

With a little help from my friends...

*A series on contemporary supports to people
with mental retardation*

Real Lives

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Acknowledgments

The President's Committee on Mental Retardation (PCMR) is proud to present *With A Little Help From My Friends*...a series on contemporary supports to people with mental retardation.

This forward thinking series of booklets is intended to support people with mental retardation and related conditions to participate as full citizens in their communities in every aspect of their life.

The President's Committee has made a commitment to contribute information to the field that will promote the quality of life and inclusion of people with mental retardation and developmental disabilities. This series of five booklets provides timely, innovative and creative 'possibilities' for issues ranging from; how people can direct their own services to assure a full life in the community...to critical issues of addressing challenging behaviors to funding options for supports and services.

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It is our belief that this PCMR publication series will contribute to the future direction of services and supports for people with mental retardation into the next millennium. Our work is cut out for us but, *With A Little Help From My Friends*, we can achieve our ultimate goal of lifelong community inclusion for people with mental retardation.

Valerie J. Bradley
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PREFACE

Services and supports to people with mental retardation have undergone significant change in the last 50 years. Today people with disabilities are living longer. They and their families are asking for and expecting meaningful support to live their lives as full citizens in their own communities.

This series of five booklets provides information in a comprehensive but basic manner designed for individuals who do not know much about how supports are currently provided, but who would like to know more about the history of services and supports as well as current issues and future trends.

The following is a brief overview of the information and issues covered by each booklet:

Speaking Up, Speaking Out (Booklet #1): This booklet covers definitions and prevalence of mental retardation, issues in the current legal system, along with self-advocacy and self-determination.

Growing Strong (Booklet #2): This booklet covers issues and topics in early intervention, family supports, and the educational system.

Real lives (Booklet #3): This booklet covers services and supports in the areas of supported living, vocational opportunities, and supported recreation.

I Am Who I Am (Booklet #4): This booklet covers a variety of specialized support needs including **challenging behaviors, supports to the aging, culturally competent supports, and person-centered planning as a tool for providing supports that are meaningful to the individual.**

Changing Systems (Booklet #5): This booklet covers issues in quality assurance and funding of supports and services.

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Note About Language

Who we are is as much about how others see us as it is about our physical beings. We can eat right, exercise, and believe in ourselves all we want, but if no one ever notices it won't last for long. So what does it mean to be "a person with mental retardation?" Does it say something about a person that is meaningful and relevant? Does it tell people something about that person that is valuable, helpful, or essential?

When asked, most self-advocates with mental retardation will make it clear that the label "mentally retarded" is stigmatizing and limiting. If the label comes before the person then a large part of who that person is has already been defined.

Despite clear indications from self-advocacy groups that the words mental retardation should be "retired," support professionals and agencies that oversee support systems struggle with how to provide the necessary assistance to people who need it, without defining who is eligible (i.e., creating a label). By its very nature service provision hangs onto labels in order to know where to best put resources. The dilemma of dropping all labels and still accurately describing who can receive supports through State agencies is not solved. But there is a clear mandate from the people who receive these services and supports that people—not labels—always come first.

That part is simple. It's a commitment that when we talk, write, or otherwise communicate about people with mental retardation or any disability we never put the word "disability" before the word "person;" that when we have the chance to educate others about people-first language, we do; and that as we look at the global issues of how to support people, we remember that it's the person, not the service, that matters. It's a sign of respect. It's a sign that although not all the questions have been answered correctly, we are up to the challenge. Spread the word: "People First!"

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Overview

Not all people with mental retardation and related conditions need special services after they graduate from high school. They are able to find employment and a satisfactory place to live by using the natural supports they have in place, such as family members or friends who can help them meet the day to day challenges of life. But many people with mental retardation and other developmental disabilities do need significant supports from paid providers to maintain their homes, their jobs, and to actively participate in their communities. This booklet provides information about supported living, supported employment, and supported recreational options for people with mental retardation and related conditions.

Residential Options and Supports

Residential options for people with mental retardation and other developmental disabilities have significantly changed over the last twenty-five years. The end of this century has been marked by a rise in community living options and the fall of large institutions. As a nation we have moved from offering essentially one type of residential option—the institution—to offering predominately community residential supports through an array of options including in-home family supports, small group homes, supported living, and foster care.

Today, in most States, people with mental retardation and other developmental disabilities live in homes in a community, with fewer than fifteen other people. Living in the smaller decentralized homes provides people with opportunities to be included in community activities and to gain life experiences and skills that assist them in living more independently. More importantly, community living and home control provides people with a sense of accomplishment and pride.

People with mental retardation who need assistance or support in their homes receive that assistance in a number of ways. Many people, live with family members who provide all needed supports. Others live away from their families and rely completely on paid support staff. Yet others are somewhere in-between, they may live at home with family members and paid support staff may come into the family home, or they may live in a home run by an agency but remain heavily connected with family members.

Where people live, how much support they receive, and the kinds of supports they get, often has more to do with how those supports are funded and when the person entered the social service system than what the person actually needs. In addition, there are many people waiting, in family homes, nursing homes, or institutions, for appropriate supports in the community to become available. The primary locations where people receive paid "residential supports" today include institutions, Intermediate Care Facilities for persons with Mental Retardation (ICFs/MR), group homes, and supported living arrangements funded by the Home and Community Based Services (HCBS) program, nursing homes, and homes or apartments owned by the person receiving services or their families.

Institutions

Most people who needed daily assistance and supervision before the 1970's and who couldn't live with their families, lived in large institutions. It has been well-chronicled that the conditions of these underfunded and overcrowded institutions of the mid-1900's were deplorable. They were described by some as "hell on earth" and the "land of the living dead" (Blatt & Kaplan, 1974) and many people with mental retardation and developmental disabilities living in these places were neglected, abused, and deprived of basic human rights. Exposés such as that presented by Geraldo Rivera on television in the 1970's regarding the Willowbrook institution in New York or the photographic essay book, *Christmas in Purgatory*, which depicted care in the institutions, brought public attention to the undesirable conditions

(e.g., overcrowding, abuse, inadequate food and shelter, lack of personal property, no privacy, lack of opportunities to participate in typical activities).

In 1971, in response to these horrifying conditions, the Federal government became involved in monitoring the provision of residential services to people with mental retardation and other developmental disabilities by providing States with the opportunity to cost-share certain residential services that met specific standards of quality. These standards specified such things as the number of staff who needed to be present in relationship to the number of people served, maintenance of health regulations, and availability of therapeutic supports (e.g. dental, medical, speech).

Since that time there have been improvements in the environment and conditions of many institutional settings. Most are no longer so overcrowded. They have more staff, provide more activities, meet the basic health care of the people who live in them and provide basic food and shelter. However, it is still clear that institutions are not places where people with mental retardation are empowered and have full, enriched lives. People who live in institutions have virtually no privacy. They have few opportunities to meet new people, to go new places, or to participate in community activities. They are typically separated from family by large distances and have little control or choice in their lives.

Facts about institutions in the United States:

As of 1998, every State except New Hampshire, Vermont, Rhode Island, New Mexico and the District of Columbia was operating at least one large State-run institution for people with mental retardation and developmental disabilities.

Between 1980 and 1996 the average number of people living in these state-run institutions decreased from 131,088 to 59,936 with more than half of all States reducing their average number of people served in institutions by 50% or more.

Today, many large institutions for people with mental retardation and developmental disabilities still exist, but their numbers are shrinking and fewer people are living in them. A few States (New Hampshire, Vermont, Rhode Island, New Mexico and the District of Columbia) have successfully closed all of their large institutions. The population remaining in institutions today is aging, with dramatically fewer children being admitted. Many people who live in institutions have a combination of disabilities and/or behaviors that pose a challenge to community living, still others have criminal backgrounds. While people continue to leave the institutions, others are entering (and presumably re-entering), suggesting a lack of adequate supports in smaller community programs. What has been learned about institutional and large congregate care settings vs. smaller community living options for people with mental retardation and developmental disabilities is that people are more

likely to experience lives which are similar to their same-age peers without disabilities when they live in the community. In addition, institutions are the most expensive type of residential services.

Closing Institutions

It seems very clear that as a nation we have embraced the notion of community living. Unprecedented numbers of individuals with mental retardation are now living in the community. However, a number of people continue to reside in institutions. The process toward closing institutions is never easy and is often marked with varied opinions and passions. We can look to those States who no longer have large institutions for guidance and experience, but more importantly should listen to the people whose lives are affected by institutions closing.

Many people with mental retardation and other developmental disabilities are very clear that they want all institutions throughout the United States to close. Self-Advocates Becoming Empowered (SABE), a national grass roots organization of local self-advocacy has identified this as their top priority. "Campaign for Freedom, Closing the Doors" is an organized effort to close the doors of institutions and

open the pathway to community living across the nation. SABE believes "that people with disabilities should be treated as equals. Which means they should be given decisions, choices, rights, responsibilities, chances to speak up and to empower themselves and opportunities to make new friendships and renew old friendships, just like everyone else" (Nelis & Ward, 1996).

Family members also have opinions about whether their loved ones should move from institutions into community settings. However, their opinions range from strong opposition to strong support. In a review of twenty-one articles regarding parental attitudes and expectations related to deinstitutionalization, researchers at the University of Minnesota, have identified the following emerging themes about parental attitudes toward their children living in institutions and the community:

- ◆ The vast majority of parents were satisfied (secure, content, and comfortable) with their family member's public institution placement.
- ◆ The vast majority of parents changed their attitudes about community placement after their family member had moved to the community.
- ◆ After experiencing community services, parents viewed the institution less positively than they did when their family member lived there.
- ◆ Parents observed improved quality of life and relationships for their family member after the move.

Those parents initially opposed to their child's move to the community offered a number of reasons for their attitude. Parents said they were initially opposed to the move because they felt that: 1) the institutions were better than community homes at responding to the specific characteristics or needs of their children; 2) available homes were inadequate in terms of safety, service quality or staffing; 3) the process involved in the decision to move people was unfair, improper or disrespectful; or 4) they felt movement to the community would increase the care-giving responsibilities of the family members.

“Campaign Freedom, Closing the Doors” is a national grass roots effort by Self-Advocates Becoming Empowered (SABE) to close the doors of institutions and open the pathway to community living across the nation.”

While most parents were ultimately satisfied with the community placement, many offered recommendations for lessening the fear about the move. They suggested those planning for people's moving must acknowledge as legitimate the fears and wishes of the family and respond to them as well as they can. They must include the person who is going to move and the family members in decisions related to the move. Visits should be arranged for family members to potential community sites, and parents who have been involved in previous moves should act as guides in these visits and/or be available in other ways to parents. Government agencies should assist in establishing communication between families and community providers. Finally, they emphasized the importance of public statement of government commitments to funding and other policies that ensure the viability, continuity, and quality of community settings.

A self-advocate perspective of the realities of institutions: "Should we spend money on institutions or to support people in communities? As a self-advocate, it bothers me that people are still arguing about this. I'm not quite sure what all the graphs and charts and numbers mean, or what the latest research says, or whose reports to believe. So, I judge by what I know. I listen to the people who live in the institutions."

Individuals with disabilities who have successfully moved from institutions into the community should also be involved in this planning process. They can serve as mentors to individuals who are moving from an institution to the community and can provide valuable insight and support.

Excerpts re-printed with permission from: "Parental Attitudes Toward Deinstitutionalization" by Lynda Anderson and Sheryl A. Larson. In IMPACT: Feature Issue on Institutional Programs. Minneapolis: MN, Center on Residential Services and Community Living, University of Minnesota.

Nursing Homes

Many people with mental retardation and developmental disabilities live in nursing homes. In 1987 the Omnibus Budget Reconciliation Act (OBRA-87) mandated that placements in nursing homes for people with mental retardation be reviewed to see if the placement was appropriate based on medical needs. It was found that the majority of people with mental retardation in nursing homes were not suitably placed. If they did not have health factors that required a nursing home setting, it made more sense to help them move to community homes which provided supports to people with mental retardation.

OBRA-87 required that alternative placements be sought for people who were only living in a nursing home because there were no other places to live, and that a plan for active treatment be put in place for those that remained in nursing homes (meaning that people had opportunities to learn new things and take care of their own needs to the furthest extent possible), however, their numbers are decreasing slowly. In 1996 there were still approximately 37,000 people with mental retardation and developmental disabilities living in nursing homes, a number which has not substantially changed since 1970.

Nationwide, approximately 10% of all people with mental retardation and developmental disabilities whose services are funded through Medicaid ICFs/MR, HCBS or nursing facility programs were in Medicaid nursing homes. In one State, nursing facilities provide supports to more than one-third of its citizens with mental retardation and developmental disabilities, and in two other States nursing homes provide supports to more than one-fifth of Medicaid long-term service recipients with mental retardation and developmental disabilities.

Nursing homes typically are designed to provide long term health and personal care services to people who are aging. Many people with mental retardation and developmental disabilities who live in nursing homes do not require "nursing care" but instead need individualized supports to assist them in becoming fully included in their communities. In many cases, nursing facilities are not equipped to provide these individualized supports.

Intermediate Care Facilities for People with Mental Retardation and Related Conditions (ICFs/MR)

The Intermediate Care Facilities for People with Mental Retardation (ICFs/MR) program was originated by the Federal government in 1971 and was the first Federal program targeted to monitor residential services for people with mental retardation. ICFs/MR programs range from supporting 6 people in a home in the community to several hundred people in large congregate settings (including units in State institutions).

Since 1994, the number of people in all ICFs/MR has been decreasing.

The standards set by the ICFs/MR program require 24-hour supervision of the individuals who live in these programs and is the most expensive type of community residential services for people with mental retardation and other developmental disabilities. The federal government pays from 50%- 80% (depending on the State's per capita income) of the costs for ICFs/MR programs. To receive this funding, the facilities must comply with an expansive number of regulations in areas such as administration, environments and personnel, along with treatment, goal planning (programming), and observation of rights of the people receiving services.

There are more ICFs/MR operating in the nation today than ever before, but they are serving less people and providing services in smaller settings. Today, more people live in privately owned ICFs/MR than in State-operated ICFs/MR. Overall, ICFs/MR serve only a small percentage of people who live in community settings and they do so at a relatively high cost per person.

From 1982 to 1993 the ICFs/MR program was notable for its stability in the number of persons served. As of June 1994 there were 142,118 persons living in all ICFs/MR. The June 1996 population of ICFs/MR was 129,449. Specially in large ICFs/MR (16 or more residents), there are fewer people living in those residences as compared to the early 1980's. By June 1996 there were 85,109 persons in ICFs/MR of 16 or more residents. In 1982 there were 130,767.

Outside of institutions, small ICFs/MR are the least flexible, most heavily regulated and expensive residential option. In a time with long waiting lists, a push for cost efficiency, continued movement toward community services, and an increased desire for individualized supports, ICFs/MR lack responsiveness to the unique needs of individuals and current societal and governmental pressures.

Home and Community Based Services (HCBS)

The Medicaid Home and Community Based Services waiver program was established in 1981. This program allows certain Medicaid requirements to be "waived" and for States to finance "non-institutional" services for people with mental retardation and developmental disabilities who are eligible for Medicaid and who, in the absence of alternative services would remain in or likely be placed in an ICF/MR, nursing home, or institutional setting.

HCBS allow for the provision of a number of services, including: 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 total costs for Medicaid funded long-term care. HCBS reimbursements can not be used to pay for room and board, but can provide services to people in their homes such as personal care, habilitation, and homemaker services. In most cases cash assistance from other Social Security Act programs (i.e. SSI) are used to fund room and board costs.

Currently, Home and Community Based Services are used to support people living in their family's home, a foster family's home, or a small congregate-care home (less than 6 people) in the community. People might receive respite services on weekends and evenings in a neighbor's home and/or a group home run by a private agency. Although flexible in funding and free from expansive Federal regulations, some States have used their HCBS waiver to simulate services found in small ICFs/MR (or "mini-institutions") by imposing highly structured regulatory requirements on these services. Most HCBS support services are provided by privately run agencies.

There is growth in the number of people receiving Home and Community Based Services. As of June 1996 there were 190,230 persons with mental retardation and developmental disabilities receiving HCBS, an increase of 27.5% over the 149,185 recipients in 1995.

Today more people receive services through HCBS funding than through ICFs/MR funding. There is a large variability between States in per person expenditures, but overall, the cost of providing HCBS services is significantly less than the cost of services in ICFs/MR and State-operated institutions.

More people receive HCBS than receive ICFs/MR services. In Fiscal Year 1996, for the first time more people were receiving out-of-home Medicaid long-term care services financed by the HCBS program (134,873 people) than financed by the ICFs/MR program (129,449 people).

In-Home Supports

Many people with mental retardation and developmental disabilities receive supports in their family home. In 1996, states reported an estimated 265,613 persons receiving services in their family homes. This accounts for 45% of all residential supports provided. However, there is great variation across the states with regard to utilization of family-based services ranging from 0%-77%.

In-home supports provide an opportunity for families to remain intact and are an alternative to out-of-home placements. The types of supports provided can be tailored to meet the needs of the individual receiving services as well as their family and friends. Typically, paid in-home services are provided based on the number of hours needed at times when family, friends, neighbors or others are not available to provide supports or do not have the necessary skills. These services range from a few hours a week to 24 hours a day depending on the needs of the individual being served. In-home supports are often funded by Medicaid through the Home and Community Based Services program, or other Medicaid programs offering personal care attendant services.

Semi-Independent Living

Many States and counties provide funding for semi-independent living services. These supports are most often provided to individuals with mental retardation and developmental disabilities who are quite skilled and may only need a few hours of support each week, typically in areas such as grocery shopping, budgeting or paying bills. Individuals who receive these supports may live alone or with roommates in apartments or homes.

From Funding Programs to Supported Living

Currently there is a move away from funding and creating "residential programs" toward creating "supported living." Supported living means providing supports to people with mental retardation and developmental disabilities based on their individual strengths, preferences, and needs, and in their preferred communities. It is based on the ideology that people have a right to live in their own homes, stay connected to families and communities of origin, choose what they want to do, with whom, when and how they want to do it. It presumes that people need more than just a place to live and someone to provide assistance to them. These may seem like basic and fundamental rights and desires of all citizens, but supported living is the exception not the rule and is certainly not the reality for most citizens with mental retardation and developmental disabilities living in the United States today.

Responding to the needs of individuals by supporting them in their own homes is clearly a growing practice in residential services today. It has been greatly assisted by the expansion of the Medicaid Home and Community Based Services waiver programs and the momentum stimulated by the Medicaid Community Supported Living Arrangements (CSLA)"pilot projects" in eight states which ended in 1995. These demonstration projects enabled states to develop separate and new supported living programs. Even after the end of the demonstration projects, supported living options continue to grow as the newly inspired awareness of the rights and human dignity of persons with developmental disabilities has required it.

The following are essential parts to the vision of supported living:

- ◆ People will have homes of their own, in which they ‘control their own front door’. This includes selecting their own homes in neighborhoods and communities of their choosing, as well as choosing who they will live with or receive supports from, as opposed to living in facilities where they do not choose their house mates, support staff, or neighborhoods.
- ◆ The selection and financing of people's housing will, as much as possible, be separate from the selection and financing of the services and supports they receive so that they don't have to move whenever they want a different service provider.
- ◆ People will define the lifestyles they want. Where people's experiences have been limited they will be given opportunities and assistance in developing and expressing preferences for their lifestyles, instead of living according to regulations.
- ◆ People who formally and informally support persons with developmental disabilities will learn and practice new ways of listening to what people want and dream about, and will redefine themselves as allies in helping people achieve as much of what they want in life as can be achieved, rather than deciding what's "best" for the person.
- ◆ Service providers will redefine their role to that of accommodating and supporting the personal preferences and desired lifestyles of persons with developmental disabilities, rather than trying to "fix" them.
- ◆ Service providers will learn how to be less intrusive in the ways that they bring services and supports into people's homes, and be sensitive to and respectful of people's homes and the rights and courtesies associated with them, rather than making these homes like institutions.
- ◆ People will exercise choice and control in what services and supports they receive and from whom, rather than taking whatever they can get.
- ◆ Service providers will improve their abilities (and flexibility) to deliver services in different ways to different people in different places instead of offering a "one-size-fits-all" approach to supports.
- ◆ Service providers will learn new ways of operating to adjust to a "market" for services in which persons served and the revenues generated are determined by demand for specific services - not a comprehensive contract to care for groups of individuals.

Vision of Supported Living

...people will control their own front door

...people will define the lifestyles they want

... people will exercise choice and control in their supports and services.

For supported living to become the rule rather than the exception, the real requirement is not primarily an issue of funding, but of commitment.

No one can predict in what ways or how much the expanding efforts to adopt supported living will affect the lives of all persons with developmental disabilities. Clearly the rhetoric is expanding, although too often the new words are applied to old ways of thinking and acting. Frequently today even people in State institutions are referred to as "consumers" as though they chose to put their money down for a "bed" in a place with 400 roommates.

Goals are now called "outcomes" but still created and imposed by that same group better known as the Interdisciplinary Team (IDT) which is now called a "support network." Continued discussions on the national level about access to federal financing of services to persons with developmental disabilities will have its effect. But ultimately supported living is not about new words or sources of funding. It is

fundamentally about new attitudes and commitments toward the rights, dignity, freedom, and humanity that people with developmental disabilities share with us all. For those who have had roles in the traditional ways of providing services, supported living is about fundamental change in service provision. At all levels of the service system, roles are being renegotiated, a necessary, but difficult process.

For supported living to become the rule rather than the exception, the real requirement is not funding, but commitment: a commitment to continuously listen to people with disabilities, to honor their requests, and to make the changes in roles and responsibilities as traditional roles conflict with the supports required. What is required is not commitment to provide better programs, but a commitment to assist people to get the lives that they want.

Adapted from: Supported Community Living: From "Facilities" to "Homes", by Charlie Lakin & Michael Smull. In IMPACT: Feature Issue on Supported Living. Minneapolis: MN, University of Minnesota.

Home Ownership and Control

To many people nothing is as liberating as the feeling of having their own homes. Most people feel a sense of pride, security, empowerment and control when they have their own home for the first time. Today, more than ever before, people with mental retardation and developmental disabilities are being given the opportunity to own or lease their own homes. In fact, about 14%, (estimated national total of 45,012) of people receiving residential services because of mental retardation or other developmental disabilities live in their own homes that they own or lease. Nationally, between 1991 and 1996 the estimated number of people living in their own home increased by 19,000 persons as the movement toward consumer controlled housing and supported living continued to gain momentum.

On September 1, 1993, the Administration on Developmental Disabilities(ADD) entered into a cooperative agreement with the Institute on Disability, a University Affiliated Program at the University of New Hampshire, to create a national information and technical assistance center on home ownership/control and personalized support: the National Home of Your Own Alliance. The NHYO Alliance is a partnership between the Federal government and nationally recognized advocates and leaders whose goal is to create housing and support opportunities that individuals choose and control.

The NHYO Alliance is working in the States of Alabama, Arizona, Arkansas, Connecticut, Georgia, Idaho, Illinois, Indiana, Louisiana, Massachusetts, Michigan, Mississippi, Missouri, New Hampshire, New Jersey, New Mexico, New York, Oregon, Pennsylvania, Texas, Washington, West Virginia, and Washington, DC, to develop local demonstrations of home ownership. Each State receiving technical assistance from the Alliance agrees to institute a pilot project to assist a specified number of people to own or lease their own homes. State coalitions are assisted by the Alliance to maximize their unique opportunities to overcome challenges in creating home ownership and control. In addition, the Alliance assists grassroots leadership in working with State systems to develop the critical mass of experience and practice within the lending and social service industries necessary to better serve people with disabilities.

The goal of the National Home of Your Own Alliance is to create housing and to support opportunities so that individuals have chose and control.

The Alliance has developed a national information clearinghouse, performing policy research, collaborating with national mortgage lenders, and conducting an evaluation related to people with disabilities owning and controlling their own homes. The Alliance works in collaboration with the Center for Universal Design in North Carolina, United Cerebral Palsy Associations in Washington, DC, Coop Initiatives in Connecticut, The Institute on Disabilities at Temple University in Pennsylvania, and the Human Services Research Institute in Massachusetts.

The lessons learned from Home of Your Own initiatives around the country raise new possibilities for the creation of person-owned/controlled housing and support. These possibilities can only become nationwide realities if local, State, and national groups focus attention on the physical, economic, social, and institutional barriers that exist.

A lack of personal financial resources and systemic dependence on programs that limit personal choices are two major barriers that deny basic opportunities and civil rights. The limited capacity to create innovative housing and support options and the limited involvement of people in these efforts are also barriers to person-owned/controlled housing and support.

The NHYO Alliance is focused on creating a foundation of exemplary practices and both public and private sector partnerships that will link the home mortgage and social service industries to better serve people with disabilities. Objectives for the Alliance are achieved within the context of three major components: (a) leadership of people with disabilities in all aspects of the Alliance, (b) intensive technical assistance to States, and (c) information dissemination.

Working for a Living: Employment

Until very recently employment opportunities were denied for people with the most severe disabilities (including people with mental retardation). If people received services at all they received them in sheltered (segregated) workshops. In 1973, armed with section 504 of the Rehabilitation Act which stated that no one could be denied access to any program or activity receiving federal funds simply on the basis of having a handicap, the disability rights movement was given fuel to start making their voices heard. The disability rights movement targeted general issues of accessibility and access to secondary education and employment opportunities were high priorities for many people with disabilities. People wanted a chance to be employed in meaningful and productive jobs. They wanted to have careers and a chance to contribute by paying taxes and meeting their own expenses. The Rehabilitation Act of 1973 gave them a legal foundation to make this possible.

In the area of employment, the disability rights movement continued to receive congressional support as more laws with increasing stronger language were passed in an attempt to set a national agenda that presumes the employability of all people with disabilities (The Rehabilitation Act Amendments of 1992). The 1984 amendments to the Developmental Disabilities Assistance and Bill of Rights Act (commonly known as the DD Act) defined supported employment and mandated that State developmental disabilities councils make supported employment opportunities a priority. The definition of supported employment in the act was essentially that the work needed to be in integrated settings, pay real wages and was for individuals with developmental disabilities for whom employment was not likely to happen without some form of support (i.e. transportation, training, or supervision). The American with Disabilities Act of 1990 (ADA) again reinforced the vision of persons with disabilities having the ability and the right to real employment choices in fully integrated environments.

In 1986 and 1987 the Rehabilitation Service Administration awarded a total of 27 grants to State Vocational Rehabilitation (VR) programs. The purpose of these five-year grants was to work toward system change which would expand employment opportunities for people with the most severe disabilities (commonly considered people with mental retardation and other developmental disabilities as well as people with mental illness or physical disabilities that profoundly effect their abilities to function). Most of the remaining States received similar grants of either 3 or 5 years within the next few years.

These systems change grants emphasized finding employment for people with severe disabilities in natural work environments where most of the other workers did not have disabilities. As a part of the

demonstration projects people with disabilities were helped to find jobs in integrated settings and were supported in one of the following three ways:

- ◆ *Competitive or time-limited employment.* Support that lasts for a limited amount of time to help the person find and keep a job, through job placement and on-the-job training.
- ◆ *Supported employment.* Support to help a person find the job and then continued support indefinitely, if needed, to maintain the job. This support may be as little as a few hours a week or in some cases consistent supervision and support through-out the work day.
- ◆ *Enclave work.* Support to teams of individuals (varies from 2 to 15) with similar disabilities who work together at one site in the community (e.g., a number of people on a lawn maintenance crew).

There has been some debate of the ability to make a lasting impact on employment options in such a short time (3-5 years) when there is a long history of segregation, low expectations for people with severe disabilities, and funding barriers to overcome. However, the grants and the integrated employment that came about because of the grants did provide some information which is useful, including the following:

- ◆ The grants were successful in increasing the percentage of people who were employed in integrated work sites.
- ◆ Estimates of the increase in real numbers is from 10,000 people participating in supported employment in 1986 to over 100,000 people participating in supported employment in 1993 with the largest growth between 1987-1990. Other estimates are as high as 250,000 people when enclave work is included.
- ◆ The changes have had a lasting impact on services provided through agencies that primarily offer vocational support to people who have mental retardation or developmental disabilities. Essentially the grants gave many agencies serving people with mental retardation and developmental disabilities the initial push they needed to start using supported employment.

What I Would Want My Job Coach to Know and Do:

- ◆ **Understand how I want to live. I know that you are only responsible for helping with work, but what I do for work has to fit with how I want to live.**
- ◆ **Please don't divide my life into compartments. Listen to what I say about the rest of my life. If I cannot speak for myself, talk to the people who support me where I live.**
- ◆ **Help me stay in touch with my friends. If I am moving to a community job from a workshop or day program, remember that I may be leaving all my friends and someone needs to help me stay in touch with them.**

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- ◆ People with mental retardation and other severe disabilities have been successfully employed when given the right kinds of support.
- ◆ People with mental retardation and other developmental disabilities are the largest demographic group to benefit from supported employment options.
- ◆ People who work at real jobs in integrated settings experience many benefits including: having more money and consequently relying less on public assistance money, contributing to their communities through the payment of taxes (1996 survey estimated that over \$100 million each year is paid in Federal and local taxes by people in supported employment), enjoying other benefits of employment such as positive relationships with coworkers and feeling good about their performance of job duties.
- ◆ Employers recognized that people with disabilities bring valuable skills and attitudes to their jobs, including being reliable, cooperative, friendly and dedicated.

Vocational Services Today

Despite the progress made through the system change grants most people receiving vocational services through agencies serving people with mental retardation and developmental disabilities still work in segregated sheltered settings. Sheltered work experiences vary from "practicing" work through simulation, participating in daily living activities, such as cleaning and cooking, to completing contract work or piece assembly. For instance, in one room of a sheltered workshop people may be cleaning casings for computers which will be assembled somewhere else, in another room people are baking together, and in yet another room someone is washing laundry. Only the cleaning of computer casings will be considered paid work and that may be as little as a few cents per tray, giving the most productive workers a paycheck of about a \$10.00 a month. If there is no "paying" work, activities that simulate work experiences such as sorting a number of items and placing them in bags, will be created to provide "work" experience.

Many people feel that in order to be successfully employed a person must first develop a certain level of competence. For this reason the focus of segregated workshops is to teach "job skills." This is done on the premise that people with disabilities have to acquire certain skills before employers will consider hiring them.

This approach of teaching people skills outside of an actual work setting has several disadvantages for the worker with mental retardation and other developmental disabilities, particularly those with more severe disabilities. For one thing, an emphasis is placed on correcting the person's deficits in order to make them appealing to potential employers, but for many people becoming the "typical" worker could never be a reality. For another, many people with cognitive impairments can not learn a skill in one environment and then perform that skill effectively in another environment (generalization) so that learning a skill in the workshop does not necessarily translate into being able to do it in a real work situation such as a laundry mat or postal room.

Motivation is more difficult to achieve in a segregated training setting than when training is provided on the job because the person does not see immediate and real benefits of performing the task such as interaction with coworkers and supervisors, or a meaningful pay-check. In addition the training of work skills in a workshop setting rarely come from the perspective of a person's interests and strengths. They are most often "generic" skills that have been selected as important by others. In the real world of employment, jobs and their related skills vary. For one job it may be extremely important that you are well groomed and friendly (e.g. restaurant hostess), at another grooming and personality may mean very little if you have certain skills (e.g. car mechanic). Without looking closely at a person's interests and abilities and selecting a career path based on those skills and interests, it is very difficult to properly train a person for a job.

While some people are satisfied with their experience in segregated settings many are not. Often people feel bored, frustrated, and angry by the limitations imposed in a segregated setting. This may create a situation where the changes for integrated employment are diminished because the people displays behaviors in a segregated setting which make support people cautious about helping them find a community jobs.

For instance, one man in his late 40's lived in a group home and worked in a sheltered workshop for people with a high level of support needs (i.e. many couldn't walk, communicate, or eat without assistance.) Although this man was able to walk, talk and communicate well, it took the staff at the sheltered workshop nearly 3 years to realize this. His work consisted of collating and stapling together a stack of papers, then taking out the staple and sorting the papers back into separate piles. During the day he often displayed short bursts of temper particularly when encouraged by staff to increase his productivity. This "challenging behavior" (occasional yelling or pounding his fist on the table), kept him

from being eligible for any integrated employment. For this man and for many others this becomes a vicious cycle where demeaning work encourages poor behavior and where the poor behavior is used as a reason for keeping the person from gainful employment in an integrated setting.

Demonstration of successful employment for people with mental retardation and other developmental disabilities, has shown that community placement and integrated employment can work. This on-the-job training model can increase motivation of workers and starts from an understanding of their strengths and interests. Rather than trying to shape the person receiving services into the standard employee, support people and employers come from a diversity perspective that embraces and uses the person's unique gifts.

As stated earlier, it is estimated that up to 250,000 people with disabilities benefit from work in integrated employment through some form of employment support (competitive, supported, enclave). The majority of these individuals are people with mental retardation or related conditions. While it has been demonstrated that people with even very complex needs can be successfully employed in an integrated setting with proper support, the majority of people with mental retardation currently using supported employment services are people with lower support needs.

Agents Of Change

Often opportunities for integrated employment only come about when a support agency makes the commitment to providing opportunities for real jobs to the people they serve. When looking at agencies who have made the conversion from primarily providing segregated vocational support to providing primarily integrated vocational supports there are a number of factors which need attention. This type of transformation has often been the result of a variety of factors including a change in philosophy at the top (often a new director with new ideas), or some financial crisis which has necessitated change.

When making these changes the direct support staff play a critical role. Direct support staff must clearly understand that part of their job is to be creative and flexible. They must have the necessary training and administrative support to achieve the goals. Job descriptions need to be revised as needed to reflect actual duties and support people must be able to redefine their jobs to build on their strengths. For instance not everyone will be good at job development but they may be very good at providing continuing supports and follow-up after the initial contact is established in a place of employment.

As agencies have tried new options for securing employment they have found a number of strategies that work including the following:

- ◆ Learn about a person's interests, strengths, personal connections and natural supports (family, friends, neighborhood, connecting events) and use this as a basis for finding a good job match.
- ◆ Use networking strategies like those traditionally used by people without disabilities. This has been associated with shorter job searches and higher satisfaction on the job. Job coaches have used their own personal and professional contacts and less often, tapped into personal and professional contacts of family members of the person receiving services in order to locate employment.
- ◆ A related approach to networking is cultivating and maintaining relationships with businesses and employers. This can be done through a series of "cold calls" with new employers or through continuing relationships with employers even when the support agency doesn't have anyone currently employed there.

Another area which will continue to push along the movement to higher rates of integrated employment for younger people is the area of transitional services in high school (commonly called "Transition"). The Individuals with Disabilities Education Act (IDEA) not only encourages fully integrated classrooms for children with disabilities it has also put an emphasis on transitional services, or preparing the young adult for their adult role, including employment or further education (post-secondary) if desired. This focus has been strengthened over the years whenever IDEA has been reauthorized.

The School-to-Work Opportunities Act of 1994 (STWO) also focuses on preparing teenagers for employment. STWO applies to all children in the public schools although it includes specific language to make clear that "all" includes even those with the most severe disabilities as well as other groups who have not always left high-school prepared for employment.

Agency tips for change:

- ◆ **Access technical assistance.**
- ◆ **Be willing to take risks and to be flexible.**
- ◆ **Call upon connections in the community for support.**
- ◆ **Have a strong sense of vision at all levels.**

For people who do not go on to post-secondary education the first few years out of high-school appear to be the most critical in establishing a positive and successful employment record. Vocational classes and employment during the school years are helpful in increasing the employability of the student after graduation. Many people with mental retardation do not make this smooth transition into employment. Without work opportunities they are less likely to have satisfying experiences in the rest of their lives as they have less money and fewer opportunities for

building self-esteem and socializing. Often they may remain in their parents home at a time when many of their peers have moved out and are making their own homes.

Work Incentives

Many people with mental retardation receive Supplemental Security Income (SSI) or Social Security Disability Income (SSDI) as primary sources of income. These benefits have a number of criteria for eligibility including limits on how much a person can earn and the value of assets that people can acquire. Some people who would like to work, avoid supported employment opportunities for fear of losing necessary benefits. The following are some of the Social Security programs people should know about:

- ◆ *1619(a) and 1619 (b)*. These programs allow people to make over the limit for SSI and still maintain some benefits. 1619 (a) uses a gradual decrease in financial benefits as people's incomes increase. 1619 (b) lets people maintain their Medicaid benefits even if they are past the amount allowable to receive cash benefits. On average the amount of money people with mental retardation make in supported employment is below the cut off level for these programs, so many people can work and maintain benefits.
- ◆ *Planning for Achieving Self-Support (PASS)*. PASS is a program that allows people to save a certain amount of money toward activities or expenses that aide in employment. For instance, education, training, work-related equipment, and funds to start a business, may all be eligible as expenses that can be saved for without reducing the amount of monthly SSI checks.

In addition to these programs, there are other work incentives built into Social Security. For instance, if people need to purchase special equipment (e.g. wheelchair) or services (e.g., personal care attendant) in order to be successfully employed, the earnings used to pay for these expense will not count as income.

For more information, contact your local Social Security Office for a publication called "Working While Disabled...How We Can Help" (Publication No. 05-10095).

Interact Center for the Visual and Performing Arts: Artists at Work

Just northwest of downtown Minneapolis, Minnesota is a quiet street of minimally converted warehouses. Look around and you'll find studios, restaurants and coffee shops. Open one set of double-hinged doors and you've entered an artist community. The walls are hung with large colorful paintings, sculpture covers the tables. In the first of two large rooms a group of artists have stopped working on the sculpting materials in front of them. Their hands are moving in unison as they practice sign language.

In the next and larger of the rooms six actors are rehearsing a scene. They are acting out the process of an "annual review" similar to those that take place regularly for people who receive support services for developmental disabilities. The six actors each represent a different part of the "interdisciplinary team" (IDT): a psychologist, a county case manager, a parent, two direct support workers (one from work, one from home), and a person receiving services.

The script is written; a short but accurate story in which the person receiving services and his dream of being an actor is minimized ("Oh Eric, you won't make any money as an actor! "He was a donkey in the Christmas play last year." "Maybe we could enroll him in drama therapy or face painting class!" "I think he's out of touch with reality, we may need to increase our sessions."), but the actors are free to improvise based on their experiences. And for four out of the six, the experiences are very close to reality because they have identified disabilities. In fact the whole scene is a page out of Eric Wheeler's life and the actor is playing himself.

Welcome to Interact Center for the Visual and Performing Arts (ICVPA). Here actors, sculptors, dancers, painters, writers, artists of all types have come together to mentor each other. Artists with and without physical disabilities, artist with and without mental illness and artists with and without mental retardation and related disabilities are all part of ICVPA's unique take on vocational services.

Through a process of core course work and masters classes, people of varying abilities and talents, hone their skills. When ready, artists can begin working with a mentor in a chosen medium. They create portfolios, write resumes, or develop other tools necessary for a career of their choosing and begin the search for a job. After course work is done ICVPA continues to help these artists by being a resource for job placement.

According to Jeanne Calvit, the Artistic Director of ICVPA this kind of program couldn't have come about by thinking in traditional services mode. "People already in the system give up too easily when a bureaucrat says 'No.'" she claims. And no one could fault Jeanne for lack of persistence. Although ICVPA has only been open since September of 1996, there were years of work in order to get it up and running.

While changing the system to create opportunities for people with mental retardation and related disabilities is important, the opening of ICVPA shows the kind of initiative it sometimes takes to work within the existing system. For instance, in Minnesota licensing for vocational programs for people with developmental disabilities was too restrictive in the types of people who could participate and the kinds of activities which could take place at Interact. Instead of giving up, the advocates of this program looked around and found that being licensed as an Adult Day Care gave them the kind of flexibility they needed.

In the scene from the play, actor Eric Wheeler is encouraged by his team to continue learning to mop in a sheltered workshop for \$1.40 an hour ("You got a raise?!"), with the eventual hope of someday being able to mop "in the community." This scene is followed by a monologue in which the actor directly

speaks to the audience about his real life and how not so long ago he was encouraged to give up on his dream of being an actor and stay with his job vacuuming at a fabric store. He relates to the audience the way he rode the bus an hour and a half each way to work for a little over an hour at below minimum wage. "Today," says Jeanne Calvit, "Eric makes more money in one performance than he did for a month of work as a janitor."

But it's about more than money. It's about expression, following dreams, being challenged and valued. As Eric comes to the climax of his story his voice raises, his face is in anguish "They told me I'd never be an actor!" he roars. Then he pauses for a very long time. "Come on Eric!" The voice of Mary Brown, Outreach Director and Artistic Associate directs him. "You need to say that, then immediately switch to a happy mood and say, and now I am."

Apparently his timing is off. Apparently Interacts is not.

Skatasaurus Rex: A Story of Success

Jim has spent most of his career in sheltered work environments. While living in institutions this was his only option because people never left the grounds to pursue off-campus employment as it was "against the rules." While living in a group home he attended a local sheltered workshop which he found boring, uninspiring and demoralizing. Because he didn't want to be there and found little reward in his \$2.00 - \$10.00 checks for two weeks worth of work, he often caused "a little havoc" on the workshop floor or in the greenhouse.

Jim always knew that he was worth more and could contribute to his community by engaging in real work. He always wanted a real job. It just took a very long time for him to convince the system and those in control that he deserved the opportunity. The first couple of community jobs he had failed miserably. Jim has Tourette's syndrome, a condition which causes him to have uncontrollable verbal and physical tics. These tics are often exacerbated by quiet places and high demanding and intense activities. His first community job was washing dishes and busing tables in an executive suite in a prominent office complex. A very quiet place...for executives who conducted important business meetings over lunch. Needless to say, an environment and people who didn't take kindly to crashing dishes that were dropped when Jim had a physical tic or to his verbal outbursts of profanity. He was fired shortly after he started for things he couldn't control due to his disability. His next job was at a manufacturing place where he was expected to complete piece assembly at a rapid pace. He basically didn't like this job and after the person who hired him left, again Jim was fired.

He spent a few years back at the sheltered workshop after these unsuccessful community jobs. Often not getting out of bed in the mornings because he didn't want to go to work and often getting in trouble because of his "poor work skills" and "lack of work ethic." Finally, after he moved into a supported living arrangement, the people who knew him well and cared about him listened and took action. A list of his strengths, interests and already established community connections resulted in him securing the perfect community job for him.

Jim has always loved loud music, lots of action and being the center of attention. He prefers to sleep in the mornings and he likes to do things that enable him to use his gross motors skills (e.g. walking, moving around a lot). He is an excellent "tattle tale" when he sees people doing things they shouldn't (in particular his roommate which causes him a lot of grief), loves his niece and nephew and he enjoys roller-skating several times a week in his leisure time. He interviewed at a pre-school for children with attention deficit disorder but turned down a job offer because he thought it was too quiet in the room and was afraid that the kid's parents might not appreciate his verbal tics. Then a staff person suggested to the employment specialist they might see if the roller-skating rink Jim frequented had any openings. Sure enough they did. Jim was offered a part-time job working as a floor guard and as the Skatasaurus Rex.

He gets to roller-skate as much as he wants, is the center of attention as the Skatasaurus Rex on the dance floor for children's parties and gets paid a decent wage for all of it.

Yes, it is the perfect job for Jim and everyone who cares about and loves him is thrilled that he has it. Jim is beyond thrilled. However, the sad reality is that Jim has always had these same strengths and interests...it just took 15 years for people to really rally behind him, listen and support him in realizing his dreams!

Looking to the Future

While much has been accomplished through the supported employment movement there are some troublesome trends that have emerged particularly since the early 1990's. Some of these include the following:

- ◆ Segregated employment is still growing, suggesting that integrated employment has become viewed as one option available for employment rather than an achievable goal for every person with a disability.
- ◆ Nationally most of Federal and State funds (80-90%) used by agencies that provide supports to people with mental retardation/developmental disabilities still goes to pay for segregated employment in day activity centers and sheltered workshops.

Some additional barriers or concerns about the move to integrated employment which have been identified include the following:

- ◆ Federal mandates like those found in the Rehabilitation Act give a mixed message about supported employment by presuming employability but not funding extended follow-along and proactive service planning necessary to make supported employment successful for all people with disabilities. Many agencies which do provide proactive and long-term services do so without being fairly reimbursed.
- ◆ For some people full-time employment is not feasible or desirable (for example, older people at retirement age or people who have a number of medical conditions that make extended activity difficult or uncomfortable).
- ◆ In some cases "integration" has meant people working in the same building or even room but having very little contact or interaction with other employees. This may increase their risk of isolation if they have no peer relationships at all.
- ◆ Average monthly wages, while far superior to those earned in segregated settings, average under \$400.00 per month. This is still far below the poverty level.

There are still financial disincentives to full inclusion in integrated settings for all people. For instance, parents and consumers of services may hesitate to try supported employment because if the employment situation is not successful they feel it will be difficult to reinstate public aid money when looking for a new job or employment opportunity.

Agencies which support people with developmental disabilities tend to be very compartmentalized. Vocational support agencies typically provide supports during daytime hours Monday through Friday. Residential supports are usually only available at complimentary hours to those traditional work times. As people's preferred lifestyles are taken into account this structure will have to be more flexible. For instance one man with a developmental disability was told at his most recent annual meeting that the job he desired could not be obtained even though he appeared to have all the necessary skills to get and maintain employment (in this case he wanted to buff floors with a buffing machine). The reason had nothing to do with his skills or abilities but the fact that there was no job coach available after 5 p.m. to

provide support. His residential provider also had to discourage a night job because of the difficulty in staffing his home facility 24 hours a day.

Overall, great strides have been made in supported employment opportunities for people with mental retardation and other developmental disabilities in the last 10-15 years. But there is still much work to be done. As with all services to people with disabilities there needs to be a continued focus on greater opportunities for integrated employment for all people regardless of ability level. This will mean continued systems change and a sustained ability to provide individualized supports on the part of all participating agencies.

Initiatives like the Social Security work incentives should be expanded and strengthened to allow people to have an extended trial time at a new job before losing cash benefits or to allow for the maintenance of Medicaid coverage when income levels become too high to keep cash benefits. Like all people, people with mental retardation may have times in their lives when they do not have stable employment for a variety of reasons. If they need or want to change jobs, a safety net of easily accessible assistance money and guarantees of employment support could make them feel more confident in trying integrated employment options.

Agencies which provide supports will need continued technical assistance and seed money to redesign services that fit individual needs. In order to make these changes financially viable and to create an environment which is open to people with disabilities in the work force an increased dependence on natural supports is necessary. For instance people's families and friends need to be active in checking their connections for possible employment just as they would for a family member or friend without disabilities. More emphasis on tapping into the community's capacity to adapt training for people with disabilities when they are employed is needed rather than having training filtered through a job coach. People with disabilities need opportunities and training on how to foster relationships and network, and the system needs to increase its tolerance for job shifting as people begin to build careers rather than just taking jobs. These changes require a tolerance for change and the natural tension that comes from providing person-centered rather than system-centered supports. But with continued creativity and effort, integrated employment can be a reality for all people with mental retardation who desire it.

Playtime: Recreation and Leisure Opportunities

After the work is done it's time to play, or at least relax. Since the beginning of this century there has been an interest in providing recreational opportunities for people with mental retardation and related disabilities. These opportunities have generally been organized as separate activities where all the participants have some form of disability (segregated options). More recently efforts have been underway to open generic (those available to all community members) recreational opportunity to people with disabilities providing an integrated environment where people with disabilities are just one of many people participating (for example, YMCA programs, community centers, etc.).

Recreation and leisure is an area that has certainly not gotten the attention it deserves. Outside of work or school, organized recreational activity is one of the best ways to develop and maintain relationships, an area that is severely lacking for many people with mental retardation. In fact for people with mental retardation who live in group homes and work in segregated environments (or attend segregated classes), integrated recreational and leisure activities may be one of the few opportunities they have to spend time with peers of the same age who don't have disabilities.

Like many areas of support to people with mental retardation, the area of recreational supports has seen changes in the last 10-20 years. The initial push in recreational and leisure services recognized the need for people with disabilities to participate in fun activities. Now there is an increased emphasis on using

recreational activities as a way to promote social connections between people with and without disabilities, and in recognizing the need for people, regardless of their abilities, to have a full range of access to generic community services including areas of recreation (e.g. health clubs, summer camp, public beaches, swimming lessons, local drama clubs, gymnastics).

Legislation such as the Individuals with Disabilities Education Act (IDEA), the Rehabilitation Act, and the Americans with Disabilities Act (ADA) have opened more opportunities for inclusive recreation. The ADA and the Rehabilitation Act have mandated making buildings and public transportation reasonably accessible and prohibited programs which accept federal funds (or other local tax dollars in the case of the ADA) from excluding people with disabilities. The ADA specifically states that separate but equal facilities and programs are discriminatory and requires that recreational services be provided in the most integrated setting possible. Outside of these direct mandates, concepts like the Least Restrictive Environment (LRE) clause of IDEA have set the tone for providing recreational supports in typical settings using generic community facilities and programs whenever possible.

Barriers to Integrated Recreation

Despite the legislative progress many of the recreational programs which are available to people with mental retardation and related disabilities continue to be segregated. There remain a large number of attitudinal (prejudice, over-protectiveness), and physical barriers (inaccessible facilities, lack of assistive technology, lack of transportation, etc.) to inclusion in a full range of recreational opportunities.

For most people with mental retardation, recreational time is spent in the company of others with disabilities or when "integration" does occur, it could be defined as doing the same activity as others but not interacting with them (such as, "special" campers in a separate building and enjoying similar activities but not with peers who do not have disabilities). Too often opportunities for recreation revolve around which segregated program is available or activities which are of interest to support people with disabilities. For school-age children this can mean missing out on the majority of fun and challenging extra-curricular activities like sports teams, cheer-leading squads, and student government.

In most States, recent years have brought supports to people with mental retardation into the community. Part of that vision was that people living in homes in their own communities would also use the same generic resources as their neighbors and peers without disabilities. This presence in the community would then lead to full integration into society as people became known by their local businesses and neighborhoods.

To some extent this has come true. It is common for people who live in small community homes to go to the same local mall (restaurant, movie theater, bowling alley, etc.) that others in the community use or to be employed at the local grocery store or fast food restaurant. What is less common is the participation in structured integrated recreational activities such as softball leagues, folk dance clubs, or mall-walking groups. For children, attending community schools often still means segregated classrooms and transportation and few if any opportunities to participate in integrated after-school or summer break activities.

Sometimes recreational options are selected or eliminated based on what the staff or other support people

Why are inclusive recreational and leisure opportunities important?

- ◆ **People deserve to have access to fun and stimulating activities and places that others have access to.**
- ◆ **People want to meet and make friends with a variety of people.**
- ◆ **People benefit from being challenged.**
- ◆ **These activities can promote good physical health and build self-esteem.**

find preferable. In group homes even simple things like having friends over to visit requires approval of the staff on duty. The less the person with mental retardation is able to express themselves the more likely it is that they will participate in staff-initiated activities designed to get them out but not necessarily based on their own preference.

In addition to limitations in what types of recreational activities people are using, there are other barriers in the way people with disabilities are participating in recreational activities. For instance, people who live alone in their own apartments or homes with minimal paid supports may lack the initiative, money, or companionship which makes using recreational options possible, or they may not have enough paid or natural supports to help them. Most often support is provided in those life skills deemed "most important" (i.e. financial, medical, or general home living such as shopping, cleaning etc.).

In many group homes it is standard practice to take people out in groups of two, three, or more people with disabilities and one or more accompanying paid support staff. While the intention of this group use of a community resource is to provide more people with more recreational opportunities, often the quality of the activity is decreased in terms of making real connections with others. In these large group activities, people with disabilities are more likely to be noticed as "a group with disabilities" rather than as unique individuals. Other members of the community are less likely to directly relate to them and paid support people are more likely to orchestrate interactions with other people (for instance ordering all the food for everyone at a fast food restaurant).

The experience is similar with segregated recreational programs (community dances, day camps, softball teams, etc.) that use generic facilities. Regardless of the quality of the program, the participants are often most notable for the fact that they have disabilities. It is unlikely that the couple without disabilities looking for a drink and some music at the local dance hall is going to be comfortable staying if they walk in on 20 or 30 people with disabilities dancing and drinking. For people with mental retardation who want to get out and participate in a variety of activities, waiting for the monthly segregated dance is hardly a full menu of options.

For children whose only option is segregated recreation there are a number of limits and concerns as well. For instance because of the small number of children who would use segregated activities they are often scheduled infrequently, may be of great distance from the child's home, and may combine children from a wide variety of ages. Parents may be concerned about having their child participate in activities with much older or younger children. The inconvenience of having to get a child across town may make it impossible to use the programs that do exist.

For all children, active, less structured time with peers is where the real lessons of life occur. Having a tantrum around a group of friends usually doesn't get the same kind of attention as having a tantrum around mom and dad. What happens when you hit a friend? What toys are the coolest and what TV shows do you just have to watch? Children who only participate in activities with other children who have disabilities miss out on the necessary development of appropriate interactions with peers.

The affect of paid staff on recreational opportunities can be powerful as well. In group homes there are staff-to-consumer ratios which have to be met, meaning either some people go places they don't really care for or they miss out on activities that don't meet with the majority's approval. In individual placements staff time is at a premium and recreational opportunities aren't always given priority. For many agencies the bottom line of paying staff salaries is a limitation. Often the times in which people can participate in recreational activities is limited by the staffing patterns available where they live. On any night of the week, all around the nation people with mental retardation are expected to leave in the middle of ball-games, movies, and musicals because a staff person isn't scheduled to stay past a certain hour and can't be paid overtime wages.

Why have these barriers to inclusive recreation continued in the face of legislative support and the push for inclusion in residential, vocational and educational areas? The following are just some of the reasons why this is so:

- ◆ Generic community programs do not have enough information on what types of accommodation are needed for people with cognitive impairments, they may be afraid of additional liabilities or cost associated with making their programs more open.
- ◆ Segregated programs may currently be the only programs reasonably available to people with disabilities who need a number of accommodations, and some people feel that segregated programs offer participants special services they can't get elsewhere or that they offer respite from competition with people of greater abilities.
- ◆ Consumers with mental retardation, their parents, and other support people may be unsure about how to proceed in overcoming barriers to inclusive recreation. They may not have the time or know how to effectively advocate for change.

Facilitating inclusion and integration, especially with a focus on relationship building and community connections requires a high level of sophistication on the part of support people. Simply putting people together is not always enough and may actually be detrimental if it serves to reinforce rather than break-down stereotypes. There is very little systematic attempt to provide support people and generic providers with the training and resources they need.

Strategies for Support and Inclusion

For people with mental retardation and their advocates, there are two areas of primary importance in the area of recreation and leisure that currently stand out.

- ◆ Making generic recreational and leisure sources accessible to people of all abilities by eliminating physical and attitudinal barriers.
- ◆ Developing strategies for using those activities as opportunities to build connections with the community through the development of friendships and through the general presence of those with disabilities.

A number of studies have looked at ways to promote inclusive recreation and community options and overcome barriers (both the physical and attitudinal). Strategies that are useful in helping individuals to pursue integrated recreational activities include the following:

- ◆ *Start with the individual.* This is a critical piece. It makes the activity meaningful and increases the likelihood of success. Thoroughly explore the person's interests and current abilities. Think about what gives the person pleasure and what activities have or have not been successful in the past. Sample or view different activities if a person lacks the experience to know what is available. Think about the skills the person already possesses that can be built on. Let the person make the final choice about what activities they will or will not participate in.

Some common barriers to recreational and leisure activities:

- ◆ **Transportation**
- ◆ **Experience**
- ◆ **Prejudice**
- ◆ **Lack of support personnel**
- ◆ **Expense**
- ◆ **Companionship**

If they do not have a choice the activity stops being a leisure activity since the purpose of leisure is to enjoy oneself.

- ◆ *Select an activity.* Match the person's interests and skills with an activity. Try to find activities that match social norms for a person of that age, gender, and cultural or ethnic background. It's not uncommon for paid staff to be a different age, gender, or race from the people they are supporting. This means that many people who rely on paid support staff participate in activities very different from their peer groups. Seek help from others if necessary to identify which activities might be appropriate and enjoyable.
- ◆ *Explore the activity and setting.* Are there things that will be barriers to this activity (e.g. accessible building, transportation, materials in alternative forms, etc.)? Assess the demands of the activity in comparison to the skill levels of the potential participant. Develop solutions to address barriers and maximize participation. In some cases this may be dealing with the physical barriers by working with the recreational provider to make some changes. Or it may mean locating the proper assistive technology. Maybe it is providing education to the program director on strategies for including people of varying abilities.
- ◆ *Provide necessary supports.* Don't initiate the activity without building in the necessary supports to make it a success. Often there may be an initial investment of resources to get a person established in an area. If support people think proactively this original intensity may be lessened as the person gains confidence and skill and as natural supports take a larger role (i.e. perhaps a new friend will come pick the person up for the activity).
- ◆ *Establish goals for the participant.* (e.g. learn new skills, make a friend, improve mobility, increase self esteem). The goals help to maintain a focus for support people as to which areas they should devote their energies. Setting goals (which are identified by the person receiving supports) helps support people know if the process is working (i.e. if the person is learning how to play bridge better but their goal was to make a new friend, interventions and supports may need to be modified).
- ◆ *Monitor and evaluate progress.* Keep tabs on whether the activity is working for the person. Look at what can be improved and what is working well. This will help in future planning for further integrated activities.

The above list adapted from: "Facilitating Integration in Recreation Environments" By S. Schleien, J.E. Rynders, & F. P. Green. Chapter in Challenges for a Service System in Transition (1994) M.F. Hayden & B. H. Abery (Eds.)

Besides just being able to access the community fully, people with mental retardation and related disabilities are very often socially isolated. People act differently in the company of friends than they do in the company of paid staff, parents, or teachers. There is no substitute for friendship, belonging, and intimate relationships. These types of relationships promote good health and a sense of balance in life. If friendship or connections to other community members is the primary goal for involvement the following should be considered:

- ◆ *Work with the person on an individual basis.* If roommates with disabilities want to go to the gym together and work out that's fine, but always going everywhere in a group with people who have similar disabilities serves to limit interaction and to stigmatize.
- ◆ *Think of places the person can fit in "as is."* While new skills may develop due to the activity, attempt to find a place where the person can fit in from the first day and where differences are minimized. For instance if a person wears a helmet for protection because of self-injurious behavior, think about activities where others wear helmets (e.g. football, biking, in-line skating).

- ◆ *Think of logical connections to people.* Support people can think about the people they know who have similar interests to the person and try connecting them with each other. Don't frame it as a volunteer situation but as bringing together two people who enjoy the same thing.
- ◆ *Be consistent.* Visit the same places (coffee shop, library, etc.) over and over. Let the persons face become familiar.
- ◆ *Look for activities that the person can contribute to.* For example church pot-luck, carrying the pompoms for the cheer-leading squad or equipment for a team.
- ◆ *For children prepare or select activities that are cooperative in nature.* Cooperative activities have a high level of interdependence where cooperation, mutual support, and use of all types of abilities is required (baking activities, jumping rope). Preparing children without disabilities in advance in areas like how to deal with communication barriers, or the types of adaptive equipment their peer might use can be effective as long as similarities and capabilities are emphasized and the other children do not feel they are being put in a supervisory role with the child with disabilities.

The above list adapted from: Making Friends: Using recreation activities to promote friendships between children with and without disabilities. (1993) by L. Heyne, S. Schleien, & L. McAvoy. Minneapolis MN: Institute on Community Integration, University of Minnesota (Distributor), and Friends: A Manual for Connecting Persons with Disabilities and Community Members. (1990). by A.N. Amado, F. Conklin, & J. Wells. St. Paul, Minnesota: Human Services Research and Development Center.

People with mental retardation should have full access to public recreational activities and shouldn't have to wait until the "special" programs are offered. They need a chance to challenge themselves by participating in activities with people of varying abilities. Recreational opportunities can provide prime opportunities to develop relationships with peers of differing abilities based on a common area of interest or skill.

Training for support personnel is critical. Integration without proper preparation can actually back-fire and reinforce negative stereotypes. Agencies that provide supports to people with mental retardation, school systems, and their staffs are often the primary sources for creating opportunities for inclusive recreation. They need training and technical assistance on how to best use existing resources, how to foster real friendships and community connections, how to fully use existing natural supports (family, friends, generic resources).

Although the ideal is a fully inclusive community which provides access to all areas, attempting to deal with this problem by closing or not funding segregated recreational activities and programs will not be met by great enthusiasm on the part of people with mental retardation or their advocates. For many the reality still is that in order to participate in many activities the only current option is a segregated specially supported program.

Some ways to work on inclusion include the following:

- ◆ Work with segregated and generic community settings/programs to think about how to broaden their scope and include people of varying abilities. Try integration both ways. Bringing people without disabilities into a segregated program as well as bringing people with disabilities into generic community activities.
- ◆ Challenge communities to build accessibility into their generic programs up front instead of after the fact. Studies have shown that integrating recreational opportunities after the fact, either by opening disability-only programs up to the general public or by trying to adapt the program created strictly for people with typical abilities to people with significant disabilities may produce less than satisfactory results and that headway is often temporary in nature. A better approach is to plan in

advance when developing new programs. Just as architects are asked to plan and build structures that are accessible and welcoming to people with physical disabilities, the same attention needs to be brought into planning public recreational activities to be inclusive of people with cognitive impairments.

- ◆ Educate people on how to overcome barriers associated with transportation, facilities, finances, etc. Assist people in identifying fun, inexpensive activities in their communities. Provide generic facilities and city planners with information on how to make reasonable accommodations for people with mental retardation or other disabilities.
- ◆ Support and fund training and resource opportunities for both paid and unpaid support people (staff, teachers, parents/families, scout leaders, etc.) in the area of facilitating relationships with others in the community. Instead of seeing this as a secondary or specialized skill for paid support staff see it as a primary role. In order to make headway to inclusion we must have people who can think creatively, work independently, and facilitate opportunities and advocacy.

Conclusion

People with mental retardation and related conditions live in a variety of settings with a variety of supports available to them. While there is no magic formula or funding service which guarantees a good quality of life, they and their families have been asking for individualized, flexible supports which nurture people's connections with their families and preferred communities. They don't want to be shut away. The past shows that when they are they have less fulfilling lives, lose contact with natural support systems (family, friends, and neighbors), and are more likely to be abused or neglected. People want to make choices about how they spend their time and with whom.

As a nation we have made considerable steps in the right direction toward providing people with residential, vocational, and recreational options in their communities. Many fantastic supports and services exist. But, we have a long way to go. Do people really have the power to control their own lives (e.g. what they do in their free time, who their friends are, what they eat for dinner, where they work and live) or do they just live in different and smaller places? It is true that more and more people with mental retardation and other developmental disabilities are living in their own homes that they own or lease. However, it is also true that many people remain as "guests" or "residents" where they live and are subject to strict schedules, house rules, pre-determined menus, roommates they may not like, restricted access to phones and privacy, goal plans created by professionals, and imposed values and attitudes from paid support staff. More people are having the opportunity to work at real, integrated jobs with real pay, but many more continue to put in time at segregated workshops. Serious, proactive planning needs to take place so that people with mental retardation do not have to continue to wait to be full citizens in their communities.

Resources

Supporting People with Severe Reputations in the Community. (1992). M. Smull and S. Harrison. This handbook describes, through many practical examples, methods of planning community living with people who have histories of challenging those around them. Available from: the National Association of State Directors of Developmental Disabilities Services, 113 Oronco St., Alexandria, VA 22314. (803) 683-4202.

Patterns of Supported Living: A Resource Catalogue. (1993). B. Allen, J. Shea, and C. Forrest for the California Department of Developmental Services. This source book was developed to assist people in understanding the principles and values underlying supported living and some of the processes that have been developed to support implementation. Available from Allen, Shea and Associates, 1040 Main St., Suite 200B, Napa, CA 94559. (704) 258-1326.

National Home of Your Own Alliance. For more information call 1-800-220-8770 or visit the Alliance's web site at <http://alliance.unh.edu>.

Christmas in Purgatory - A Photographic Essay on Mental Retardation . (1974). B. Blatt and F. Kaplan. This book of photographs depicts the conditions of public institutions in the period just a few years after deinstitutionalization began and major federal reforms were instituted. Available from the Center on Human Policy, Syracuse University, 805 S. Crouse Ave., Syracuse, NY 13244-2280. (315) 443-3851.

Residential Services for Persons with Developmental Disabilities: Status and Trends Through 1996 (Report 49). (1997). R.W. Prouty & K.C. Lakin (Eds.). This report summarizes the status of residential services in each state through June 30, 1996. Available at the Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455. (612) 624-4512.

Bibliography of Supported Employment. (April 1993) Available from the Employment Network, University of Oregon, 135 Education Bldg., Eugene, OR 97403. (503) 686-5311

President's Committee on Employment of People with Disabilities Information Line. 1331 F Street NW, Washington, DC 20507. (800) 232-9675; (202) 376-6205 (TDD). Provides information regarding employment of people with disabilities and how to make job accommodations.

Supported Employment: A Step By Step Guide. (1992). PACER center, Inc. This book explains the adult service delivery system and how to get or improve supported employment for an individual with developmental disabilities, mental illness, traumatic brain injury or other disabilities. Available from PACER Center, Inc. 4826 Chicago Ave. S., Minneapolis, MN 55417. (612) 827-2966.

Social Security's Work Incentive Programs. To find out about eligibility and guidelines contact: Social Security 1-800-772-1213(V), 1-800-325-0778 (TTY) or visit the Social Security website at: <http://www.ssa.gov>.

The Association for Persons in Supported Employment. It is a national organization established to improve and expand integrated employment opportunities and services for persons with severe disabilities. (804) 282-3655.

Friendships and Community Connections Between People with and without Developmental Disabilities. (1993). A. Amado. A resource for supporting friendships and full community participation through the use of natural social connections. Paul H. Brookes Publishing Company, Baltimore, MD. 1-800-638-3775.

Making Friends: Using Recreation Activities to Promote Friendship Between Children with and without Disabilities. (1993). L. Heyne, S. Schleien, and L. McAvoy. A handbook that assists parents, community recreation staff, and teachers to support friendships between children with and without disabilities, grades K-6. Available from the Institute on Community Integration, University of Minnesota, MN 55455. (612) 624-4512.

Interact Center for the Visual and Performing Arts. For more information and other opportunities in the Arts, refer to the IMPACT Feature issue on Persons with Disabilities in the Arts (Winter 1997) Available at the Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455. (612) 624-4512.

Project TRAIL Publications. A number of publications are available, including 'Leisure Education Self-Contained Instructional Packages for People with Cognitive Impairments', a manual for use in creating educational board games that can be used with persons with developmental disabilities in leisure education programs; 'Community Support Through Leisure Coaching', a guide to ways that family and friends and community volunteers can assist a person with developmental disabilities in leisure pursuits; and publications on how to develop detailed leisure education curriculum for persons with developmental disabilities. Available from Project TRAIL, The University of Georgia, Athens, GA. (706) 542-5064.

Check out these websites and link to other disability related sites:

<http://www.napanet.net/business/personal/ASA/articles.html>

<http://TheArc.org/faqs/leisure.html>

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Glossary

Action Plan: One of many terms being used for creating a plan for people receiving services that is based on their abilities, strengths and personal desires or goals. These plans are created by support teams or circles of support (the people who know the person best and who the person would like to have participate in planning), and professionals who are only invited at the request of the rest of the support team. Action plans are more and more being used to replace previous deficit based planning (see IEP/IPP/IHP/ISP).

Case management or care coordination: A system in which a single professional is responsible for ensuring that a recipient obtains the full range of services required.

Community integration: A concept that reflects the practice of sharing in community life, involving at least these four aspects: (a) physical integration where the individual actually lives in the community, (b) cultural integration where the individual exhibits locally valued lifestyles and roles, (c) integration where the individual enjoys reciprocal relationships with others in the community, and (d) self-determination (see definition of this term below).

Competitive Employment: Typical employment in which a person is placed in a job and requires no additional support or supervision other than that which is typically provided by that employer.

Consumer: A term often used to describe a person with a developmental disability who receives some type of services from a government or private agency. A consumer of services. This term is used in place of client to put the emphasis on the person as someone who uses services rather than someone who has a problem which needs professional help.

Decentralized: Spread out, not in one place. Residential services for people with developmental disabilities has become more decentralized since institutions have been replaced by many small group homes. This trend toward decentralization will continue as more people are supported in their own homes and with individual vocational supports.

Demographics: Percentages and real numbers that are useful in describing populations and understanding trends. For example, the percentage of people with disabilities between the ages of 25-40 who are employed full-time compared to the percentage of people without disabilities between the ages of 25-40 who are employed full-time.

Direct Service (Support) Work force: The collective group of paid Direct Support Professionals working throughout the United States or within any given State, region or local entity.

Direct Support (Service) Professional (Worker or Staff): An individual who may or may not be paid who assists individuals with developmental disabilities to lead self-directed lives and to contribute to their communities; and encourages attitudes and behaviors that enhance inclusion in their communities. DSPs provide supports in a variety of settings to people with a variety of types of disabilities.

Enclave: A type of supported employment option where groups of people with similar disabilities work together in a community setting. These groups typically vary in size from 2-15 people. This type of supported employment is advantageous for people who may not be able to work consistently enough to maintain a daily job. The disadvantages are that the group situation makes social contact with workers without disabilities less likely and that the person will be seen as one of "those" workers with disabilities.

Generalization: Being able to apply a skill or knowledge to different situations. Many people with mental retardation have difficulty with generalization. This means the best place for them to learn a skill is in the place they will use the skills, for instance being trained in job tasks at the actual job or learning home-making skills in their own homes.

Generic: As in generic community resources. Public resources available to all people regardless of ability such as parks, swimming classes at the local YMCA, or professionals like doctors/dentists.

Group Home: A typical home in the community which has one or more people with disabilities living in it and receiving services. These homes can range in size from 2 to 15 people and can be publicly or privately owned and operated.

Home and Community Based Services: A variety of services which are funded through the Federal Medicaid Home and Community Services Based Waiver program. HCBS unlike ICF/MR funding is a less regulated and more flexible pot of money which can help fund services provided in a number of settings including small agency run group homes, family homes, and a person's own home or apartment.

IEP/IPP/IHP/ISP: Individual Educational/Program/Habilitation/Service Plan. Individualized plans for a person receiving services which includes goals to be achieved in an upcoming time frame (usually 1 year). Traditionally these plans have been developed by teams of professionals with some input from family members and the individual receiving services. Goals focus on improving in areas where a person has a weakness.

In-home services: Services provided in a person's home.

Institution: Large public or private residential program in which 16 or more people with mental retardation and other developmental disabilities live. Institutions are most often part of State-run hospitals and usually comply with the Intermediate Care Facility (ICF/MR) standards set by the Federal government. Institutions were once the only place where people with mental retardation could receive residential supports, they are now the place of last resort for residential placement.

Integrated: A setting where people of all abilities and backgrounds work, live, or play together.

Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR): The first Federal program targeted to residential services for people with mental retardation. The size of ICFs/MR range from 6 people living in a community home to several hundred living in a large congregate setting (including units in state institutions). These programs require 24 hour supervision of the people who live in them.

Long term services and supports: Supervision or assistance given to a person with disabilities to help the individual complete daily living activities (e.g., eating, dressing, bathing, communicating, keeping a job, taking prescribed medications), learn new skills, maintain a general sense of safety and well-being, or otherwise pursue a normal daily life rhythm. Such assistance typically excludes medical interventions due to injury or illness.

Managed care: Various strategies that seek to maximize the value of services by controlling their cost and use, promoting their quality, and measure performance to ensure cost effectiveness.

Natural Supports: Supports which naturally occur in all people's lives. Some examples include, a friend who helps paint your house, a neighbor who picks up your mail when you are out of town, a coworker who picks up your paycheck when you are sick, a family member who introduces you to a potential new employer.

Outcome: The benefit of services or supports.

Personal assistance: One person assisting another with tasks individuals normally would perform for themselves if they did not have a disability.

Qualified Mental Retardation Professional (QMRP): A person with a four year degree in a human services field and a minimum of 2 years experience working with people who have mental retardation or related conditions. The ICF/MR regulations require that a QMRP review and approve any program developed for people receiving services.

Segregated: An environment where only people with a certain label or defining characteristic work, live, or play.

Semi-independent Living Services (SLS): A program for people with mental retardation who have low support needs and live for the most part independently with a few hours of services each week from paid staff.

Sheltered work: A work setting in which only people with mental retardation and other disabilities work.

Supported employment: Describes services to help individuals with disabilities to find and keep a paid job in a regular community business (not counting employment in sheltered workshops or similar service environments). Paid staff can: (a) work with the individual to determine the type of job preferred, (b) find appropriate employment, (c) work with the employer to modify the job, apply assistive technology, or otherwise assure that the individual can perform the job, (d) provide support to the individual on the job or to his or her coworkers, and (e) monitor quality and provide support as needed.

Supported living: A residential service model which is based on the provision of only those supports which the person needs-tailoring services to meet individual needs.

Common Acronyms

The field of services to people with mental retardation and other related developmental disabilities uses literally hundreds of acronyms. While they can be useful for brevity, common courtesy requires that assumptions are not made while speaking, presenting, or writing. A term should always be defined the first time it is used and more frequently if the information is intended for people who are not professionals in the field. The following are just a few of some of the most common acronyms used:

AAMR - American Association on Mental Retardation (formerly Mental Deficiency)
AAUAP - The American Association of University Affiliated Programs for Persons with Developmental Disabilities
ADA - Americans with Disabilities Act
ADD - Administration on Developmental Disabilities (Washington, DC)
AFDC - Aid to Families with Dependent Children
ARC - Association for Retarded Citizens
ASO - Administrative Service Organization
BIA - Bureau of Indian Affairs
CAP - Community Action Program, or Client Assistance Program
CEC - Council for Exceptional Children
COBRA - Consolidated Omnibus Budget Reconciliation Act
COLA - Cost of Living Allowances
CP - Cerebral Palsy
CSLA - Community Supported Living Arrangement
DAC - Developmental Achievement Center
DD - Developmental Disabilities
DHHS - Department of Health and Human Services (Washington, DC)
DHS - Department of Human Services
DRS - Division for Rehabilitative Services (federal level); Division for Rehabilitation Services (state level)
DSP/W - Direct Support Professional or Direct Service (or Support) Worker
E/BD - Emotional/Behavior Disorders
ECFE - Early Childhood Family Education
ED - Emotionally Disturbed
EEOC - Equal Employment Opportunity Commission
ELP - Essential Lifestyle Plan
EMH/R - Educable Mentally Handicapped or Educable Mentally Retarded
EPS - Early and Periodic Screening
FAPE - Free Appropriate Public Education
FAS - Fetal Alcohol Syndrome
FERPA - Family Education Rights and Privacy Act
FY - Fiscal/Budget Year
GAO - General Accounting Office
HCBS - Home and Community Based Services
HCFA - (Federal) Health Care Financing Administration
HCPA - Handicapped Children's Protection Act
HMO - Health Maintenance Organization
ICAP - Instrument for Clients and Agency Planning
ICF/MR or ICFs/MR - Intermediate Care Facility or Facilities for Persons with Mental Retardation
IDEA - Individuals with Disabilities Education Act
IEP/IFSP/IHP/IJP/IPP/ISP/ITP - Individual Education Plan/Individualized Family Service Plan/Individualized Habilitation Plan/ Individual Justice Plan/Individual Program Plan/Individual Service Plan/Individual Transition Plan
IQ - Intelligence Quotient
LEA - Local Education Agency

LRE - Least Restrictive Environment
LTC - Long Term Care
MA - Medical Assistance
MH - Mental Health or Mentally Handicapped
MI - Mental Illness
MR/RC- Mental Retardation and Related Conditions
NASDSE - National Association of State Directors of Special Education
NASDDD - National Association of State Directors of Developmental Disabilities
NIDRR - National Institute on Disability and Rehabilitation Research
OASDI - Old-Age, Survivors and Disability Insurance (also RSDI)
OSERS – Office of Special Education and Rehabilitation Services
OT - Occupational Therapist
P&A - Protection and Advocacy (System)
PASS - Plan for Achieving Self-Support, Social Security Administration, or Program Analysis of Service Systems
PCA - Personal Care Attendant
PCEPD - President's Committee on Employment of People with Disabilities (formerly PCEH)
PCMR - President's Committee on Mental Retardation
PCP- Person-Centered Planning
PFP - Personal Futures Planning
PKU - Phenylketonuria
PL - Public Law
PT - Physical Therapist
QA - Quality Assurance, or **QE** - Quality Enhancement
QMRP - Qualified Mental Retardation Professional
RFP - Request for Proposal
RRTC - Rehabilitation Research and Training Center
RSA - Rehabilitation Services Administration
SABE- Self-Advocates Being Empowered
SE - Special Education or, Supported Employment
SILS - Semi-Independent Living Services
SLA - Supported Living Arrangements
SLF/SLS - Supervised Living Facilities/ Supervised Living Services
SNF - Skilled Nursing Facility
SSA - Social Security Administration
SSDI - Social Security Disability Insurance
SSI - Supplemental Security Income
STWO - School-to-Work Opportunities Act
TASH - The Association for Persons with Severe Handicaps
TDD - Telecommunications Devices for the Deaf
VR - Vocational Rehabilitation
WAC - Work Activity Center

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