With a little help from my friends…

A series on contemporary supports to people with mental retardation

Speaking Up-Speaking Out

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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
Chair

Gary H. Blumenthal
Executive Director

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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A 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

The field of supports to people with mental retardation and other developmental disabilities has been rapidly changing since the mid 1960's and early 1970's. At that time, a series of media exposes helped to make people aware of how poorly citizens with mental retardation were being treated. In those days not only were there limited educational opportunities for children with disabilities, adults received little or no support outside of their families unless they resided in an institution. For those who did live in institutions, the conditions were often horrible: overcrowded, unclean, unsafe, and often hotbeds of abuse and neglect.

Even at the better facilities, people exercised few rights, had few possessions, and were cut off from their family, friends, and communities.

Since that time there have been a number of changes which have improved the lives of many people. Concepts of how best to provide supports have changed from that of providing basic care to that of providing supports which are unique to each individual, and which help empower the individual to maintain important relationships and lead a self-determined life.

This booklet starts with definitions of mental retardation and a look at how many people are estimated to have mental retardation and related conditions. It provides an overview of many recent changes in concepts of support, including legislation which affects those with disabilities, and other issues of the law such as guardianship, protection and advocacy, and the criminal justice system. The chapter ends with a discussion of self-determination and self-advocacy on the part of people with mental retardation.

WHAT DO PEOPLE WANT?

"We all want the same basic things out of life: a decent and comfortable place to call 'home', something meaningful to do during the day, some close friends with whom to share the good times and from whom we receive support in difficult times, and the opportunity to make our own decisions about things that will affect our personal lives. People with disabilities want these same basic things and are increasingly speaking up for themselves about what they want. And staff, family, and State agency professionals are beginning to really listen."

—excerpts from "Home, Sweet Home" by Susan L. Babin, IMPACT : Feature Issue on Supported Living (1995)

Definitions of Mental Retardation / Developmental Disabilities

How should mental retardation be defined? How many people with mental retardation are there and what kinds of supports do they need? These are questions that State agencies which serve people with mental retardation and related conditions must answer in order to best plan for providing adequate supports to those that need them.

Definitions of mental retardation have changed over the years. In the past a person's IQ score was used as the sole determinant of mental retardation, with the cut-off point being somewhere around 75 points or less. Today, several different associations and agencies define mental retardation in different ways. However, almost all of them use an IQ score as only one criteria and usually pair it with an assessment of how well a person can manage daily tasks which are appropriate for his or her age.

For instance, the Federal definition of developmental disability, a term which includes most people who have mental retardation, as found in the Developmental Disabilities Assistance and Bill of Rights Act (P.L. 103-230) is as follows:

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

- Is attributable to a mental or physical impairment or combination of mental and physical impairments.
- Is manifested before the individual attains age 22.
- Is likely to continue indefinitely.
- Results in substantial functional limitations in three or more of the following areas of major life activity—

    1. self-care;
    2. receptive and expressive language;
    3. learning;
    4. mobility;
    5. self-direction;
    6. capacity for independent living;
    7. economic self-sufficiency; and
    8. reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

While not all people with IQ scores in the mid-70's or lower will fit the current Federal definition of a developmental disability, many will. This definition of developmental disability does not talk about specific disabilities such as mental retardation, autism, cerebral palsy, spina bifida, or epilepsy,—all of which could be developmental disabilities—but instead focuses on the severity of the disability, and how well the person functions in several major life activities.

This increased emphasis on how well a person is able to function in their environment is important. If a group of people were randomly selected based simply on the fact that they had an IQ score of 100 on a standardized test—a score that puts them firmly in the realm of "average"—it would be very difficult to try to define what they need and want out of life without any other information. Some may be unable to keep track of the checks they write, while others balance their checkbooks to the penny. Some may be great athletes; others may be "couch potatoes." Some may be firmly on a career path; others may leave a job every six months or so. A few may be deeply satisfied with their lives, while the rest are still searching. People with mental retardation show the same kinds of variability. Their abilities are related to their lives, their interests, their personal histories, and their opportunities.

The American Association on Mental Retardation's (AAMR) most current definition of mental retardation (1992) also has a strong emphasis on a person's abilities and limitations, as well as an IQ score. The following is the newest definition developed by the AAMR:

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

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

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

The AAMR guidelines on using the definition describe the importance of supports and states that supports serve various functions and may come from a number of areas.

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

Support Functions: Supports can come from a number of resources, including oneself, other people, technology and services. The following are examples of each type of support:

- *Individual.* Skills, competencies, the ability and opportunity to make choices, money information, spiritual values.
- *Other People.* Family, friends, coworkers, roommates, mentors, staff.
- *Technology.* Assistive devices, behavioral technology, job/living accommodations.
- *Services.* Currently available services that are to be used if natural resources are not available.

The AAMR lists seven support functions:

1. Befriending.
2. Financial planning.
3. Employee assistance.
4. Behavioral support.
5. In-home living assistance.
6. Community access and use.
7. Health Insurance.

There are three key points to consider relative to the support functions listed above. First, the major purpose of supports is to enhance successful integration. Therefore, we should strive to use natural supports whenever possible. Second, supports may either be of life-long duration or their need may fluctuate during different life stages. Third, supportive services should not be withdrawn unless the service provider continues to monitor the person's current and future needs for support (AAMR, 1992).

Natural Supports

This AAMR definition of mental retardation has some other critical differences beyond IQ and functional skills. It recognizes that a person's abilities are related to their natural support system and environment. For example, there are many people without mental retardation who show a lack of initiative in paying bills on time. Very often this "deficit" in functional skills can be masked by a good partner. Natural supports are part of everyone's lives. They may be the coworker who reminds us to punch in at the beginning of a work shift, or the neighbor who lets us know that our dog is loose in the neighborhood.

In addition, careful selection of where to work or live can be a critical part of how dependent a person is on others. People who don't like to drive and do not want to be overly dependent on others, will most likely want to live where public transportation is available and where a grocery, a hair stylist, a doctor and other service providers are within walking distance. People who have limited mobility are much more capable of doing things for themselves if the home they live in is set up to be accessible. For instance, someone who uses a wheelchair may choose to put the kitchen items they use daily in the lowest cupboards and shelves and store those items that are used less frequently in the upper cupboards. Environment can make a difference in ability to function effectively.

Prevalence

How many people have mental retardation and need supports? There are over 20 prevalence studies completed in the last 25 years in the United States, Canada, and Western Europe which have attempted to quantify the number of people who have mental retardation and related conditions.

Based on current information, estimates are that 1-2 % of the US population will have a label of mental retardation at some point in their lives. One of the most consistent elements of prevalence studies to date is a temporary increase in the number of people identified as having mental retardation in the years between the ages of five and 21. This temporary "growth" in the number of people with the label of mental retardation is related to the fact that many people who do quite well in caring for themselves at home, in the community and at work may struggle a bit more with traditional academics. During their school years, they may become eligible for special education services and then have little need for special services after the school years have ended.

Some people, those with a wider range of adaptive skills and natural supports, will have the label of mental retardation only intermittently in relationship to temporary need for services. Others will be identified as having mental retardation early in life and because of their continual need for supports and services will retain this label throughout their life. The number of people who are persistently identified as having mental retardation throughout life can be estimated at about .5% with another .5% needing services at any given time.

The Changing Face of Services and Supports

The President's Committee on Mental Retardation's (PCMR) vision for supports to people with mental retardation is one in which supports and services are individualized in a manner which is based on a person's needs and desires. This is contrary to the current standard of supports which is based on "one-size-fits-all" approach of creating service models where the person must take all or nothing. The Work Group on Long-Term Care Reform at the PCMR Presidential Forum, April 1994, laid out what they saw as some challenges and needs in the evolution of supports to people with mental retardation. The following is their description:

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

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

- The provision of services and supports tailored to the needs and aspirations of each individual, rather than a "continuum " of prefabricated long-term care program options.
- An emphasis on consumer choices, either made directly or, where necessary, through a facilitator.
- The opportunity for people with lifelong disabilities to have dreams and the chance to achieve them.
- Outcome-based accountability systems that operate on all levels of the service delivery system.
- Children with disabilities should live with families.
- Independence and productivity are highly valued service outcomes for all consumers, and public policy and funding should be directed toward eliminating barriers to achieving such outcomes.
- Eligibility should be based upon the individual's needs and not labels.
- People closest to those in need of supports should be empowered to help them realize their personal goals, wherever possible.
- Funding should be based on individual needs and wants, not program slots.
- Individuals who work directly with consumers and their families should be given considerable latitude in designing and carrying out support strategies.
- Emphasis should be placed on developing community partnerships in which responsibility is shared by individuals with disabilities, their families, and friends, as well as the community at large. The role of formal services should be modulated to take into account such informal, indigenous community support networks.
- Quality assurance mechanisms should be strengthened, with the emphasis on achieving meaningful individual outcomes; people with disabilities should be involved in monitoring the quality of services and supports that are provided.

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

This concept of services, where people can choose their own supports, where services forge and re-enforce the connections between people and their personal networks (family, friends, coworkers, etc.), and where services are delivered in natural environments and the community of the person's choice, would seem to be a logical and reasonable position. It has been in the forefront of progressive thought for many years. However, as the PCMR description for future changes points out, there are historic reasons why services and supports for people with mental retardation are still not provided in a way that is directly related to what people want, and how they want it.

Although fewer people than ever live in large institutions, there are over 50,000 people still residing in large State-run facilities. But even more importantly, those who have left the institutions very often still receive supports in a manner which is rooted in the institutional model. This legacy of medically-oriented, deficit-based supports reaches out to touch even those who have never and will never live in an institution. The following chart shows the evolution in services to people with disabilities over the last four decades:

The Evolution in Services and Supports

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

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

While there are increasing numbers of individuals, service providers and States recognizing the need for the change to supports which foster full community membership for people with mental retardation, the funding sources, and the measures of quality in services remain fixed in the past. Nationally there are many demonstration projects currently in progress to look at these necessary changes. The following are some of the types of projects which will have an influence on what kinds of supports and services will be available in the future:

Managed care models. Projects which are looking at how managed care can be used to improve services rather than be detrimental to them.

Self-determination projects. Projects that look at ways to foster choice and decision making in people with developmental disabilities and at ways to make services responsive to those choices.

Models of quality assurance based on consumer outcomes and satisfaction. Projects which are looking at making consumer satisfaction with services the main criteria for judging quality of services, rather than using compliance to process oriented regulations as a marker of quality.

WHAT IF IT HAPPENED TO YOU?

At a recent trip to a midwestern State fair a 35-year-old man with Downs Syndrome was not allowed to ride on a roller coaster unless he had the companionship of an adult without disabilities. Children as young as 7 were riding the roller coaster alone while this gentleman, who could independently navigate the metropolitan bus system, was told he was too incompetent to ride without supervision. At the same fair a friend of his with cognitive disabilities was not served beer at a stand because his form of identification was the State issued ID and not a driver's license.

A 32-year-old man who was his own guardian almost lost his appointment for a critical CT-scan while hospital staff frantically searched for someone who could give permission (sign the forms) allowing the procedure. Not only was the man not directly asked about his guardianship status directly, the hospital staff didn't even inform him that his appointment was about to be cancelled.

A 28-year-old woman with Downs Syndrome didn't like her job in a sheltered workshop. She complained about having to go every morning and then began refusing to get on her bus. Rather than helping her seek alternative employment, group home staff were given permission by a behaviorist to physically "escort" her to the bus (i.e. force her on against her wishes) every morning.

In the current system, services are usually part of a "package deal" where the State pays for a "slot" or "bed" in an agency-run home or at a day habilitation center and then places a person who is in need of services in an open "slot." Most likely, one of the critical components that will be identified in these types of projects is that services and supports can not become responsive to consumer needs if the consumer is not in control of the money to pay for these services.

People with Mental Retardation as Citizens

Infringements of personal rights are far from uncommon for people with mental retardation. In fact it is often an integral part of the disability experience. In the majority of community group homes, people with mental retardation are denied basic rights like having access to their own money, choosing when they will leave their own homes, or making a phone call whenever they wish. Even choosing to eat their dinner in front of the TV after a hard day at work can often be a major battle with direct support staff.

Discrimination can be done with ill intent, but more often it is done out of ignorance and with an emphasis on protecting people with mental retardation from harm. The balance between "protection from harm" and the opportunity for people to exercise their rights and to take risks is often difficult for service providers, family members, guardians, conservators, legal systems, and advocates. Despite these difficulties, today people with mental retardation are exercising their rights more than at any time previously in this century. Yet, as a society we have a long way to go in protecting and advocating for basic civil rights for people with all types of disabilities.

The following are some important issues today for people with mental retardation and their advocates:

- To work toward the continuation, supplementation, and full implementation of current Federal laws which promote civil rights, protection and advocacy, community access, and opportunities for people with disabilities.

- To look at and revise current guardianship statutes so that they work well for people with mental retardation and related conditions.

- To look at the current criminal justice system and its ability to work effectively for both victims and suspected perpetrators of crime who have mental retardation and related conditions, and to make the necessary changes to protect people.

- To continue to educate people with mental retardation and their families, advocates, and service providers on full expression of rights and methods of self-advocacy. The area of laws, rights and justice is one where education is of critical importance. Not only is the average citizen greatly ignorant of the rights of people with mental retardation but so are many of the people who provide daily supports. In fact in many cases the very people in the best position to facilitate the expression of rights for people with mental retardation (paid support staff, families, guardians, etc.) are also very likely to be obstructing the expression of those rights.

In fairness to these people, they are often charged with the complex and sometimes completely contradictory expectation of simultaneously advocating for an individual's rights and ensuring the complete safety of the individual from any form of harm. The guardian, for instance, may be legally liable for choices or actions on the part of the ward. Direct support staff and provider agencies may find themselves unpleasantly scrutinized should an individual's choice lead to injury, exploitation, loss of property, or harm to others. Families are not likely to give permission to the pursuit of activities which they perceive as harmful or inappropriate (e.g. sexual activity, gambling, drinking, vegetarianism), even if the majority of the individual's same-age peers are participating in such activities.

The public often perceives people with mental retardation as incapable of good judgment, needing constant supervision, and as inordinately vulnerable to victimization and danger. To varying degrees people with mental retardation experience this type of discrimination starting the minute they are born. Much of the time they are unaware that they are being denied their rights and because of various conflicts of interest there are few to guide them in speaking out. Continued education for everyone (self-advocates, families, paid providers, legislators, judges, lawyers, communities, etc.) is imperative in order to provide the best balance of reasonable protections with expression of a full range of rights for people with mental retardation.

National Legislation

As with any group who is discriminated against it sometimes takes a special law to set things right. There is no doubt that legislation has been very instrumental in forwarding the cause of inclusion for people with mental retardation. State and Federal laws have helped speed the process of moving people from institutions to the community, as well as guaranteeing education and employment opportunities, fair housing, and protection of civil rights for people with disabilities.

For instance, prior to the Education for Children with Handicaps Act of 1974 (now a part of Individuals with Disabilities Education Act), many children with mental retardation did not have the option of attending public school. Not only were they denied an appropriate education, community participation, and relationships with their peers, the end result for many was that they had to leave their family homes to reside in institutions because there were no other support services or forms of respite for parents of this era.

Federal legislation affecting the lives of people with mental retardation and other developmental disabilities:

- **Individuals with Disabilities Education Act**
- **The Rehabilitation Act**
- **The Americans with Disabilities Act**
- **The Developmental Disabilities Assistance and Bill of Rights Act**
- **School-to-Work Opportunities Act**

Another example is section 504 of the Rehabilitation Act of 1973 which stated that "No otherwise qualified Handicapped individual...shall, solely, by reason of his handicap, be excluded from participation in any program or activity receiving Federal financial assistance." This language applied to public schools, parks, libraries, postal offices, hospitals, youth centers, etc. and offered people with disabilities a legal route to insist on access to things most people take for granted.

There are several Federal laws which mandate access to certain types of services or which define the expression of civil rights for people with disabilities. The following are brief descriptions of the major components of some of the national legislation which strongly affects service, supports, opportunities and financial status of people with mental retardation and related disabilities.

The Individuals with Disabilities Education Act

The purpose of this act is to ensure a free and appropriate education to children with disabilities including mental retardation. It contains in it the Least Restrictive Environment (LRE) clause which requires that students with disabilities are educated to the maximum extent possible with children who are not disabled. Children with disabilities may only be excluded from regular education settings when the nature and severity of their disability is such that education in those classrooms with the use of supplemental aids and services cannot be achieved satisfactorily. IDEA also authorizes early intervention services for young children and transitional services for older students to make sure they are fully prepared and supported in their transition to adult living. IDEA gives parents of children with disabilities a way to advocate for the most inclusive setting possible for their children and to receive the necessary supports and services to make this happen. This law requires parents, professionals, and the student to create an Individual Educational Plan (IEP) which outlines what goals the student will strive for and how these goals can be achieved.

Despite the presence of this law there are still a number of problems relating to the education system and children with mental retardation. For instance, the majority of students do not experience full or often even partial inclusion in their educational settings, nor do they have ready access to effective early intervention services. Transition services are not always as successful as hoped. Some States misinterpret some aspects of this law and don't correctly implement it. For instance in some school systems reimbursement for services in segregated environments is higher than reimbursement for services in inclusive/integrated environments. There is also a real lack of cohesion between all the necessary parties involved. Regular education teachers, other parents, and school administrators can feel pressured or threatened by the requirements of the LRE and may also lack the resources necessary to make inclusion successful.

The Rehabilitation Act

The purpose of this act is to support training, research and services that help to create comprehensive and coordinated programs of vocational rehabilitation and independent living for people with disabilities. The act provides Federal funds and support for training and placement of persons with disabilities into competitive employment. It also contains language that safeguards civil rights for people with disabilities and promotes activities that help people access independent living services.

Grant money made available through this act has been instrumental in beginning the movement toward supported employment (i.e. integrated community employment that pays real wages) for people with mental retardation and other severe disabilities. Recent amendments to this act have affirmed social recognition of people with disabilities as capable responsible citizens who deserve fair treatment and opportunities for personal growth. This act assumes the employability of all people regardless of disabilities.

The Americans with Disabilities Act (ADA)

The purpose of this act is to coordinate and expand civil rights for people with both physical and mental disabilities and to eliminate discrimination against individuals with disabilities. It mandates equal opportunity in the areas of transportation, public accommodations, employment, State and local government services and telecommunications relay services for people with disabilities.

The ADA applies to all people with disabilities including cognitive disabilities. Employers, businesses, and other entities covered by this act must provide any reasonable accommodation to people with disabilities. For instance employers may need to make minor alternations in job duties or provide specialized equipment so that a person with disabilities can perform the job.

Making accommodations to people with physical disabilities, (e.g. access ramps, curb cut-outs, signs in Braille) is probably more intuitive to the public. Accommodations for persons with cognitive disabilities may require more forethought and creativity. People with mental retardation and their advocates can help by providing information and education on how to make reasonable accommodations (e.g. providing written materials in simplified language or alternative formats, using symbols as well as words on public signs) for people with cognitive impairments.

The Developmental Disabilities Assistance and Bill of Rights Act

This act was the first congressional effort to address the needs of persons specifically with developmental disabilities. The act and its subsequent amendments provide for several important services and systems which help to increase opportunities for full citizenship for people with developmental disabilities in our society. These systems and services include the following:

♦ *The establishment and funding of University Affiliated Programs (UAP).* UAP's are programs at institutions of higher education designed to learn about and share information about the best possible services that will support people with developmental disabilities to achieve independence, productivity, and integration into the community.

- *Basic State grants for planning and coordinating services for people with developmental disabilities.*
- *Establishment of protection and advocacy systems in individual States, to advocate for the rights of persons with developmental disabilities.*
- *Grant money for demonstration projects of national significance designed to improve services to people with developmental disabilities.*

Amendments to this act have recognized and emphasized the capacities of people with developmental disabilities rather than their limitations. It recognizes the primary role that family, friends, and neighbors can play in enhancing the lives of people with developmental disabilities. In addition it defines developmental disabilities in terms of functional skill level rather than by listing specific disabilities or IQ levels.

School-to-Work Opportunities Act

The School-to-Work Opportunities Act (STWO) is part of our nation's current attempt to redesign public education so that every student will receive a meaningful education which adequately prepares them for a role as a productive adult in our society (other related acts include Goals 2000: the Educate America Act and The National Skill Standards Act). STWO makes Federal funds available to individual States and regions for the purpose of developing effective school-to-work transitions for all students including those with disabilities. For some students this may mean preparation for further education to achieve their career goals, for others it may mean active job placement to develop necessary skills prior to leaving school. STWO seeks to decrease drop-outs and to encourage the broadening of career choices and development to students who have typically had these choices limited (women, minorities, and students with disabilities)

The School-to Work Opportunities Act can serve to solidify and strengthen many of the achievements already made in transition services to people with mental retardation. It can bring new energy and funds to these initiatives. The STWO Act also specifically encourages the development of opportunities for people to prepare for careers that are not traditional for their disability and could serve to expand choices in employment to people with mental retardation.

While this act specifically uses language that includes students with disabilities the focus is much broader and is meant for all students. As States look at how they will utilize the Federal funds that become available to them it will be important for the voices of people with mental retardation and their advocates to be heard in shaping these programs so that adequate resources and planning goes in to making these School-to-Work opportunities viable for people with mental retardation. The work already done in transitional services for people with mental retardation and other disabilities should provide useful information and models to broader based initiatives.

There are many more Federal and State laws that apply to people with mental retardation. Public law is an important tool in the fight for full inclusion and citizenship. However, because it is possible for people to follow the letter of the law without the intent of the law, cooperation with the law and enhanced understanding of why it's important rather than mere enforcement should be a primary goal. Continued education and training to members of our communities and businesses is critical in achieving this cooperation.

Guardianship

For people with mental retardation guardianship can be a double edged sword. On the one hand, for some there are real difficulties in sorting out the information necessary to make informed choices. On the other hand, in many cases, guardianship has been over-used for people with mental retardation and many State statutes regarding guardianship do not work effectively to protect the rights of people with mental retardation.

Since there are no Federal laws that oversee guardianship issues, each State has its own set of statutes that govern guardianship. While these specific statutes vary from State to State, few States have established useful guardianship statues which are sensitive to the circumstances of people with mental retardation. The following is the official position statement on guardianship of Arc National, a national advocacy group for people with mental retardation.

Issue. The need for legal intervention in the decision-making of persons with mental retardation is much less than perceived by public policy makers, providers of services and family members. Guardianship has often been over-used by those who simply wanted to have their wishes prevail over the wishes of the individual. Frequently, lesser forms of legal intervention such as limited guardianship and the use of powers of attorney have either been overlooked or intentionally avoided.

A snapshot of Protection and Advocacy activity over the years:

Ten years ago... a typical P&A case handled by the Texas office prevented, through mediation, four separate school districts from placing children with disabilities into segregated special education campuses.

Five years ago...the Vermont P &A obtained a consent judgment and damages against a landlord who summarily evicted a tenant because the person had a disability.

Four years ago...the New Jersey P&A negotiated with a major university on behalf of a 22-year old woman with a disability for accessible bathroom facilities. The university agreed to establish a committee for disability issues chaired by this woman.

Last year...the Maine P&A was instrumental in reversing a hospital psychiatric unit's unlawful seclusion policy regarding children.

Position. The majority of persons with mental retardation can manage their own affairs with informal assistance and guidance from family, friends, citizens, and service agency support staff. The appointment of a guardian is a serious matter involving the limitation of a person's independence and rights. When guardianship is appropriate, it should be sparingly used and adequately monitored by the legal system and advocates to insure that the best interests of the individual are protected.

- Appointment of a guardian should be made only to the extent necessary for the protection and welfare of the individual and not for the convenience of the family, the service system, or society.

- Less restrictive alternatives to full guardianship should always be considered first.

- Since guardianship represents a transfer of responsibility for exercising an individual's rights, adequate safeguards are needed to assure the individual retains as much decision making power as possible.

- The restrictions on the individual's rights and decision making powers should be confined to those areas in which the individual clearly cannot understand the serious consequences of his or her decisions or lack of foresight, such as through the use of limited guardianship, power of attorney, etc.

- The guardian—preferably a family member—should be someone who is committed to the well-being of the individual, knows and understands the individual's needs and wishes and acts in accordance with them whenever possible.

- The guardian should become knowledgeable of services, supports and systems that could impact significantly on the life of the individual.

- The guardian shall be accountable for his or her actions and those actions reviewed periodically.

Adopted by the Arc Delegate Body, October 1995. (For other Arc position statements published on the Web go to – http://TheArc.org/posit/posindx.html)

While the Arc National position Statement is a vision for the judicious use of guardianship for people with mental retardation and related disabilities, the reality in most States is not consistent with this position. Why is there such a discrepancy between the "ideal" way in which guardianship should be used and common practice? The following are some of the reasons:

History. Some people, especially older individuals, are under guardianship status as a vestige from a time when it was deemed appropriate or necessary for the majority of people with mental retardation, or in circumstances when the only "support" options available (institutions) required the person to be a ward of the State in order to receive services. There is usually not a meaningful review of this arrangement so people often remain under guardianship status long after it is no longer necessary.

Conflict of interest. In both public and private guardianship there are some inherent conflicts of interest. In public guardianship (when the guardian is some entity of the State) the guardian often also has other duties which conflict with the individual's best interest. For instance, the State may simultaneously function as the guardian and as the entity that funds, determines eligibility for, or provides support services. If there is a conflict between the ward and the State system it is difficult for the guardian to look first to the individual's interests. In private guardianship a parent or other relative may be convinced that their family member will need a guardian in order to successfully navigate the service system, however, family members quite often make different choices than the individual might make.

Lack of education/training. There is very little training for those who take on the role and responsibility of guardianship. The role is largely misunderstood and (often with the best intentions) people perceive the role of a guardian as limiting a person's rights rather than helping the person to effectively exercise their rights. In addition people with mental retardation have access to very little non-bias training and information to help them understand and advocate for their rights.

Assumption of permanency (unchanging) of disability. Usually when guardianship is sought for people with mental retardation and related disabilities it is made with the assumption that this will be a life-long situation (i.e. a person with mental retardation once in need of a guardian is always in need of a guardian). While it is certainly true that it is not likely someone will raise their IQ, it is not true that a person with mental retardation does not change or develop new skills and abilities over time.

Lack of options or confusing options. Some States do not have much choice in terms of limited guardianships or conservatorships. Many States do have separate statutes regarding the guardianship of adults with developmental disabilities, unfortunately many of these separate statutes are more likely than general guardianship statutes to be overly restrictive (e.g. assuming permanency of functioning level, having a less thorough rather than more thorough pre-trial assessment).

Poor or under-used pre-hearing assessments. Prior to determining if a person is in need of a guardian it is typical to have some form of assessment of the need. For people with permanent cognitive disabilities this is too often simply an establishment of the fact that the disability exists without thoroughly examining the person's functional skills or quality of supports.

Poor and under-used review systems. There is usually some mention in the statutes concerning the review of guardianship at specific times. Very often a guardian will have to fill out some justification for decisions made on the ward's behalf, particularly in the area of finances. However, due to large case loads and other conflicts of interest these reviews are often skipped or filed away without being read.

States need to review and assess their guardianship statutes to eliminate these conflict of interests and false assumptions about people with mental retardation and related conditions. Guardianship is a radical approach to trying to guarantee safety. Too often guardianship serves to limit not preserve rights for people with mental retardation; therefore, it should be considered a last resort. If guardianship is necessary, whenever possible the guardian should be someone without any conflict of interest toward the ward (for instance a paid guardian or conservator or a family member who is willing to stay educated and put the ward's interests and desires first whenever possible). Guardianship or conservatorship should be limited to only the precise areas where a person needs the substitute judgment.

The Role of Protection and Advocacy in Rights Issues

Protection and Advocacy services (P&As) and Client Assistant Programs (CAPS) are mandated by Congress to provide legal representation and advocacy services on behalf of all persons with disabilities. These services were provided through a variety of methods: individual representation, educating policy makers, advocacy on behalf of groups, information and referral services, and education efforts.

The central mission of the P&A system is to respond to allegations of abuse, neglect and violations of rights of persons with disabilities or discrimination based on their disability. P&As pursue legal, administrative, and other appropriate remedies upon their behalf.

There has been a tremendous expansion in both the quantity and quality of services provided under these programs over the past 20 years. Since the inception of P&A systems, Congress has expanded their mandate from serving only persons with developmental disabilities to becoming a comprehensive cross-disability program.

Protection and Advocacy cases regarding people with developmental disabilities have focused primarily on the following issues:

Education	36%	Habilitation	8%
Conditions in facilities	2%	Guardianships	3%
Abuse/neglect	18%	Financial entitlement	6%
Medical services	2%	Employment	2%
Housing	5%	Other	23%

All P&A and CAP advocacy is governed by the values of independence, equity, meaningful choice and empowerment, and the presumption that people with disabilities are entitled to equal opportunities and full integration and inclusion in society. Recently, P&As and CAPs have had success in promoting these values for persons with disabilities in such areas as self-determination, access to employment, education, health care, public accommodations, community integration, and ensuring safe and humane living conditions. P&As have made significant progress in assuring that persons with disabilities live and receive needed services in environments which are age appropriate, culturally competent, consumer driven and responsive.

P&A programs must give high priority in their services to eligible individuals who are in the greatest need of services. These may be individuals who were previously unserved or underserved by provider agencies or the P&A. P&As must also ensure they serve the most vulnerable populations or those with complex advocacy needs before serving less vulnerable populations.

Over the last two decades, as people with disabilities have moved from institutional settings to community environments, there has been a noticeable shift in the types of strategies used to protect and advocate for persons with disabilities. The need for appropriate and culturally competent services is also more complex, and involves not only habitation but also access to inclusive educational programs, adequate financial entitlement programs, health care, integrated housing and productive employment opportunities.

The information for this section was adapted from the Annual report of the P&A System 1996-1997 identified in the Resource section of this booklet.

The Criminal Justice System

The criminal justice system as it is today is inadequately prepared to protect and serve people with mental retardation and other related conditions. People with cognitive disabilities are at a great disadvantage when they come in contact with this system both as victims and as potential perpetrators of crime. Unfortunately there has been very little time, effort or money put into the study of how the criminal justice system works or doesn't work for people with mental retardation on a national level. The individual States and locality vary greatly in their ability to preserve the rights of people with mental retardation when they come in contact with the criminal justice system.

Consider the following issues in regard to people with mental retardation and similar conditions when in contact with the criminal justice system:

- Due to the fact that people with disabilities are often socially isolated, they are more likely to be the target of crimes including sexual assault and other violent crimes than the general population (estimates range from 2 to 10 times more likely) but these crimes are less likely to be reported than crimes perpetrated on others. These crimes are often perpetrated by someone who knows the person well such as a paid caregiver, a family member, or a neighbor.

- Many crimes against people with mental retardation are reported as abuse or neglect to special State offices and are dealt with outside of the criminal justice system.

- People with mental retardation who receive support services are actively encouraged in behaviors that make them more vulnerable to crimes. For instance they are expected to accept even the most intimate of physical care from new staff (strangers) without complaint. Often they are expected to turn over their money and personal items at the request of staff for their own "protection."

- Many people with disabilities who receive services are encouraged in behaviors that can lead to legal difficulties. For instance most people who reside in residential programs which are staffed 24 hours a day are denied any training or experience in appropriate forms of sexual expression. This practice can lead to unwanted behaviors such as masturbation in public areas or selection of inappropriate partners.

- People with disabilities displaying characteristics of their disability (such as autism, epilepsy, cerebral palsy, etc.) have been inappropriately arrested for drunken driving, drug abuse, voyeurism, assault and other crimes.

- There is evidence to suggest that when crimes are reported, the rate of police follow up, prosecution, and conviction of crimes against people with disabilities is lower than that of crimes against people without disabilities. Some of the reasons that this may be so include the lack of acceptance of people with mental retardation as credible witnesses, and lack of education on the part of criminal justice officials to work with the victim who has mental retardation.

- Police officers, members of the court system and prison officials lack even a basic understanding of how to identify people with mental retardation and related conditions and how to protect their rights. Often people with cognitive disabilities are confused with people who have mental illness or are seen as difficult, uncooperative, or intoxicated.

- People with mental retardation may act in ways that incriminate themselves even if they are not guilty of a crime such as "confessing" to crimes, saying they understand their rights even when they don't, not understanding how to request a lawyer, or trying to run away from the police when confronted.

- Like others, people with mental retardation can be "recruited" into crimes by others without their knowledge because they may not fully understand what is happening, because they are eager for friendship, or because they wish to be helpful.

- Many people with mental retardation may wish to hide their disability making it hard for people to identify and meet their specialized needs.

- People with disabilities who are imprisoned are at higher risk of being victimized by other prisoners while incarcerated.

- Many States have some aspect of sentencing that is unfairly biased toward people with mental retardation and denies them their rights. For instance in some States both people with mental illness and mental retardation are treated similarly by the law and may be sentenced to a facility until they have "recovered." Since people with mental retardation can not "recover" from their disability this effectively sentences them to incarceration for life.

- Many people maintain the untrue stereotypes perpetuated earlier this century that claimed that people with mental retardation were more likely to participate in criminal behavior than other people.

Contact with the criminal justice system is a confusing and sometimes frightening experience regardless of abilities. For people with cognitive impairment clearly there are a number of factors that put them at a higher risk of having unfortunate outcomes when dealing with the criminal justice system. As more people with mental retardation begin to participate fully in their communities the number of contacts with the criminal justice system will most likely increase and without careful planning and attention people with cognitive disabilities are likely to suffer unfortunate consequences. As with other aspects of life many people with mental retardation will need specialized supports to navigate the legal system and to be provided with consequences, treatments, and rehabilitation options that make sense, are fair, and protect their rights.

Of great concern is the use of the death penalty for people with mental retardation. Given the number of factors that put people with mental retardation at serious risk of being falsely accused and found guilty of crimes, the risk of putting the wrong person to death is very real. Since the reinstatement of the death penalty in 1976, 31 people with identified cognitive disabilities have been put to death. These executions have taken place in 12 different States. Eleven other States and the Federal government have banned the death penalty for people with mental retardation, but because there is little planning for how to identify who has mental retardation, the risk still remains.

In Minnesota the development of the Minnesota Extended Treatment Options (METO) program is almost completed. This program is designed to intervene with people who have developmental disabilities and who are participating in extreme behaviors that put them at risk for incarceration (e.g. sexual misconduct, arson, assault), or to work with the courts to provide a fitting rehabilitative experience when a person with developmental disabilities has been adjudicated. The goal of the program is to work with the individual to learn alternatives and control over the unwanted behavior or activities and to help them return to the community as soon as possible. The ability to move supports into the community with the person provides the opportunity for the person to learn new behaviors in real environments with the safety net of extra supports.

In Oklahoma, offenders with low IQs and limitations in one or more of seven defined life activities such as self care, learning, mobility, and economic self-sufficiency are admitted into a specialized program which is meant to ensure the best adjustment possible for the offender during the time spent in prison and to help prepare the person for returning to the community successfully at the end of the sentence. The offender is evaluated in a number of areas such as the ability to read, write and perform mathematical operations, vocational interest and skills, skills in self-care, and other life skills. Offenders are provided with a number of instructional opportunities to help them prepare for life outside of prison including the following: life skills instruction, vocational skill development (such as plumbing, carpentry, small engine repairs, etc.) communication (assertiveness, empathy, basic conversation, etc.) related job skills (filling out applications, resume writing, etc.) and other opportunities to help offenders be successful upon release. Since initiation of the program three offenders have successfully graduated and have not returned to the court system.

Some States such as Nebraska and Nevada use individualized plans (called Individual Justice Plans in Nebraska and Cooperative Services Plan in Nevada). These plans focus on providing treatment as an alternative to incarceration with persons who may have difficulty in understanding the consequences of their behaviors but who participate in activities or behaviors that are not acceptable. The plan requires coordination of a number of parties and details the outcome of contact with the criminal justice system as would be appropriate for the particular individual, along with plans for treatment and follow-up.

Because there is no national agenda to deal with these issues each State has been left to make its own decisions about how best to work with people who have disabilities in the criminal justice system. A recent informal survey of States asked how they were currently dealing with the issue of people with developmental disabilities who were involved in serious criminal behavior. The majority said that they simply shipped the people out of State presumably to another State that had a plan in place for such people. For less serious crimes many people with developmental disabilities are placed in restrictive facilities in the community and provided with 24-hour supervision. Because these facilities are not jails these people may miss out on the due process allowed people without disabilities which could allow them to eventually return to less restrictive settings.

What States and Localities Can Do

The Rand Corporation is currently undertaking a national survey to collate what has been done in the area of criminal justice for people with mental retardation and to make recommendations for future directions. However this information will not be available for several years. In the meantime individual States can increase the potential of positive outcomes for people with mental retardation when they come in contact with the criminal justice system by doing some of the following:

- Educating police officers and other criminal justice personnel on how to identify and work with the victim or suspected offender with developmental disabilities. Early identification is critical to preserve a person's rights when they come in contact with the criminal justice system.

- Discourage practice in service delivery systems that "creates" victims and perpetrators. Allow people receiving services choice and freedom of expression. Encourage expression of dissatisfaction with services when appropriate. Provide people with mental retardation information on what constitutes criminal activity, how to identify people who are perpetrators, how to report crimes and how to protect their rights if suspected of a crime.

- Work toward the prohibition of the death penalty as punishment for a crime for person's with mental retardation.

- Work with the criminal justice system to create consequences, treatments, and rehabilitation options that make sense, are fair, and protect people's rights.

Public laws, the courts and the criminal justice system were meant to protect and create opportunity for all citizens of the United States. For people with mental retardation and related disabilities the system isn't always working. While there is a greater awareness of the capabilities and adaptations necessary for people with mental retardation and related conditions there is a long way to go. People with cognitive disabilities are at greater risk of being victims of crime, of being unjustly accused and found guilty of crimes and of having opportunities denied to them because of their disabilities. The serious implications to quality of life for many people with mental retardation requires that continued education, training, dissemination of information, and planning in this area needs to begin now so that all people can enjoy life with the same freedom, liberty, and access to justice.

Self-Advocacy & Self-Determination

What is self-advocacy ? It is different from "advocacy" for people with mental retardation and developmental disabilities which is some other individual advocating on behalf of the person with a disability. Self-advocacy is about people with mental retardation and other developmental disabilities advocating for themselves. It means different things to different people involved in the movement but to most people with developmental disabilities involved in the movement, self-advocacy is about civil rights, supporting people in speaking up for themselves, and effecting changes in policy, attitudes, and opportunities for people with disabilities. Over the past 20 years, self-advocacy groups have been springing up all over the country and a national network of these groups has been established through Self-Advocates Becoming Empowered (SABE). The numbers of self-advocacy groups has continued to grow from the initial group in 1973 to over 700 groups listed in the United States and Canada in 1995 (University of Minnesota, 1995).

SABE was conceptualized in 1990 at a national self-advocacy conference held in Colorado and in 1992 was officially named. The SABE mission is to ensure that people with disabilities are treated as equals; are given the same decisions, choices, rights, responsibilities and chances to speak up to empower themselves; are able to make new friendships and renew old friendships; and are able to learn from their mistakes like everyone else.

SABE has several primary goals, including:

- Making self-advocacy opportunities available in every State.
- Providing opportunities to those living in institutions, those still in high schools, those living in rural areas, and those living with families.
- Providing local supports and advisors to help self-advocacy groups.
- Working with the criminal justice system and people with disabilities about their rights within the criminal justice system.
- Closing institutions for people with developmental disabilities labels nationwide and building community supports.

SABE has been involved in a number of special projects, received a number of awards and grants, presented at numerous State and National conferences about self-advocacy and produced a number of publications and products. Currently SABE is actively working on the National Advisory Group for Justice project which is designed to facilitate self-advocates having an influence on how police operate and how people with disabilities are treated in the criminal justice system. Another current project of SABE is their Close the Doors: Campaign for Freedom. This project is designed to develop and implement a national plan to close institutions for people with developmental disabilities and to develop appropriate supports for these individuals to live in the community.

What If..You never got to make a mistake?
What If...Your money was always kept in an envelope where you couldn't get it?
What If...You were never given a chance to do well at something?
What If...You were always treated like a child?
What If...Your only chance to be with people different from you was with your own family?
What If...The job you did was not useful?
What If...You never got to make a decision?
What If...The only risky thing you could do was to act out?
What If...You couldn't go outside because the last time you went it rained?
What If...You took the wrong bus once and now you can't take another one?
What If...You spent three hours every day just waiting?
What If...You grew old and never knew adulthood?
What If...You never got a chance?
(anonymous)

Self-advocacy is a relatively new movement. To some it may be viewed as just a new trend and not acknowledged fully as the civil rights movement that it is. The movement has been around for over 20 years but has almost doubled in the 1990's. This "youth" brings with it a number of issues that self-advocates, parents and "professionals" must struggle with, learn about, and attempt to resolve. The following are some of these issues:

- Self-advocacy is a grassroots movement and should be run by and for people with developmental disabilities. Recently it has become "politically correct" and in some cases required by law or policy for trade associations, provider organizations, government agencies to include self-advocates in planning meetings, on Boards of Directors, advisory groups, etc. Although it is critical for self-advocates to always be invited and to have a voice, it is more important that they feel free to choose their own issues, plan their own agendas, and participate only on advisory groups, Boards of Directors, or in planning meetings for which they feel the issues are important. Additionally, it is not enough to just invite one self-advocate to participate in activities and groups. Self-advocates often need support to participate fully or else it becomes a token gesture. Examples of support include transportation to meetings, providing materials in advance, having meeting agendas and minutes read to the individual or altered to include pictures or large print, taking the time to explain issues fully, having several self-advocates involved, or being paid for participation if it takes them away from their paid job or requires travel.

- The role of an advisor to self-advocacy groups is confusing and needs greater clarity and understanding. For many advisors it is difficult to separate out what are self-advocate issues vs. what are advisor issues. One advisor said, "I often find myself saying 'we' vs. 'they,' that's when I know I need to step back and remind myself that this isn't about me, it's about what self-advocates want, say and do." Advisors are involved in self-advocacy groups to assist and support, not to guide and direct. For many advisors it is difficult to sit back and watch self-advocates fail or make mistakes, however, advisors themselves say this is an essential role of an advisor. Advisors need greater opportunities to network, learn from one another and to develop checks and balances that uphold the integrity of being there only to support and advise.

- Funding is an issue for many self-advocacy groups. These groups are funded in many different ways, including: Arc chapters, States, private foundations, Governor's Councils on Developmental Disabilities, and local chapter fund raising. Although self-advocates and advisors don't always agree on where money should come from, there are two things that most self-advocates and most advisors do support: 1) self-advocacy groups need long-term funding, 2) irrespective of the source, funding provided to these groups should come with "no strings attached" so that there is no conflict of interest.

- People working with children and adults with developmental disabilities (e.g. teachers, direct support workers, parents, professionals) need to gain better understanding regarding self-advocacy, self-determination and their importance. However, self-advocates and their advisors strongly suggest that the best way for these individuals to learn about self-advocacy is to learn about it from those who have developed it and are experiencing it: self-advocates. If an organization or group is interested in getting self-advocacy groups started, or involving self-advocates in policy or decision-making, then they should call a local self-advocacy group or SABE for assistance.

There are a number of barriers which have slowed or made the development of self-advocacy groups and implementation of their efforts more difficult. Some of these barriers as identified by self-advocates and advisors include:

- Not having enough money.
- Difficulty in building training and groups across a State due to distance and costs.
- Parents not allowing their children to become involved in self-advocacy.
- Group home staff not providing transportation for self-advocates to attend meetings.
- Day program staff not allowing self-advocacy groups to meet.
- Everyone focusing on the word "retarded" and not giving us a voice or credibility because we are labeled with that word.
- Not having a place to meet.
- People in wheelchairs not being able to get into cars to go to meetings.
- People with disabilities always having to conform vs. others and the system conforming for us.

The self-advocacy movement, like any other civil rights movement, is lead by a few vocal and determined people. At the core of the self-advocacy movement is the concept of self-determination. Self-determination is about people controlling their own lives. It is not the same thing as self-advocacy. It refers to basic things in one's life such as other's respecting your feelings, choices, preferences and behaviors. It is something all people have a right to regardless of age or ability. Self-determination is closely linked with how people view themselves, how others view the person and a person's general quality of life. All people with mental retardation and other related conditions should be afforded the opportunity to live a self-determined life, yet not all people will become involved in the self-advocacy movement.

One mother provided insight as to how self-determination is best facilitated, "Self-determination is not synonymous with independence. Rather it is best facilitated by interdependence: connections and support from those around us. Our brain, our spirit, our emotions, our psyche and our sexuality all function better in social interaction than in isolation." (IMPACT, 1994, pg. 1) Self-determination is experienced through opportunities to make choices and to have these choices honored. A few simple examples include:

- People who live in regulated facilities choosing what they want to eat and where they want to eat it.
- People choosing who they want as staff.
- People choosing what they want and do not want to learn.

- People talking on the phone when they want.
- People choosing where they work or not to work at all.

Even at it's most minimal level self-determination is something which most people with mental retardation have not experienced in any meaningful way. The emphasis of supports has always been on (over) protection and habilitation which leaves little room for individual decision making.

In order for people to truly experience self-determined lives, it will be critical for service providers, government entities which fund services and regulators and families to work with self-advocates and to take a serious look at the "system" we have built in this country to serve people with developmental disabilities. This means to look at the way service providers deliver services, the way direct support staff interact with people who receive services, the rules and regulations that exist to monitor services, the way people access services, the way we define quality of life and quality services, how services are funded and who controls the money and has the power. We must examine and remove barriers to self-determination so that people with developmental disabilities can live real lives as full citizens determining their own destinies.

Conclusion

The types of supports which will be available to those that need them in the upcoming years is not clear. The service system is under stress to change from a variety of sources. Not only is there increasing dissatisfaction in the way services are delivered and assessed for quality on the part of consumers, families, provider agencies and others, but there are real financial pressures in terms of governmental reform (block grants, Medicaid, welfare) as well.

On the other hand, the systems in place are deeply entrenched. Services to people with mental retardation and other developmental disabilities are some of the most highly regulated and expensive government-funded services. The difficulty in streamlining services comes from a variety of sources. Parents, consumers, and advocates may fear that changes will reduce protections for people with mental retardation. Service providers and governing agencies are unsure about how they will fare in the new system and can be overwhelmed at the task of retraining or eliminating personnel.

Federal legislation (e.g., Individuals with Disabilities Education Act reauthorization of 1997) has usually been favorable in continuing to strengthen and re-enforce the concepts of full citizenship for people with mental retardation and other disabilities. On the other hand the amount of money set aside for the States to accomplish these changes has at best remained stable while the needs and demands for services have simultaneously increased.

This time of increased expectations and reduced resources will call for creative thinking. Already States, school systems, provider agencies, and localities have begun to find ways to make changes happen given the resources they have, but these changes are not currently widespread. To make the necessary changes is a reality service providers will have to redefine themselves.

Our current system of services and supports has been built on the premise that it requires a "specialist" to work with people who have mental retardation. We have "special" educators, "special" recreational programs, and "special" rules and regulations which apply only to people with mental retardation and related conditions. The original intention of this investment in building a capacity to support people with mental retardation was to provide them with opportunities that were not easily available at the time (i.e., an education, jobs, homes in the community). However the result of this "specialization" is a system that is expensive to operate, and increases the isolation that many people with mental retardation experience in their communities.

What the future holds depends on how well the "specialists" are able to share what they know in order to build the community capacity to include people with mental retardation and related conditions in all aspects of daily life. There will have to be a more proactive pooling of resources with generic services and programs already in the community to make needed supports available to people with disabilities. For instance, special education teachers will more and more find themselves as floating resource personnel, rather than in charge of self-contained classrooms. They will need to come to the table when school systems are meeting and planning in order to make sure that the whole system is prepared to teach and support all students. They will need to be able to collaborate well with a variety of "regular" education teachers who will provide the primary teaching experience to all children regardless of ability.

Support agencies and direct support staff will have to be more knowledgeable about generic services available and have a role in strengthening and developing natural supports. For instance, day and habilitation agencies, which currently put a lot of effort into training and supporting employees with disabilities, will have to reorganize around job development and training of coworkers and supervisors on how best to work with the employee with mental retardation. Agencies that provide residential supports which currently provide a limited menu of services built around funding sources will have to reorganize around offering a wide variety of services and supports from which people with mental retardation can pick and choose. In addition, to be affordable these services will have to foster the natural supports from families, neighbors, coworkers and friends.

Planning councils, advocacy groups, and State and county agencies will have to become part of the generic community planning and development processes. They will have to be there at the beginning to ask how these plans will affect citizens with mental retardation and to provide insight on how planning can include all citizens.

Never has there been a time with more challenges and more opportunities toward the creation of whole communities that welcome all people regardless of ability. Fortunately there is already a generation of people with mental retardation who have had more opportunities through education and available family supports than ever before. As these young people come into adulthood and each generation after, they will be expecting more from life than ever. They expect more than what is available today. They expect the support to have the full range of experiences and opportunities that are available to people without disabilities. And we all have a role to play in seeing that they get what they want.

Resources

Annual Report of the P & A System 1996-1997. A federally mandated network of disability rights agencies: Protection and Advocacy Systems and Client Assistance Programs. To obtain a copy, contact Advocacy Training/Technical Assistance Center for P & A's and CAPS of the National Association of Protection - Advocacy Systems, Inc., 900 Second St. NE, Suite 211, Washington, D.C. 20002, (202) 408-9514, (202) 408-9520 FAX, (202) 408-9521 TDD.

IMPACT: Feature Issue on the ADA. (1992-1993). By K.C. Lakin, R.A. Jones & D. Leuchovius (Eds.). This publication looks at what the ADA means for people with developmental disabilities. Available at the Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455, (612) 624-4512.

Unequal Justice: The Case for Johnny Lee Wilson. (1995). This video documentary tells the Story of Johnny Lee Wilson a man from Missouri with mental retardation who was wrongfully imprisoned for the murder of an elderly woman in his hometown. Available at the Institute on Disabilities, Temple University, College of Education 004-00, Room 423 Ritter Hall Annex Philadelphia, PA 19122, (215) 204-1356, c/o Lisa Sonneborn. Cost: $35.00.

The Access to Justice National Resource List. This list of resources relating to criminal justice issues as they apply to the person with mental retardation and related disabilities is maintained by ARC National. Contact ARC National at: P.O. Box 1047, Arlington TX 76004, (817) 261-6003 or (817) 277-0553 TDD, or visit their website to review the list at http://www.TheArc.org/welcome.html.

No More B.S.: A Realistic Survival Guide for Disability Rights Activists (1992). A book addressing self-advocacy as part of the broader disability rights movement. Available from People First of Washington, P.O. Box 648, Clarkston, WA 99403, (509) 758-1123.

Circles: Intimacy and Relationships. This training material explores the complex issues of individuals with disabilities and their rights regarding sexuality. To obtain a copy, contact James Stanfield Co., Inc., Drawer 24, P.O. Box 41058, Santa Barbara, CA 93140.

Tools for Change. A video-based curriculum that builds skills and knowledge in self-advocacy. To obtain more information about these training materials contact: Advocating for Change Together, 1821 University Avenue, St. Paul, MN 55104. 612/641-0297

Self Advocates Becoming Empowered. SABE is a national grassroots organization of self-advocates groups. To obtain more information contact SABE P.O. Box 15165 Loves Park, Illinois 61132.

Self-advocacy Print and Media Resources. A guidebook listing nearly 150 publications and media materials about self-advocacy. Available from the Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455. 612/624-4512.

Voices That Count: Making It Happen. A presenter's guide written to help self-advocates learn the necessary skills to speak to groups about leadership roles and opportunities. Available from Cincinnati Center for Developmental Disorders, 3300 Elland Ave., Cincinnati, OH 45229. 513/559-4639, 513/559-4626 TDD.

IMPACT: Feature Issues on Leadership by Persons with Disabilities, Self-Determination and Self-Advocacy. These newsletters provide research to practice articles as well as best-practice examples on these topics. All three issues are available from the Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN 55455. 612/624-4512.

Open the Doors. A community living leadership training package that shares the accomplishments and activities related to self-advocates building supports for each other to open doors within their communities across the nation in the areas of community living, housing, work and relationships. Available from Self-Advocates becoming Empowered, c/o People First of Tennessee, P.O. Box 121211, Nashville, TN. 615/256-8002.

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Glossary

Advocate: A person who speaks up and is active in working toward equal rights, opportunities, and respect for individuals with developmental disabilities.

Arc National: A national advocacy group for people with mental retardation. There are also many State and local Arc chapters throughout the United States.

Autism: A severe disorder in which the person affected may have difficulty in both verbal and non-verbal communication, and may relate to others or events in unexpected ways such as appearing disinterested, aloof, or unable to concentrate. Autism occurs in five out of every 10,000 births and is four times more likely to occur in boys than in girls. People with autism may exhibit repetitive behaviors such as rocking, banging their heads against objects, touching, or hand flapping.

Cerebral Palsy: A central motor deficit that results from injury to the brain which can occur prenatally, perinatally or postnatally.

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).

Conservator: A person in a legally defined role of protector. Similar to a guardian, a conservator oversees the decisions of another person who is unable to adequately care for themselves. Conservators usually have narrowly defined areas which they oversee such as finances, or major medical decisions.

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.

Down's Syndrome: A genetic disorder which results in several characteristics including: a shortened stature, mental retardation, small nose, upward slanting eyes, short stubby fingers, poor muscle tone and frequently heart problems.

Epilepsy: A disorder which affects about 1% of the population and which seizures are a primary symptom.

Family support: Describes service programs for families who provide support at home for children, and sometimes adults, with developmental disabilities. Within a family "centered" or "driven" context, the programs make use of structured services, natural supports, and often cash assistance to: (a) make it possible for families to keep their family member at home, (b) assure that the person with disabilities receives needed services at home, (c) enhance the capacity of families to provide supports at home, and (d) realize some cost savings related to promoting care at home over out-of-home options.

Functional skills: The skills a person needs to do the ordinary tasks of day to day life. Functional skills may be an ability to read, open a door without assistance, or cook a meal.

Generic: Not specific to people with disabilities. 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 people to 15 people and can be publicly or privately owned and operated.

Guardian: A legal relationship with another where the guardian is responsible for overseeing the decisions the other person makes. Guardianship usually covers a broad range of standard areas such as financial and medical matters.

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 had 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.

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

I.Q.: Intelligence quotient. The numerical measure of a person's intelligence, often used in definitions of mental retardation.

Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR): The first Federal program targeted to monitor residential services to 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.

Least Restrictive Environment: A clause in Individual's with Disabilities Education Act which mandates that children receive education in the least restrictive settings possible.

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, the family member who introduces you to a potential new employer.

Person-centered planning: A planning process which looks at the person's strengths, needs and personal goals as a basis for service delivery. There are formalized forms of person centered planning such as Essential Lifestyle Planning, MAPS, or Personal Futures planning, as well as informal ways of gathering information and listening to a person to see what they consider important in relationship to services and supports.

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 programs developed for people receiving services.

Quality assurance: This term is generally used to refer to the complex web of regulations and standards, that have been determined to define quality, as well as the licensing and certification processes that enforce them. The focus of these programs is changing to include quality of life outcomes and quality assurance programs are starting to include expectations for quality improvement. Within managed care environments this means an organized set of activities intended systematically to ensure minimal safety of service recipients and to foster performance improvements.

Self-advocate: A person with a developmental disability who is active in standing up and speaking out for the rights of all people with developmental disabilities.

Self-determination: To be a person who makes choices and decisions regarding one's own life without undue influence or interference from others.

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.

University Affiliated Program: Programs at institutions of higher education designed to learn about (research) and share information (dissemination & training) about the best possible services that will support people with developmental disabilities to achieve independence, productivity and community integration. These programs are authorized under the Developmental Disabilities Assistance Bill of Rights Act.

Ward: A person under guardianship.

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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