I lived in the institution, and I lived in a group home ...I want you to look at me as a person, like I am going to look at you as a person. I am going to look at you as an expert, but I want you to look at me as an expert because who is going to make it work? You and People First and people with other disabilities...

I know you are experts in this field because of your schooling, training, family, and professional experiences. I am also an expert in this field because of my firsthand experience: living in institutions and the community, fighting for a good education, getting a real job, searching for good health care, struggling to pay my bills, looking for long-term support, and speaking up for my needs and my rights to lawmakers.
Excerpted from speech by self-advocate T.J. Monroe to the PCMR conference on the National Reform Agenda (PCMR, 1994a).

Self-determination can be encouraged from early intervention through aging and retirement; self determination is relevant regardless of people's level of mental retardation. As described in a discussion of self-determination as an educational outcome, "Although many skill areas related to self-determination are more applicable to older students or students with mild disabilities, self determination is not the sole domain of secondary education or students with mild disabilities. Making choices, indicating preferences, and developing self-awareness and confidence involve lifelong experiences and instruction, independent of level of disability" (Wehmeyer, 1994).

Federal policies encouraging self-determination include a requirement under the Individuals with Disabilities Education Act that students' preferences and interests be included in their transition plan from school to work and that they be invited to their IEP/transition plan meeting (Thompson and Corbey, 1994). The 1992 amendments to the Rehabilitation Act defined policies in support of self-determination, requiring that each person's Individualized Written Rehabilitation Plan be developed jointly by the consumer and his/her vocational rehabilitation counselor, focusing on the person's career goals and specific job preferences (West, Kregel and Revell, 1994).

State policies are encouraging self-determination through such activities as supports to self advocacy organizations (often done through State Developmental Disabilities Planning Councils), State education policies requiring collaboration with students planning, as well as with their parents, and incorporating choice, self-determination and consumer satisfaction in State quality assurance systems. In the State of Washington, for example, "having power and choice" is one of six benefits (outcomes) expected for people with mental retardation/developmental disabilities who receive community residential services. The State's *Residential Service Guidelines* are used to assess the degree to which consumers are experiencing power and choice as well as health and safety, personal value and positive recognition, experiences helping people participate in the physical and social life of their communities, good relationships with friends and relatives, and competence to manage daily activities and pursue personal goals.

Washington's service program assessment criteria include evidence that individual planning *efforts* focus on listening to the person and the person's friends and allies to discover individual goals and preferences, that the environment allows people to express preferences and to make decisions, that staff demonstrate respect for choices and encourage the expression of personal power, and that the program encourages participants to seek information about their rights and responsibilities, and to act on what they learn. The State's underlying concepts of quality in residential services include the following beliefs about power and choice:

- People should experience power, control and ownership of their personal affairs. Expression of personal power and choice are essential elements in the lives of people. Such expressions help people gain autonomy, become self-governing and pursue their own interests and goals.
- People grow and develop by expressing their own unique preferences; by choosing and trying for their own important objectives, whether or not they succeed in getting them. People also learn by being able to say what they want and figuring out how to obtain other people's cooperation.
- In order to respond effectively, residential programs and their staff must listen carefully to what each individual expresses in terms of desires, plans and preferences. By listening carefully, programs and staff will also be able to discern how each person expresses those choices (Washington Developmental Disabilities Services, 1994).

Mike's Story

Mike is a 24 year-old self-advocate who lives happily with three other men. He and his housemates receive support from the local social service agency as they need it, to live in the house and to do what they want in personal and community activities. Mike is politically involved through his various self advocacy activities, and his participation on the Advisory Council of the Institute on Community Integration, University of Minnesota.

Mike thinks his life is much improved compared to the past, when he lived in various foster homes where he wasn't given the opportunity to say or do what he wanted. Things are much better since he has become better informed about his rights and has moved into a supported living situation.

Mike explains his views on self-direction as follows:

> For me, a good service provider lets persons with developmental disabilities be in charge of their lives. They do more than just pay attention to licensing

> requirements. They recognize when someone can make their own choices and let people give some input into the services they want ... What it all boils down to is to let the consumer have choices about their jobs, and where and how they live.
>
> The main way a service provider can meet my needs is by asking me what I want, and not assuming what I want. Service providers need to let each individual have choices as far as how they want their services provided ...A good service provider knows the capability of each consumer which whom they work. Every individual is given the opportunity to have some degree of self-determination. Providers need to work with individuals instead of for them.
>
> The most important aspect of self-determination for me is respect: respect the individual, allow them to make choices if they are able and willing to do so, and then respect those choices. Ultimately, I would like to own my house and choose who works for me and what agencies and providers I hire. I hope service providers in the future will be able to support me in this dream.

Adapted from Williams, 1994.

One way local, State and the Federal governments are promoting self-advocates' participation in the policy-making process is by appointing individuals with disabilities to governing boards as well as to advisory committees and task forces. Legislation in Illinois specifically mandates the inclusion of individuals with disabilities on all governing bodies that affect such individuals, including entities such as zoning commissions, health boards and social services boards. At the Federal level, key appointments of individuals with disabilities include Susan Daniels, Associate Commissioner, Social Security Administration; Bob Williams, Commissioner of the Administration on Developmental Disabilities, Department of Health and Human Services; Judy Heumann, Assistant Secretary of Education and Rehabilitative Services; Fredric Schroeder, Commissioner of the Rehabilitation Services Administration; Katherine Seelman, Director, National Institute on Disability and Rehabilitation Research, Department of Education; and Elizabeth Savage, Special Assistant to the Attorney General for Civil Rights, U.S. Department of Justice. Individuals with disabilities also have been appointed as staff and members of the Equal Employment Opportunity Commission, the National Council on Disability, and the President's Committee on Employment of People with Disabilities. Most important of all, for the first time in its history, the PCMR membership now includes two self-advocates, Ann Forts and T.J. Monroe.

Partners in Policymaking

The Minnesota Developmental Disabilities Council pioneered the "Partners in Policymaking" program in 1987. It has been replicated successfully in over 35 States. Partners in Policymaking provides information, training and skill building to people with developmental disabilities and family members, so they can become more effective partners with professionals and policy makers in planning and developing services at the local, State and Federal levels.

The Minnesota Council has maintained a leadership role in providing training to self-advocates and family members of people with developmental disabilities which promotes their active involvement in developing a consumer-driven service system. The Council has also provided support and guidance to numerous other States, who have replicated this program to increase consumer involvement across the country.

During 1994 the Minnesota Partners in Policymaking program provided outreach to rural communities to seek potential Partners who are geographically isolated and unable to travel to the Minneapolis/St. Paul area on a regular basis. The initiative was successful in linking rural residents with disabilities and family members with the statewide network. The rural graduates of the Partners program are now more connected, less isolated, and richer in resources (Zierman, 1995).

Some State Developmental Disabilities Councils have provided advanced Partners in Policymaking training, to further significant consumer involvement. In Iowa, for example, the Council designed an advanced Partners program specifically to help people with disabilities who had been appointed to policy-making boards increase their skills to participate effectively.

Supports to self advocates in policy-making are important in obtaining the maximum benefits from their participation. For individuals with mental retardation, this may mean assistance with reading materials, providing additional time for discussion and questions, and making sure that people have resources for travel and meeting-related expenses. These kinds of supports are being made available to the self advocates who are members of the President's Committee on Mental Retardation.

Supports are available in Colorado from the Consumer Involvement Fund of the Colorado Developmental Disabilities Planning Council. The Fund provides funds for people with disabilities, their family members or their guardians to participate in conferences, training events, public forums, task forces, hearings and other similar activities. The Council designed the Fund "to empower people with disabilities and their family members with the opportunities, experiences and information they need to meaningfully participate in the decisions that are being made which affect their lives" (Colorado Developmental Disabilities Planning Council, undated).

Family involvement and empowerment are equally important in supporting the journey to inclusion. The value of family-centered supports is increasingly recognized in designing family support programs. Policy makers are realizing that listening to what parents say they need makes sense in making decisions about family support programs. In Alaska, for example, the State developmental disabilities agency decided to ask families on the waiting list for residential and other specialized services what it would take for them to get off the list. Much to the agency's surprise, the limited budget was able to stretch much further than projected, when families asked for such relatively inexpensive supports as home modifications and respite care. Most of the waiting list was eliminated, with significantly reduced use of out-of-home placements. This experience became the basis for a new person- and family-centered service system, in which the dollars follow the individual, and family and consumer satisfaction is the primary criterion for service quality (Renfro, 1995).

Although family focus is increasing, many services continue to be dominated by professionals who do not always convey respect for parents' knowledge and loving concern for their children with disabilities. Families also may need support in dealing with professionals, such as help with in the IEP process.

Families as well as professionals also struggle with the transition from parental decision-making to self-determination as young people with mental retardation move into adulthood. Systems that include families as well as consumers in the transition process and in planning for community living arrangements have found that solutions can be developed that all parties can support.

Leslie's Story

Leslie is a 34 year-old young woman with autism and mild mental retardation. Her mother reports that she has made every effort to incorporate Leslie's choices into daily activities, but that choice was often difficult for her. When she reached the age when her brothers had moved out of the family home, her mother had explained to Leslie that she needed more time (and skills) before that could be considered.

With help from Leslie's case manager, her mother started a group home for her, where she is now living successfully. Her mother reports that Leslie has made more progress in the three and onehalf years she has lived there than she had ever dreamed possible:
She has mastered self-care skills that she never would have at home and taken pride in her mastery. She has learned to do household chores such as washing her own clothes and cleaning her bathroom-because now she lives in a cooperative setting, not her parent's home. Without a particularly rigorous diet and with some judicious exercise that others around her were also doing, she has lost over 80 pounds and now loves to shop for "thin" clothes. Leslie has also been taught and now practices some valuable self-regulatory skills; when she feels herself becoming agitated or annoyed, she often asks if she can go relax for awhile or responds to that suggestion from a staff person.

There is still a ways to go before Leslie will be able to take full personal control of her residence, job and other activities. That time may never come in its entirety. But she has been given the opportunity to learn what choices she can make and to see what choices are out there. I am extremely proud of the progress she has made. And I know how important it is for her to continue to learn to make her own choices for that time when I will no longer be here to be involved in her life.
Adapted from Polister, 1994.

Family members are participating in policy-making alongside self-advocates, as members of State Developmental Disabilities Councils, governing boards, and Partners in Policymaking training sessions. In Philadelphia, PA, for example, Family Advisory Committees and a city-wide Steering Committee, composed of family and agency representatives, participate in program design and development. Each agency's family-driven family support program is developed with input from the Family Advisory Committees. In another Pennsylvania county, family members sit on a review committee that reviews applications for innovative family supports that are outside current State guidelines for expenditures.

Resources to family involvement and empowerment in addition to Partners in Policymaking include the PACER Center in Minneapolis, MN, and the Beach Center on Families and Disability, based at the University of Kansas. The Beach Center has developed several resources on family (and individual) empowerment through its research on supports.

PLANNING THE JOURNEY TO INCLUSION

One of the first steps States are taking on the journey to inclusion is the review of current policies and the resultant outcomes in the lives of people with mental retardation and their families. An important starting point is listening to consumers and family members, to be clear on what outcomes are important to them.

States also are taking a systematic look at the outcomes of current policies.For the National Collaborative Academies, for example, States are reviewing the degree of inclusion currently present in their educational system, community living options, and employment options. Indicators include trends in the:

- Portion of students with mental retardation in regular classrooms and resource rooms, as opposed to segregated classes and facilities.
- Number of children with mental retardation/developmental disabilities in institutions.
- Development of community living arrangements, including supported living options, small settings, and the related decreasing use of State and private institutions.
- Use of Medicaid waivers and optional services to finance supports to inclusion.
- Number of people with mental retardation in supported employment.

States also are looking at their expenditures, and the relative portions that finance inclusive and non-inclusive supports. Major resources to States in reviewing outcomes and expenditures include:

- The Annual Report to Congress on the Implementation of The Individuals with Disabilities Education Act published by the U.S. Department of Education, which provides State and national data on the number of children receiving special education services and the portion in each type of educational setting, for all special education students and for those with mental retardation and other types of disabilities.

- The longitudinal data and analysis of residential services to individuals with mental retardation/developmental disabilities published by the Institute of Community Integration at the University of Minnesota/University Affiliated Program (UAP). The multi-year series of reports include profiles of national and State trends in institutional and community services, including an annual profile since 1977, differences among the States in use of the Medicaid ICF/MR program, and characteristics of residents of State operated facilities.
- Data on trends in adult services and employment options, maintained by the Training and Research Institute at Children's Hospital in Boston.
- Vocational data specific to supported employment, including longitudinal analysis of the level of mental retardation among supported employees, available from the Rehabilitation Research and Training Center, Virginia Commonwealth University.
- Periodic reviews of trends in family support services developed by the Human Services Research Institute, including types of supports being funded, source of funding, numbers of families, and principles associated with effective family support programs.
- Ongoing analysis of the ways States are using the Medicaid HCBS waiver program, published periodically by the National Association of State Developmental Disabilities Services Directors.
- Data published by the Social Security Administration on numbers of individuals with mental retardation and other disability diagnoses receiving Supplemental Security Income and Social Security Disability Insurance, as well as those participating in Social Security Work Incentive programs and the number of individuals receiving Supplemental State Payments in various living arrangements.
- Medicaid program information published annually by the Health Care Financing Administration on each State's array of optional services and use of the medically needy option, and periodic publication of Medicaid program participation trends by the Ways and Means Committee of the U.S. House of Representatives.
- The primary resource on trends in public expenditures for mental retardation/developmental disabilities services, developed by the Institute on Disability and Human Development, University of Illinois at Chicago/UAP. The longitudinal analysis includes national and State expenditure data comparing institutional and community service expenditures, relative level of effort in

> relation to State population, local government expenditures, and special initiatives in early intervention, family support, aging, supported employment, supported living, assistive technology, and personal assistance services.

States are using these resources to examine outcome and expenditure trends over time, as well as comparing their State profile with national averages and with other States in their region or of comparable size. State analysis of outcomes and expenditures also requires meshing national reports of State data with current information from the State budget and program agencies. Because most nationally published data is one or more years old, States need updated information on inclusion outcomes and expenditures to be clear on the current picture.

In addition, States need to obtain additional clarification on specific outcomes and expenditures that is available only from the relevant State program agencies. For example, States with the Medicaid rehabilitative services option may be using it to finance a significant array of services to individuals with mental retardation, including home- and school-based services, or may reach only a small portion of the population because of the State's limits in amount, scope and duration, or limits on the service settings where Medicaid rehabilitative services are typically available.

States also are reviewing their policies on inclusion and the ways that policies are implemented in relation to inclusion outcomes. An important starting point is the official statement of mission, goals and principles, in State legislation, on mental retardation/developmental disabilities services, as well as the relevant State agency policy statements. Although "walking the walk" is ultimately more significant than "talking the talk," official policy statements can form the basis for planning and taking the journey to inclusion.

It is helpful to look across agency and State budget policies, to see if they are consistent in their support of inclusion. For example, pressures to maximize Federal Medicaid revenues may inadvertently contribute to the use of more restrictive (and often more expensive) service options than State-funded family supports and informal services.

Input from individuals with mental retardation, family members, and those providing supports and services also helps identify barriers to inclusion as policies are currently being implemented. The Three Year Plans published by each State's Developmental Disabilities Council provide a summary of strengths and weaknesses in the service system from the perspective of people with developmental disabilities and their families. Most Councils hold public hearings prior to developing their Three Year Plans, and all Councils include consumers and family members on the Council. The most recent Three Year Plans cover Federal fiscal years 1995-1997.

The input of stakeholders also is helpful in clarifying the messages being given by State funding priorities and financing mechanisms. For example, States with stringent limits on family supports and extensive approval requirements by professionals send a message to families that their knowledge and concern for their son or daughter with mental retardation is not recognized as valid. Conversely, States with family subsidies or programs that emphasize family choices on the supports they need send a message of family empowerment and appreciation of the tremendous contribution families make in caring for their loved ones with disabilities.

The Colorado Story

The values of community inclusion, responsible choice, control, belonging, relationships, competencies, talent, security and self-respect are encompassed in the mission statement of the Colorado Division for Developmental Disabilities, and reflected in legislation on developmental disabilities services. The Colorado Progress Assessment Review (COPAR) was developed to evaluate outcomes based on these values, for individuals receiving State-funded supports. The program began in 1986 in response to a legislative mandate that the State Auditor's Office do an independent evaluation of the progress of individuals with developmental disabilities.

The State contracts with a private research firm to conduct in-person interviews with people receiving services, family members and service providers. Surveyors question people to find outcomes, differences across programs, settings and regions, and other factors. They also ask questions about experiences before and after new service initiatives, to determine the effect on people's quality of life. Studies also are conducted of the decision-making, satisfaction, community inclusion, relationships, talents, security and self-respect of people in Colorado's general public. These findings serve as standards for services provided to people with developmental disabilities.

The Division for Developmental Disabilities uses COPAR reports to monitor how well its mission is being carried out, determine satisfaction of its customers, recognize exemplary services, and demonstrate cost-effectiveness of State expenditures.

Summary information from COPAR surveys on service outcomes is submitted to the State Legislature as part of the annual budget request, and is used to guide the State in making decisions about the success of its programs and to support allocation of resources to new program models.

Adapted from Ruth (1994) and Jaskulski (1994a).

Another way States send messages on inclusion is through the quality assurance systems that monitor services to individuals with mental retardation/developmental disabilities. The questions asked in the quality review process have a powerful effect on the services being provided.

Legislative task forces on quality issues and legislation calling for reforms in quality assurance systems to place more emphasis on inclusion outcomes, satisfaction and quality of life for individuals with mental retardation are a significant tool in the journey to inclusion. A major resource to States in looking at quality assurance strategies is the series *Innovations in Quality Assurance,* published through the University of Minnesota/UAP in *1993, 1994* and *1995.* The 1994 edition leads off with a keynote address by Clarence Sundram, executive director of the New York State

Commission on Quality of Care for the Mentally Disabled, and recently nominated for a Federal judgeship, including the following observations on inclusion and quality:

[Recent] changes in values emphasized the right to live in the community. Policies changed. Programs for funding community placement increased. Monitoring and evaluation, licensing and certification processes proliferated.

Now the voices of consumers, their families and their allies, are pushing us to an acceptance of fundamentally different values; values rooted in an appreciation of the same human dignity that animates every human life. We are beginning to acknowledge more explicitly that the same self-determination, preferences, and choices that we value in our own lives are also valuable in the lives of people with disabilities.

We are increasingly coming to appreciate that the lives of people with developmental disabilities can be limited by other people's decisions and confining expectations. By ignoring, discounting or underestimating their abilities, countless lives have been relegated to a wasteland barren of expectations and opportunities. Yet our quality assurance activities have traditionally dwelt in the world of standards designed to avoid abuse and neglect, and have rarely addressed this systematic deprivation of autonomy and opportunity for greater self-direction, for a chance to live a life with a meaning. But isn't this the essence of what quality is? This latter aspect poses a much more formidable challenge than dealing with incident reporting and similar QA activities.

These insights are leading us to policies that unequivocally proclaim that segregation in separate residences and separate programs based on disability alone is wrong. That in turn will lead us to programs that provide housing, supports and opportunities guided by the individual preferences of people with disabilities. The changes that service systems are undergoing, although they may seem painfully slow to impatient advocates, are mercurial when viewed in the broader historical context. In twenty short years, we have come to a point of abandoning institutions that took us 200 years to establish (Sundram, 1994).

RESOURCES FOR INCLUSION STRATEGIES

There is no lack of suggestions and examples of "what works" in making inclusion a reality for people with mental retardation. The resources and references highlighted throughout this report provide hundreds of possible strategies for States, communities and organizations to consider in designing their own journey to inclusion. Resources within the State, particularly individuals with mental retardation, family members, advocates for inclusion throughout the disability network, and those who have already made inclusion work, can provide expertise that is particularly relevant to each State's political and social context.

The National Conference of State Legislatures continues to be a major resource to States in developing strategies for inclusion. The NCSL Developmental Disabilities Task Force, a group of over 130 State legislators from 43 States, meets two or three times a year, in conjunction with NCSL national meetings, to exchange information on legislative strategies and best practices and to advise relevant NCSL policy committees. With voluntary support from participating Developmental Disabilities Councils, through the National Association of Developmental Disabilities Councils, the Task Force also publishes resource materials such as the recent monograph on family support (Bauer, 1994). Earlier the Developmental Disabilities Task Force sponsored publication of Americans with Developmental Disabilities: Policy Directions for the States (Wright et al., 1991), summarizing concepts, reasons for legislators to be concerned, Federal and State activities, and recommendations for State action in the following areas:

- Early intervention
- Family support
- Transition services
- Community living
- Supported employment
- Funding

The NCSL Task Force on Developmental Disabilities lists the following recommendations for State action on funding:

> l. Develop financial goals, based on values that empower individuals, for community services and support systems for persons with developmental disabilities.
>
> 2. Provide fiscal incentives and technical assistance to help service providers move from center-based early intervention, employment, or residential care to community-integrated and individualized approaches to early intervention, supported employment, and housing.
>
> 3. Take advantage of the full range of Federal funds and options under current law.
>
> 4. Work with business and industry to develop creative public/private financing mechanisms, such as State high risk pools, State subsidies for private health insurance, State-financed catastrophic health insurance, or a Self-Sufficiency Trust.
>
> 5. Examine pay levels of community-based personnel, as compared with institutionally based personnel, to try to reduce turnover and increase quality (Wright et al., 1991).

The National Association of Developmental Disabilities Councils also has teamed up with NCSL to publish resources on quality assurance reforms, *Promoting Quality in Developmental Disabilities Services-Considerations for State Legislators* (Jaskulski, 1994a) and *Deinstitutionalization-From Theory to Practice* (Records, 1994). These and other NADDC publications, along with resources published by the Institute on Community Integration, University of Minnesota/UAP, the University of Illinois at Chicago/UAP, the President's Committee on Mental Retardation, and the National

Association of State Developmental Disabilities Services Directors, are especially targeted to States.

The Massachusetts Story

The Massachusetts Department of Mental Retardation recently restructured its licensing, quality assurance, and human rights divisions into a single Office of Quality Enhancement. The cornerstone of the office is a new certification system that replaces the previous licensing and program evaluation procedures and instruments with a process that uses a single instrument: QUEST, the Quality Enhancement Survey Tool.

Certification based on QUEST began for all providers in January 1994. The survey process assesses the quality of life of a sample of individuals served by providers. The QUEST consists of six quality of life areas: rights and dignity; individual control; community membership; relationships; personal growth and accomplishments; and personal well being. In addition, the QUEST contains a seventh area that defines outcome measures for the organization.

Teams of State Quality Enhancement Specialists, consumers and family members conduct the surveys. The surveys focus on observation, discussion with consumers, staff and family members/friends, and related documentation, rather than focusing primarily on "paperwork." Programs receive various levels of certification, depending on the extent to which the target outcomes are present.

The Department of Mental Retardation has found QUEST to be both effective in evaluating the quality of life for people with developmental disabilities, and cost effective, in that it combines several quality assurance/quality enhancement functions into one process.
Adapted from Rowe, 1994.

The ultimate resource on the journey to inclusion, however, continues to be individuals with mental retardation. How well States listen to these voices may be the most significant factor in making the commitment to inclusion and in making it work.

The views of self-advocates meeting in 1994 as the Steering Committee of Self-Advocates Becoming Empowered, are summarized in Taking Place: Standing Up and Speaking Out about Living,in Our Communities (SABE Steering Committee, 1994). They talked about what they would like to see happen in their communities by the year 2000 that is not happening now. Their vision for the year 2000 is as follows:

- A person with a disability as mayor.
- A service system where the money follows the person and where the person gets what he/she says is needed (not what others say is needed).
- For hospitals not to discriminate against people with disabilities.
- For this group to have no other work to do, because we worked ourselves out of a job!
- To have no waiting lists for services, anywhere.

- To eliminate the word "retarded."
- Fully integrated communities, without prejudice and discrimination.
- Supported employment and real jobs for everyone ... no more sheltered workshops!
- To have everyone learn about self advocacy, to eliminate the hate, war and violence so the world would be a better place to live.
- To have transportation for everyone who needs it.
- To see people believe in disability unity, and to sustain the disability community.
- To have children with disabilities included in regular classes.
- To have young people included in the self-advocacy movement.
- To have professionals get their act together by the year 2000, so they'd actually be supportive.
- That people with disabilities are accepted in their communities.
- To have people with disabilities improve the postal service.
- To draft a proposal for the country on how to treat and speak or write about people with disabilities.
- To have universal health care (SABE Steering Committee, 1994).

Efforts to bring other voices in harmony with self-advocacy voices are paying remarkable dividends on the journey to inclusion.

Appendix A
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Appendix B
The President's Committee on Mental Retardation 330 Independence Avenue, S.W., Wilbur J. Cohen Building, Room 5325, Washington, D.C. 20201

Members:

Donna Shalala, Chairperson, Secretary of Health and Human Services Valerie J. Bradley,
Vice Chairperson Lorenzo H. Aguilar-Melancon
Jane Browning
Robert Dinerstein
Steven M. Eidelman
Ann M. Forts
Gisselle Acevedo Franco
Joyce Keller
John F. Kennedy, Jr.
K. Charlie Lakin
Ruth Luckasson
T.J. Monroe
Elizabeth Pittinger
Michael Remus
Tom E.C. Smith
Deborah Spitalnik
Cathy Ficker Terrill
Jacquelyn B. Victorian
Barbara Yoshioka Wheeler
Sheryl White-Scott
Virginia Williams

Ex-Officio Members:

Janet Reno, Attorney General
Robert Reich, Secretary of Labor
Henry Cisneros, Secretary of HUD
Eli J. Segal, CEO, Corporation for National and Community Service
Richard Riley, Secretary of Education

Staff:

Gary Blumenthal, Executive Director
John Pride, Deputy Executive Director
Laverdia Roach
George Bouthilet
Thelma Lucas
Marci Whiteman

Bena Smith
Ross Singletary
Peggy Butler
Angie Green
Terri Lion
Dina Bergman

Administration for Children and Families
Mary Jo Bane, Assistant Secretary

Appendix C

National Organizations Dealing with Mental Retardation and Other Developmental Disabilities

The Accreditation Council for Services for People
with Disabilities
100 West Road, Suite 406
Towson, Maryland 21204
Ph: (410) 583-0060
Fax: (410) 583-0063

The Arc - National Headquarters
(Formerly Assoc. for Retarded Citizens of the United States)
500 East Border, Suite 300
Arlington, Texas 76010
Ph: (817) 261-6003
Fax: (817) 277-3491

The Arc - Governmental Affairs
(Formerly Assoc. for Retarded Citizens of the United States)
1522 K Street, N.W., Suite 516
Washington, D.C. 20005-1247
Ph: (202) 785-3388
Fax: (202) 467-4179

American Association of University Affiliated Programs
8630 Fenton Street, Suite 410
Silver Spring, Maryland 20910
Ph: (301) 588-8252
Fax: (301) 588-2842

American Association on Mental Retardation
444 North Capitol Street, N.W., Suite 486
Washington, D.C. 20001
Ph: (202) 387-1968
Fax: (202) 387-2193

American Network of Community Options
and Resources
4200 Evergreen Lane, Suite 315
Annandale, Virginia 22003
Ph: (703) 642-6614
Fax: (703) 642-0497

Joseph P. Kennedy, Jr. Foundation
1325 G Street NW, Suite 500
Washington, D.C. 20005
Ph: (202) 393-1250
Fax: (202) 824-0351

National Association of Developmental Disabilities Councils
1234 Massachusetts Avenue, N.W., Suite 103
Washington, D.C. 20005
Ph: (202) 347-1234
Fax: (202) 347-4023

American Occupational Therapy Association
4720 Montogomery Lane
P.O. Box 31220
Rockville, Maryland 20824-1220
Ph: (301) 652-2682
Fax: (301) 652-7711

American Rehabilitation Association
1350 I Street, N.W., Suite 670
Washington, D.C. 20005
Ph:(202)789-5700
Fax: (202) 789-5942

Consortium for Citizens with Disabilities
1522 K Street, N.W., Suite 516
Washington, D.C. 20005
Ph: (202) 785-3388
Fax: (202) 467-4179

Council for Exceptional Children
1920 Association Drive
Reston, Virginia 22091
Ph: (703) 264-9409
Fax: (703) 264-9494

Institute on Community Integration
University of Minnesota
150 Pillsbury Drive, S.E., 6 Pattee Hall
Minneapolis, Minnesota 55455
Ph: (612) 624-4848
Fax: (612) 625-6619

Institute on Disability and Human Development
University of Illinois at Chicago
1640 West Roosevelt Road
Chicago, IL 60608
Ph: (312) 413-1647
Fax: (312) 413-1326

National Down Syndrome Congress
1605 Chantilly Drive, Suite 250
Atlanta, Georgia 30324
Ph: (404) 633-1555
Fax: (404) 633-2817

National Down Syndrome Society
666 Broadway, Suite 810
New York, New York 10012
Ph: (212) 460-9330
Fax: (212) 979-2873

National Association of Protection and Advocacy Systems
900 2nd Street, N.E., Suite 211
Washington, D.C. 20002
Ph: (202) 408-9514
Fax: (202) 408-9520

National Early Childhood Technical Assistance System (NEC*TAS)
Frank Porter Graham Child Development Center
University of North Carolina at Chapel Hill
Suite 500 Nations Bank Plaza, 137 East Franklin Street
Chapel Hill, North Carolina 27514
Ph: (919) 962-2001
Fax: (919) 966-7463

National Association of State Boards of Education
1012 Cameron Street
Alexandria, Virginia 22314
Ph: (703) 684-4000
Fax: (703) 836-2313

National Governor's Association
444 North Capitol Street, N.W., Suite 267
Washington, D.C. 20001
Ph: (202) 624-5300
Fax: (202) 624-5313

National Association of State Directors of Developmental Disabilities Services, Inc.
113 Oronoco Street
Alexandria, Virginia 22314
Ph: (703) 683-4202
Fax: (703) 684-1395

National HOYO Alliance
University of New Hampshire
Heidelbert-Harris Building 125 Tech Drive
Durham, New Hampshire 03 824
Ph: (603) 862-0550
Fax: (603) 62-0555

National Conference of State Legislatures Task Force on Developmental Disabilities
1560 Broadway, Suite 700
Denver, Colorado 80202
Ph: (303) 830-2200
Fax: (303) 863-8003

National Parent Network on Disabilities
1727 King Street, Suite 305
Alexandria, Virginia 22314
Ph: (703) 684-6763
Fax: (703) 836-1232

National Council on Educational Restructuring and Inclusion
The Graduate School and University Center
The City University of New York
33 West 42nd Street
New York, New York 10036
Ph: (212) 642-2656 or 2151
Fax: (212) 642-1972

Rehabilitation Research and Training Center on Supported Employment
Virginia Commonwealth University
P.O. Box 842011

Richmond, Virginia 23284-2011
Ph: (804) 828-2325
Fax: (804) 828-2193

Self-Advocates Becoming Empowered 1601
S. Main, Suite 300.
Tulsa, Oklahoma 74119
Ph: (918) 582-8272
Fax: (918) 582-3628

United Cerebral Palsy Associations, Inc.
1660 L Street, NW, Suite 700
Washington, D.C. 20036
Ph: (202) 842-1266
Fax: (202) 776-0414

Training and Research Institute for People with Disabilities
Children's Hospital of Boston
300 Longwood Avenue
Boston, Massachusetts 02115
Ph: (617) 355-6506
Fax: (617) 355-7940

Research and Training Center on Community Living
University of Minnesota
214 Pattee Hall, 150 Pillsbury Drive SE
Minneapolis, MN 55455
Ph: (612) 624-6328
Fax: (612) 625-9344

Appendix D

Federal Agencies Dealing with Mental Retardation and Other Developmental Disabilities

Administration on Developmental Disabilities U.S. Department of Health and Human
Services Hubert H. Humphrey Building, Room 329-D
200 Independence Avenue, S.W.
Washington, D.C. 20201
Ph: (202) 690-6590
Fax: (202) 690-6904

Centers for Disease Control and Prevention
Center for Environmental Health
Developmental Disabilities Branch
U.S. Department of Health and Human Services
4770 Bufford Highway, N.E.
Atlanta, Georgia 30341-3724
Ph: (404) 488-7360
Fax: (404) 488-7156

Community Planning and Development
U.S. Department of Housing and Urban Development
751 7th Street, S. W., Room 7244
Washington, D.C. 20410
Ph: (202) 708-1911
Fax: (202) 708-3363

Coordination and Review Section
Civil Rights Division
U.S. Department of Justice
10th and Constitution Avenues, N. W.
Washington, D.C. 20530-0001
Ph: (202) 616-7779
Fax: (202) 307-0595

Division of Adult Education and Literacy Office of Vocational And Adult Education
U.S. Department of Education
Mary E. Switzer Building, Room 4415
330 C Street, S.W.
Washington, D.C. 20202
Ph: (202)205-5410
Fax: (202) 205-8973

National Institute on Disability and Rehabilitation Research Office of Special Education
and Rehabilitation Services

U.S. Department of Education
Mary E. Switzer Building, Room 3060
330 C Street, S.W.
Washington, D.C. 20202
Ph: (202) 205-8134
Fax: (202) 205-8997

General Accounting Office
Housing and Community Development Issues
441 G Street, N. W., Room 1842
Washington, D.C. 20548
Ph: (202) 512-7631
Fax: (202) 512-8774

Health Care Financing Administration Division of Coverage Policy
U.S. Department of Health and Human Services
6325 Security Boulevard, Room 300
Baltimore, Maryland 21207
Ph: (410) 786-5659
Fax: (410) 786-3252

Maternal and Child Health Bureau
Division of Services for Children with Special Health Needs
U.S. Department of Health and Human Services
Parklawn Building, Room 18A-27
5600 Fishers Lane
Rockville, Maryland 20857
Ph: (301) 443-2350
Fax: (301) 443-1728

Mental Retardation and Developmental Disabilities Branch National Institute of Child
Health and Human Development National Institutes of Health
U.S. Department of Health and Human Services
6100 Executive Boulevard, Room 4BQ9
Bethesda, Maryland 20892-7510
Ph: (301) 496-1383
Fax: (301) 496-3791

National Council on Disability
1331 F Street, N.W., Room 1050
Washington, D.C. 20004
Ph: (202) 272-2004
Fax: (202) 272-2022

Office of Special Education and Rehabilitative Services Office of Special Education
Programs

U.S. Department of Education
Mary E. Switzer Building, Room 3086
330 C Street, S.W.
Washington, D.C. 20202
Ph: (202) 205-5507
Fax: (202) 260-0416

Office of the Assistant Secretary for Planning and Evaluation
U.S. Department of Health and Human Services
Hubert H. Humphrey Building, Room 405-F
200 Independence Avenue, S.W.
Washington, D.C. 20201
Ph: (202) 690-7853
Fax: (202) 690-7383

Office of Special Education and Rehabilitative Services Rehabilitation Services Administration
U.S. Department of Education
Mary E. Switzer Building, Room 3228
330 C Street, S.W.
Washington, D.C. 20202
Ph: (202) 205-9297
Fax: (202) 260-9772

Office of Disability
Social Security Administration
U.S. Department of Health and Human Services
Altmeyer Building, Room 545
6401 Security Boulevard
Baltimore, Maryland 20235
Ph: (401) 965-3424
Fax: (401) 965-6503

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

Office of Disease Prevention and Health Promotion
U.S. Department of Health and Human Services
Mary E. Switzer Building, Room 2132
300 Independence Avenue, S.W.

Washington, D.C. 20201
Ph: (202) 205-8611
Fax: (202) 205-9478

President's Committee on Employment of People with Disabilities
1331 F Street, N.W., 3rd Floor
Washington, D.C. 20004-1107
Ph: (202) 376-6200
Fax: (202) 376-6219

Office of Elderly and Assisted Housing
U.S. Department of Housing and Urban Development
451 7th Street, S.W., Room 6130
Washington, D.C. 20410-0001
Ph: (202) 708-4542
Fax: (202) 708-1300

President's Committee on Mental Retardation Administration for Children and Families
U.S. Department of Health and Human Services
Wilbur J. Cohen Building, Room 5325
330 Independence Avenue, S. W.
Washington, D.C. 20201
Ph: (202) 619-0634
Fax: (202) 205-9519

Office of the Inspector General
U.S. Department of Health and Human Services
Wilbur J. Cohen Building
330 Independence Avenue, S.W.
Washington, D.C. 20201
Ph: (202) 619-0480
Fax: (202) 401-0556