

With a little help from my friends...

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

## I Am Who I Am

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## Acknowledgments

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

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

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

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

Valerie J. Bradley  
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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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## 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

Every person is a unique individual. What people want and need out of life varies greatly depending on their background, their circumstances, their abilities, and their culture. For some people with mental retardation and related disabilities, providing inclusive, integrated supports seems like a natural, almost intuitive process. These are people who need just a little support in order to succeed or who are comfortable with the way services are delivered (e.g., the location of services, the language service providers use, etc.).

But what about people who need more than a little support to be fully accepted and respected in our communities? What about people with disabilities that don't come from the dominant culture? What about people who behave in ways that are threatening, frightening, or socially unacceptable? Although as a nation we are providing inclusive opportunities for many more people with mental retardation, these opportunities most often exist for people who have fewer support needs. The more severe, complicated, threatening, or obvious a person's disabilities are, the less likely they are to be given opportunities to participate fully at work, at school, at home, and in their communities.

This booklet looks at some of the issues which challenge the system and require creative thinking: people with mental retardation and related conditions who are parents; people who have severe aggressive or other challenging behaviors; or people who are aging. In addition, the booklet includes information on assistive technology, culturally competent supports, and person-centered planning approaches as important components of increasing opportunities for people with mental retardation and other developmental disabilities.

## Person-Centered Planning Approaches

If there is anything that we have learned about providing services and supports to people with developmental disabilities and their families, it is that all people with mental retardation and other related disabilities are unique. Each has his or her own history, own experiences, own strengths, own preferences, own abilities and own needs. No two people will need or desire the exact same things in the exact same way. Because of this, there is not one right way to provide supports to all people with disabilities. Unfortunately, government systems that fund and regulate services and provider agencies that deliver services, often prefer to monitor and deliver services in a standard way because it is easier.

This quest for the one right way of doing things has often led to systems and processes that prescribe all things to all people. For example, regulated facilities often maintain spotless environments, may have quarterly nursing reviews or require that certain types of professionals attend annual planning meetings. However, not all people with mental retardation need or want to live in spotlessly clean environments and not all people need or want a nurse to check them on a quarterly basis. Most people would like to choose who comes to meetings which are about their lives. As more has been learned about what people want and need and how best to provide supports, new person-centered processes have been used successfully to develop individualized strategies and supports. These planning processes are particularly useful in figuring out how to best plan supports for people with specialized support needs (e.g., challenging behavior, limited expressive communication skills).

Person-centered planning (PCP) is different from the traditional interdisciplinary (IDT) planning processes. It focuses on people's gifts, strengths, preferences and what they are doing right instead of their deficits, needs, and what they are doing wrong or cannot do. In PCP approaches, an emphasis is placed on the individual, his or her family, and the specific supports these individuals need to enable them to become full citizens in their communities of choice. The tone of PCP meetings tends to be more

fun and creative. These meetings involve people who know and care about the person for whom the plan is being created, unlike IDT meetings, where typically a group of professionals sits around a table and shares deficit based information about the person receiving services. Instead PCP meetings are at times when people get together and find out from the person and his or her family members what they want, how others can respect their preferences, and assist the person in realizing his or her dreams and goals.

Person-centered planning is not simply a new group of words that substitutes for the regulatory-driven planning and review processes which are the focus of many existing program models. Person-centered planning is far more comprehensive and action-oriented and requires a considerable commitment of time and energy from the participants. Initial person-centered planning meetings take longer than traditional IDT planning meetings and involve not only the collection of a large amount of relevant information from people who know and care about the individual (e.g. a personal history, likes, dislikes, dreams) but also the development of an action-oriented plan. In most cases PCP meetings occur more than one time a year and can result in the dissemination of varied forms of "progress reports" from verbal phone conversations to pictorial essays or structured written documents.

There are a number of person-centered planning approaches that have been developed and used by many people across the United States and in other countries around the world. Some of these approaches include: Personal Future Planning; Essential Lifestyles Planning; MAPS; Planning Alternatives; Tomorrow with Hope (PATH); and Whole Life Planning. Although these planning processes have similar components, each is distinct.

In making a decision to move from interdisciplinary planning processes to person-centered planning processes it is important for agencies, states and other entities to consider the following:

1. People who are selected to facilitate these meetings will need a considerable amount of new and different training because these meetings are organized and run in a format that is very different from traditional interdisciplinary planning meetings.
2. People who are chosen by the individual and their family members to attend person-centered meetings may vary from one person to the next. Therefore it could result in case managers, day program staff, residential staff, and medical professionals not being invited to attend every meeting. Developing systems that prescribe who will or will not attend is inconsistent with person-centered planning processes which hold at their core a value that the individual should choose who attends and that the individuals who do attend should know and care about the person.
3. The person and/or their family members are the focal point of these meetings and therefore the meetings are scheduled at times convenient to the person and their family members which is typically not between the hours of 8:00 a.m. and 4:00 p.m.
4. The results of person-centered planning processes usually do not include the development of goals broken down into specific behavioral objectives. Therefore, in considering system-wide use of

**The five accomplishments which guide the development of a personal vision for the individual through Personal Futures Planning include:**

- **Community presence:** How can we increase the presence of a person in local community life?
- **Community participation:** How can we expand and deepen people's friendships?
- **Dignity:** How can we enhance the reputation people have and increase the number of valued ways people can contribute?
- **Promoting choice:** How can we help people have more control and choice in life?
- **Supporting contribution:** How can we assist people to develop more competencies?

*John O'Brien and Connie Lyle, 1992*



person-centered planning processes it is important to ensure that the outcomes of these meetings are sufficient in meeting regulatory requirements regarding the development and monitoring of program plans. Requiring both interdisciplinary planning meetings and person-centered planning meetings will likely result in confusing and sometimes contradictory plans.

Person-centered planning has dramatically changed the lives of many people with mental retardation and developmental disabilities. These planning processes focus on the things that matter to the person and those who care about the person. The more these processes can be used in developing supports and services for people the better their quality of life will be.

## Parents with Mental Retardation

*"Mary is a loving and caring mother. I first met her when I asked her to come in concerning her son. He was missing a lot of school and not performing very well academically. She came right in and I never had a problem trying to get her involved with her son, but she didn't always know how to follow through. Through our conversations I found that she was being threatened with eviction from her apartment because the landlord felt it was too dirty and was a health hazard.*

*I began looking around for someone to help her, be an advocate, but everywhere I turned I met barriers. Places that provided supports to people with mental retardation didn't serve them if they had children. Social service agencies that served parents only worked with people with mental illness. I would try to help her look for a new place to live and find that the places she thought she had lined up often didn't even know who she was.*

*The frustrating thing was that she didn't need anything incredibly expensive or complicated. Four hours a week of a life skills aide, someone to help her clean her apartment and follow through with things. Eventually I was able to get some legal help for her through Legal Aide and she didn't have to be evicted if she would pay her rent. She decided to find somewhere else to live.*

*She's happy now but I still worry about what happens in the future. Her son still isn't doing well, but not poorly enough to make the cut to receive special services. I remember too that during that time one person I talked to really wanted protective services to be involved. When I asked why he said 'because then we could have her son taken away from her.' He didn't understand how wrong that would be. She loved her son but she needed some help. I wonder how much it cost to provide someone with 4 hours of support a week compared to the salary of hiring another person who has the authority to take kids away from their parents?"*

—School Social Worker, Michigan

Just like all parents, parents with mental retardation face a number of challenges in raising their children. Their ability to meet these challenges varies depending on their individual circumstances and skills. However, parents with mental retardation are at a much higher risk of losing their children if the social service system becomes involved. In fact, until recently, children of parents with mental retardation were typically removed from their homes whenever it was discovered that the parents had mental retardation. Currently parents with mental retardation have a better chance to maintain custody of their children thanks to successful advocacy which pointed out the injustice in using mental retardation as a basis for removal. However, welfare reform and other changes pending in Congress will likely increase the risk of parents with mental retardation being denied the opportunity to maintain custody of their children.

While there are parents with mental retardation who are able to raise their children without problems, it is not uncommon for parents with mental retardation to have some difficulty with many areas of daily living that affect their children and which put them at risk of having their children placed outside of the

home. Some areas which may be difficult for parents with mental retardation include keeping the house clean, serving regular and nutritious meals, and giving children their necessary medications on time. Parents with cognitive limits may not understand typical child development. They may not understand the importance of talking to babies as well as feeding them. They may interpret normal behaviors of young children as "bad" behaviors and have difficulty disciplining in a gentle but firm manner.

Add to these limitations the fact that many parents with mental retardation rely on public assistance or minimum wage jobs. Therefore, the stress of poverty also takes a toll on these families. The parent's energy often goes to trying to make ends meet with little time left over for children. In fact households headed by a parent with mental retardation who are receiving AFDC as a primary means of support are some of the most vulnerable to welfare reform. Already on the edge of making it, a loss of benefits can mean complete devastation for these families.

Some of the risk factors that increase the likelihood that children with parents who have mental retardation will be placed outside of the home include: poverty, inadequate housing, a greater number of children, a child with disabilities, lack of proper child care, lack of child discipline, lack of support networks, having two parents with cognitive delays or having parents with both cognitive delays and some other disabling condition. Serving these families can be very difficult because of the number of issues involved. It is rarely simply that one parent has a cognitive disability that puts the family at risk.

For parents with mental retardation, training and support does have an effect on their ability to provide a safe nurturing environment to their children. Families where one parent or another active adult in the household has a high level of functioning and adequate child-rearing skills are less likely to have a child placed outside the home. In addition families where mothers are actively participating in treatment programs are less likely to have children placed out of the home. Children of parents who are given effective instruction show improvement in physical and cognitive development and respond more frequently to people and things in their environment. If the right supports are given it is possible to keep children safely with their parents. Some of the most effective methods for supporting families include the following:

- Start with an individual, person-centered assessment of the parent's skills and the needs of the family through interviewing and direct observation of activities.
- Give the family a real voice in planning for solutions that makes sense to them. This increases their investment in succeeding.
- Train people through active means by modeling appropriate behaviors or skills and providing feedback and praise as they practice the skill. For instance a mother should not only have skills demonstrated to her but should have many opportunities to demonstrate her ability to perform these skills.
- Provide training in the person's own home if possible. If this is not possible, provide training in a home-like environment.
- Supply training and support over a prolonged period of time, maybe even until the children leave home.

Families headed by parents with mental retardation face many challenges which ultimately can affect the quality of life for their children. More study of the numbers of families is needed as well as the types of supports they need. Information to date suggests that these families have a number of complex interrelated needs that would best be met by a flexible system with a single point of contact. While independence and self-sufficiency are important, for some parents there may be an on-going need for support throughout their years as a parent in order to help their children have the best possible opportunities for success.

## Homebuilders: The Extended Family Support Project in Washington State

Homebuilders has been providing assistance to families at risk of having a child placed out of the home for over 6 years, including families with parents who are mentally retarded or have other developmental delays. Homebuilders use a model called Intensive Family Preservation Service (IFPS) which has been shown to be effective in reducing or preventing out-of-home placement of children who were at high risk due to abuse, neglect, developmental disability, mental health problems, juvenile delinquency, and special needs involving adoption. However the data collected by Homebuilders has shown that client families, in which one or more of the parents has developmental delays or cognitive limitations, are less likely to receive long-term benefits from services than the general child welfare participants. Their data showed that initial rates for keeping families together were the same for both families with and without parents with developmental delays, but after one year, families in which at least one parent had cognitive disabilities, successes had significantly dropped.

**While the number of parents with mental retardation today is unknown, it is reasonable to expect that whatever the number is it will be increasing. Reasons for this include:**

- **Increased recognition of the rights of people with mental retardation to have and raise their own children if they are able.**
- **Decrease in practices such as forced sterilization of people with mental retardation.**
- **Lack of consistent strategies to inform people with mental retardation about sexuality and prevention of undesired pregnancy.**

Homebuilders' IFPS model provides intensive services in the natural environments of the person including their home, work, school, and neighborhood. Counselors are on call 24 hours a day, 7 days a week, and routine services are scheduled at the convenience of participants, including evenings and weekends. Services are provided for a limited amount of time with specific and measurable goals, and are provided in the areas the parent needs most. These services can include training in homemaking skills, learning how to use community resources, managing emotions such as anger or anxiety, building a stronger social support network, or learning appropriate methods of child discipline.

Homebuilders has a core set of values which include the beliefs that: 1) their participants are full partners in the change process; 2) children are better off being raised in their natural families whenever possible; 3) all people can learn; 4) teaching people how to handle their own problems is better than solving problems for them; 5) part of the job is finding methods for motivating families to change; 6) crisis' are opportunities for change; 7) effort to solve problems must be persistent; and 8) the safety of all family members is of primary importance.

Homebuilders recently received a three-year grant from the Joseph P. Kennedy, Jr. Foundation to adapt their model for parents with developmental disabilities. They will work to see if extended supports over time increases the ability of at-risk families who have parents with mental retardation to avoid placement of a child out of the home. The Extended Family Support Project currently offers services to 20 at-risk families with parents who have mental retardation. Ten of the families will receive the normal intensive services (typically delivered over 1-3 months). The other ten will receive the same level of intensive services in the first 1-3 months and then another 9-11 months of on-demand assistance (all services delivered in 12 months total). Families are randomly selected for the services, and outcomes for both groups will be evaluated 18 months after referral. The hope is that the extended availability of these services will help parents gain more experience and skills that will have long-term benefits for the whole family.

Information from the Extended Family Support Project. For contact information see the Resource section.

## Aging and Developmental Disabilities

*"I was born in 1944. Back then, our society did not believe in educating their disabled children, so I never had a formal education. In fact, up to this date I have been unable to get into any programs that serve disabled people. I am not saying that my parents did not try to get me into these programs, but they were from a simple background. When they tried to get help for me every door was slammed shut in their faces. This was due to two reasons. The first one was that until 15 years ago there were no programs for the severely disabled people; the second reason was that they were told that I am too old for the programs and there is too long of a waiting list.*

*So, the first 39 years of my life I sat in the back bedroom of my parents' home.*

*Sometime before I reached 39, I thought about forcing my parents to institutionalize me. Back then my parents and I thought that a person with a severe disability had to live their lives with parents, relatives, or be institutionalized and warehoused for the rest of their lives. When I was 39 my parents were getting in poor health, so I decided to force them into institutionalizing me. Basically, I did this for two reasons; the first one was because of their health and the fact that I did not want to be a burden on them anymore. The second reason was that I was getting up in age and before I died I wanted to be around people my own age."*

*Excerpted from "Living on the Edge" by Arthur Campbell, Jr. from IMPACT: Feature Issue on Aging and Developmental Disabilities Volume 6(1) 1993.*

Older Americans with mental retardation and related conditions have lived through some tough times. Unlike the generation coming into adulthood today, they did not have the political power of federal legislation like the Individuals with Disabilities Education Act (IDEA) or the Americans with Disabilities Act (ADA). They were denied opportunities for education, employment, and community inclusion. For most people of this era there were two choices, remain at home with their parents for life, or move into a large institution, usually far from their communities of origin and the people they know and love.

**"For the first 39 years of my life I sat in the back bedroom of my parents' home."**

*Excerpt from "Living on the Edge"*

Today it is estimated that between 200,000 to 500,000 people in the United States over the age of 60 have some form of developmental disability. Some of these people live at home with elderly parents or other family caregivers. Others live in small community programs or foster care. Yet others still reside in large institutions and nursing homes. As the population continues to age and the baby boomers move into their 60's there will be even more adults of retirement age with mental retardation and other developmental disabilities.

Based on information gathered in the mid 1980s, it was estimated that over half of all people with mental retardation over the age of 62 who lived in residential placements lived in nursing homes. In 1987 the Omnibus Budget Reconciliation Act (OBRA-87) mandated that placements in nursing homes for people with mental retardation be reviewed to see if the placement was appropriate based on medical needs. It was found that the majority of people with mental retardation in nursing homes were not suitably placed because they did not have health factors that required a nursing home setting. OBRA-87 required that alternative placements be sought for people and that a plan for active treatment be put in place for those that remained in nursing homes (meaning that people had opportunities to learn new things and take care of their own needs to the furthest extent possible).

The intention of OBRA-87 was that the community residential providers would create options for people who were inappropriately placed in nursing homes. Unfortunately the current number of available community residential services does not meet the demand for such placements. Older adults inappropriately placed in nursing homes are in competition for residential supports with younger adults leaving home for the first time, people moving out of state institutions, and other older adults looking for places to live who are not eligible for nursing home placement due to OBRA-87. In fact, the number of people with MR/DD reported to be living in nursing facilities in 1996 (37,600) is not substantially different from the numbers reported in 1970 (38,000) prior to the OBRA-87 mandate. In addition, the percentage of people 63 years and older reported to be living in large state facilities has gone up from 3.7% in 1977 to 7.7% in 1996 (Prouty & Lakin, 1997). These gaps in availability of needed supports are likely to continue to grow as the population ages.

Another gap in residential services for older adults with mental retardation is that of in-home family supports. For people who have lived with their parents all their lives, the realities of aging caregivers can be difficult. For families where the parents want to remain as primary caregivers for as long as possible, there is a need for flexible respite so that parents can take needed breaks. Some families may need access to assistive technologies, home modifications, or personal aides to continue to support a family member at home. These families also need guidance and resources in planning for the care of their adult child after the parents pass away or can no longer provide primary care. If the eventual transition is to the home of another family caregiver such as a sibling, there may be a need for on-going supports so that the sibling can maintain their other life responsibilities such as employment, child-rearing, or caring for an elderly parent. If the transition is to some form of residential service, family members and the person with the disability need real options that reflect their needs and lifestyles, and counseling or help in making the best choice possible.

**Elderly people with mental retardation need flexibility from the service delivery system. They need:**

- **Support in a person's own home or apartment.**
- **Job placement for those who desire it.**
- **Support people who are aware of the signs and symptoms of common conditions and illness associated with aging.**
- **Supports to stay connected to extended family.**

Many people think that people with mental retardation experience more significant health problems as they age than their peers without disabilities. There are certain disabling conditions that do appear to create special problems related to aging. For instance, people with epilepsy appear to be at greater risk for developing osteoporosis. People with Down's Syndrome seem to begin the aging process earlier than their peers without disabilities. However, studies suggest that for the most part, older people with mental retardation experience very similar health needs to other people their age in the general population.

Although most people with mental retardation have similar health needs to their peers without disabilities there are some studies which suggest that their health-related needs are underreported and undertreated. In addition, many people

who are elderly may have short-term but intensive health related needs. These sudden and intense health-related difficulties may put people at risk for having to move out of their home if the provider can not arrange for appropriate care.

Today elderly people with mental retardation need options that make sense for their individual lives. People who are older may have an even greater diversity of needs than the middle-aged person because options vary greatly depending on a persons likes and circumstances. Some people like to continue working. This may especially be true for a person who recently found his or her first job in the

community and is enjoying being productive, making money, and getting to know others. Some people may want to slow down a bit, work part-time, or quit working altogether. Some people want to travel, others want to spend more time at home in their favorite easy chair or they may want to work on the rose garden they have always dreamed about.

Because of the varied needs of aging people with mental retardation and related conditions providing person-centered planning is critical in helping these individuals make choices about how they would like to live out the remaining part of their lives. Many adults have not experienced this type of choice-making or had a voice in selecting services. They may not even know where to begin. Often they have heard it all before and may not trust the process.

One way in which providers have successfully helped people to identify what is important to them is by helping them put together "life books." This process has direct support staff talk to the person and the people they know about the person's life experiences. Sometimes "investigative" work is done to collect old pictures or to reconnect the persons to long-lost friends and family. Records from previous facilities are also researched whenever possible. A broader picture of the person's whole life is painted through this effort. Although for many people the memories are bittersweet, and often a number of losses are re-lived, the power of this personal story helps direct support staff understand the person and work toward a person-centered plan which is based on the whole person. As people who work on these books can attest, the aging person with mental retardation has a story to tell which needs to be heard. They are the people who have lived through a time where opportunities were scarce and supports were few. When we listen, they tell us of working for no wages and missing out on even basic educational opportunities; of forced sterilization; of living in institutions where they ate meals with arms over their plates to keep others from stealing their food; of victimization and abuse at the hands of staff and other people living in the institution; of seeing their families once a year or not at all; of gaining and losing friendships at the whim of the system; of "treatments" such as drugs, shock therapy and teeth extractions which left them with more disabling conditions than they started with; and of decades lost to the black-hole of no choices and nothing to do. It is the legacy of these times and these lives which must spur the system to create better choices for people with mental retardation of all ages.

## **People with Challenging Behaviors**

### **Mat's Story: Joining The Community**

Mat is a 23 year-old man with autism and mental retardation. He lives in a home with one roommate and holds two jobs. One job involves cleaning at a local bar and restaurant for an hour each morning. The second job is delivering a weekly advertiser to 170 homes in his neighborhood. In addition to working in the community, Mat goes shopping, takes walks around a nearby lake, goes to the movies, attends concerts and special events, and eats at a fast food restaurant where he uses a wallet-sized communication picture board to order his meal, independently.

Mat hasn't always been so integrated into his local community. In the past he engaged in a number of challenging behaviors including removing pictures from the wall, taking down drapes and ripping them, dismantling his bed, ripping his clothing, breaking windows, smearing his bowel movements on objects, urinating on his clothing, hurting others, stripping naked and other similar behaviors. For almost one entire year Mat refused to wear clothing and spent most of his time wrapped in a blanket. He would often cover his head with the blanket and lay on the couch for hours. He frequently stripped in community settings, on those few occasions when staff were able to coax him to go out.

After this had continued for months, the assistance of a behavioral analyst was sought. An analysis of the function that the behaviors served revealed that Mat's stripping and subsequent refusal to wear clothing were the result of his attempt to exert control over his environment, primarily to escape or avoid

undesirable events. For this reason, the behavior analyst suggested not focusing directly on the issue of wearing clothing, but rather addressing the development of a communication system for Mat. Mat was reported to know over 200 signs, however, he was rarely observed to use the signs spontaneously. When he did sign, others in his environment were unable to interpret his signing. Consequently, the behavior analyst and a consultant in augmentative and alternative communication suggested that a communication system using pictures or symbols be implemented to supplement his existing system.

The support program that was developed for Mat had two main components. The first was to enhance his communication and choice-making skills, and the second was to provide opportunities for him to participate in activities that were motivating and required him to wear clothing.

To address communication and choice-making skills, several photographs were taken of people Mat knew and had worked with, activities he liked or was required to engage in (e.g. watching MTV, go to McDonald's, shave, take a shower, etc.), and a variety of objects (e.g. lotion, pop, cookies, etc.). Then a minimum of four times each hour, Mat was presented with a choice. Mat would then pick one of the pictures, and staff would help him complete whatever activity he had chosen. Soon he had over 130 photographs in his communication system. The photographs were mounted on hooks in the hallway of the house where he lived, ensuring he had easy access to them. Over time, staff reported that Mat began spontaneously using some of the pictures to request items. He would, for example bring staff the photo for a Diet Pepsi to request a Diet Pepsi. So the communication served to help in his ability to make his wants and needs known as well as help him understand choices presented to him.

While Mat's communication system was being developed, staff were also trying to indirectly address his refusal to wear clothes by capitalizing on the fact that he seemed to genuinely like to go out into the community. Staff would periodically encourage Mat to dress. On those occasions when he would dress, he was then able to participate in a community activity that was reinforcing for him. The length of these outings was gradually increased.

**People with challenging behaviors have been served in community programs, at integrated work sites, at home and in the public schools with varying success.**

As time went on, staff tried to increase the amount of time Mat was dressed at home by requiring him to wait for short periods of time once he was dressed to go out in the community. For example, if he indicated that he wanted to go to the store, he was encouraged to get dressed before he could go. Once he was dressed, staff would say, "Mat, I have to do these dishes quickly before we go. Why don't you just watch MTV, and we'll be ready to go in just a few minutes." Staff employed similar "stalling" techniques once Mat returned from a community outing. For example, after returning home from the store, he was encouraged to help carry in the bags of groceries and to put them away. Staff continued to implement these stalling and delaying techniques over an eleven month period, gradually increasing the amount of time he would remain clothed.

Mat now wears clothes an average of 17 hours a day and during the past year he has not attempted to undress while in the community. This is not to say his challenging behaviors have disappeared. He still experiences periods when many of these behaviors escalate. But now, these periods generally last only days, not months. And staff now feel more confident in their ability to implement strategies that have been successful in the past. Perhaps most importantly, Mat's challenging behavior no longer stands in the way of his full participation in the local community.

*—adapted from "Joining the Community" by Laura Piche, Paula Krage, and Cindy Wiczek pg. 3 &18, IMPACT: Feature Issue on Challenging Behavior 4(1) (1991).*

People with challenging behaviors have been served in community programs, at integrated worksites, at home and in the public schools with varying success. Challenging behaviors are those that are disruptive to others or those that in some way limit or harm the person who is participating in them. Some behaviors are self-directed (e.g. repeatedly banging one's head against hard surfaces, biting one's finger, running away), other behaviors are directed at others or the environment (e.g. breaking dishes, hitting others, screaming inappropriately). When these types of actions are frequent and severe they can make it hard for the person to learn new things and to "fit in" with others.

People who often display challenging behaviors are less likely to be accepted in regular classrooms, at integrated work sites, and in homes in the community, and it is often more difficult to recruit and maintain staff to work with these individuals. Because of their behaviors, these individuals are at risk of repeated and lengthy stays in institutions or psychological evaluation units of hospitals. In fact, according to the *1997 Report on Residential Services for Persons with Developmental Disabilities* 47.3% of the people remaining in institutions are people who have significant challenging behaviors. In order to continue to reduce the number of people living in institutions, and to serve people with these behaviors living in the community, attention to the best ways to prevent and decrease challenging behaviors will be a critical component to State's efforts for serving people with mental retardation and other developmental disabilities.

Intervention for challenging behaviors has a long and sometimes distressing history. In the past many of the methods used were punitive and at times dangerous or harmful to the person. In the attempt to control challenging behaviors people have been denied access to food, shelter, and personal possessions. They have been locked in rooms, inappropriately drugged, shocked, hit, pinched, sprayed with caustic substances such as lemon juice, and kept in strait jackets or other restraints for hours at a time. These treatments are incompatible with the dignity, respect, and preservation of human rights which are considered essential in providing supports today, but unfortunately some of these methods continue to be used.

Once it became unacceptable to use methods which were painful or demeaning on people who displayed challenging behaviors, new ideas and interventions developed. Eventually many laws, regulations, and policies were developed which prohibited and strictly monitored the use of aversive (or punitive) procedures and asserted people's rights to fair treatment, choice, and access to their environment and personal items. One method which was given much attention as an alternative to aversive methods was positive reinforcement of desired behaviors that were incompatible with the unwanted behavior. For instance a person who hit others might be given an edible treat if they were able to go for a certain amount of time without hurting others. While this is a more acceptable and humane way of dealing with challenging behaviors it also has drawbacks. It is sometimes difficult to provide sufficiently motivating reinforcement when arbitrary limits on a person's environment are no longer considered acceptable. For instance, rewarding a person with a nice dessert after dinner for showing good table manners isn't compatible with the idea that people have a right to food whether they are perfectly behaved or not.

Ultimately many people began to acknowledge that some of the commonly used modification techniques based on strict concepts of behaviorism (punishment and rewards) were only minimally successful and sometimes completely backfired, causing the person to become more likely to engage in unwanted behaviors. Service providers and behavior specialists alike began to re-think how they could stimulate desired behaviors in people who were behaving in unwanted ways.

The missing component to these methods of trying to control unwanted behaviors was an acknowledgment and understanding of the function that the behavior served for the person. Without knowing what motivated the person to act in these ways, behavioral programs were a stab in the dark. Often, the underlying reason for the person to engage in the unwanted behavior was so strong that no matter how horrendous the punishment or how great the reward, people continued to exhibit the undesired behavior.



There are a number of reasons why a person may participate in challenging behaviors. Communication and control of the environment are two primary motivations. People who can not tell others in an appropriate way what they want or don't want are more likely to act in inappropriate ways. If they are uncomfortable in their environments or do not have opportunities to make choices about what they do, they may express their frustration in harmful ways.

In many ways, the traditional services provided to people with mental retardation and related conditions have increased the chance that people will behave in unwanted ways. Many service settings give people little choice in the most common matters of life including what they eat, where they eat, when they will shower or bath, how they spend their money and what clothes they wear. Although many people with disabilities have complied to this lifestyle, others have not.

When a person doesn't want to shower in the evening, but this was the time set aside by staff, typical strategies to get the person to comply with this schedule have been to persistently pester the person and offer rewards if he or she showers on time. In many service settings it is still considered radical thinking to allow the person to choose a time during the day which is more preferable. In fact, in some settings it is likely that a behavior modification program would be put in place without anyone thinking to check for a problem such as monitoring the water temperature to see if it's a time when the water heater has been drained and the shower goes cold half way through. People in these situations who become angry or frustrated and retaliate by yelling, hurting themselves or threatening others are unfortunately often considered to exhibit "challenging behaviors."

While communication limitations and the need for control are often the root of challenging behaviors it is not always clear what the person is trying to communicate. A behavior specialist can work with support people to determine what causes the person to display the unwanted behavior.

**Behavior analysts use a variety of methods to gather information about when challenging behaviors:**

- **Medical reasons.**
- **The person wants to avoid something.**
- **The person wants to access something.**
- **Additional considerations.**

Sometimes, especially if the person has minimal communication skills or additional conditions like mental illness or autism, it can take a good amount of investigation and observation to accurately discover the person's motivation for engaging in the challenging behavior. Sometimes the original cause is long gone and the person has simply continued the behavior as a means of getting needed attention or stimulation. Other times the cause may be imperceptible to others, as may happen if a person hears voices due to mental illness or becomes

suddenly disoriented and confused about where he or she is. People with autism and related conditions may easily become over-loaded by sights, sounds, smells or changes in the environment that are insignificant to people without this disorder.

Once the function of the behavior is clearly understood a plan for decreasing the problem behavior and increasing desired behaviors can be put in place that has a good chance of success. By helping people find new ways to express themselves and then by helping them act upon their wishes problem behaviors decrease.

Good behavioral supports do more than simply let people refuse to participate in activities. They start with a deeper understanding of why the person refuses to participate. For instance while most adults do feel that they "have to" work (or maintain a home, or take care of the dog), they do so with a sense of

choice. Many people will say they don't have a choice about working, but they do, at minimum, have choices about what types of jobs they will accept, the location of the job, the hours they work, and when they will take sick leave or vacation. Similarly at home they can choose to do the dishes right after dinner, later that night, the next morning or even eat from paper plates and avoid dishes altogether.

A person who lives in a residential program and goes to school or a vocational program during the day very often doesn't have these choices. Every part of every day may be structured by others. Most often they are required to live in the same house—maybe even the same room—with people that are selected by someone else. Household chores, meal times and even bedtimes are set to accommodate the smooth functioning of the home. At work or school similar demands are placed on the person throughout the day. Jobs and activities are decided by others. People not receiving services who decide to find a job in the afternoons because they like to sleep late in the morning can still be considered industrious. A person receiving services who prefers to sleep late in the morning is often considered lazy or non-compliant.

What about the student that won't sit in his or her chair? The chances of getting a child to remain in a chair for several minutes at a time, day after day, when they have no idea why they should sit in the chair is not very likely, yet people with mental retardation are often expected to do just that when "integrated" into typical classrooms. Sitting in a chair to listen to a lecture on something which isn't understandable is hardly motivating. Neither is just "being good." It is a teacher's responsibility, with support, to present classroom curriculum in a way that is meaningful to all the students in a class. A student who will not sit quietly in a row of desks may stay put for quite awhile at a table where they are working with other students to create a project.

Family and paid staff who successfully support people who have challenging behaviors need a number of supports themselves, including the following:

- *Proper training.* In many places proper training for serving people with challenging behaviors has been learning how to restrain a person properly and avoid getting hurt. This may be essential training for some people, however it should be considered only one of many training needs for working with people with challenging behaviors. People need training on how to understand and respect the functions of behaviors, how to provide meaningful choices, how to protect and respect rights, how to proactively avoid and de-escalate situations in which the behavior may be exhibited and how to communicate effectively and stimulate wanted behaviors.
- *Access to technologies and professional advice.* Direct support people need the advice of behavior specialists to help solve problems. They need materials, information and devices useful in augmenting communication and training on how to use them.
- *On-going support, encouragement and recognition.* Eliminating or reasonably diminishing challenging behaviors can be a long process, sometimes taking years, particularly when the person has used this form of behavior for many years and it is well established. Paid and unpaid support people need to have support from other peers, parents, or professionals for continuing with this work. Paid support people should be recognized with increased pay or other benefits such as more time off because of the special skills it takes to provide this type of support. Families may need access to competent and caring respite services.

Many people with challenging behaviors have already benefited from newer methods of understanding, preventing and responding to challenging behaviors. Continued efforts to research and evaluate the effectiveness of intervention methods is critical since many of the people waiting for community services have challenging behaviors and students with these behaviors are at high risk for being kept out of inclusive classrooms. In addition, training in these methods is necessary for families, teachers, and other support people if progress is to be made.

# The Use of Assistive Technology

## Technology and Self-Esteem

*Our son has multiple disabilities. Once we accepted that fact, we determined that we would do everything in our power to develop in him a positive self-esteem. We want him to view himself as a worthy person, to trust his own thinking, and to develop skills to be as independent as possible. This is not only our goal, but also the goal of parents and educators of other young children with special needs.*

*Building this self-confidence is a process of continual, supportive feedback from human beings in the child's environment. It also requires using a wide variety of tools to enhance the child's interests and abilities. Technology is one tool which can develop self esteem in children with disabilities.*

*By contributing to the functioning of the family or the classroom, children with disabilities build their self-esteem. At home a switch connected to an appliance allows a child to turn on the blender and help make supper. At school, a communication device can say, "My turn, please," when the child would like to participate in classroom activities.*

*Computers with carefully selected software, and adaptive devices, if necessary, allow children to control their learning environments and to learn. The resulting sense of success fosters self-esteem.*

*As parents, we desire our children with and without disabilities to view themselves as worthy individuals. We trust that the people around them will assist us in building their self-esteem. Technology is a tool that can help by allowing children to be part of the family or classroom and give them a means to experience success in learning.*

*By Brenda Carlson. Reprinted with permission from The Computer Monitor. (1996). Volume 5, Minneapolis MN: PACER Center 4826 Chicago Ave. South, Minneapolis, MN 55417-1098 (612) 927-2966, (612) 827-3065 (TTY)*

What do a power wheelchair, a fork with a built up handle, and a computer with a program that reads text out loud have in common? They are all assistive technology devices. An assistive technology device is defined as "any item, piece of equipment, or product system, whether acquired commercially, off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities," according to the Technology-Related Assistance for Individual's with Disabilities Act (better known as the Tech Act). This law acknowledges the importance of assistive technology devices and services for some people with disabilities to lead full lives.

Assistive technology ranges from the inexpensive and simple, such as books on audiotape, to the expensive and complex, such as computerized communication devices. Assistive technology can help children with disabilities participate in regular classrooms, help adults work faster and earn more money, and reduce the amount of dependence a person has on other people for self-care, homemaking, and transportation.

Assistive technology can make a real difference in a person's life. For older adults it may keep them from having to move to nursing homes by providing them with enough independence to keep working

and taking care of basic needs. For children it may help them participate in activities with peers who do not have disabilities by letting them communicate better or play an active role in projects and games.

For people with communication barriers the availability of alternative or augmentative communication devices can make a dramatic change in their lives. The inability to express even simple choices in a manner that others can understand can lead to extreme frustration and depression. For many people having access to a viable form of communication can greatly increase their opportunities and life satisfaction. While some methods of communication technologies are very expensive, others can be as inexpensive as books with pictures of recognizable objects, activities, people and places which a person uses to communicate with by pointing to the correct pictures.

Despite acknowledgment that assistive technology can be a vital part of helping people with disabilities meet their highest potential, there are still a number of barriers to providing people with appropriate assistive technology devices:

- *Finances.* Some forms of equipment are very expensive. Equipment usually must be customized to the particular person. This means that there is not a large market which would help to keep costs down. Funding can sometimes be secured through existing projects related to assistive technologies, loans from commercial banks and credit unions, health insurance, or Medicaid. However, the coordination and the availability of these types of funding can greatly vary. Because funding is usually established based on "medical necessity" or as part of an educational plan, working with medical professionals and teachers to help establish the need for a device can be critical.
- *Knowledge.* People with disabilities, their advocates, and service professionals need more information about what types of technologies are available, training on how to use the technologies, and information on how to pay for technologies when they find them.
- *Creativity.* Not all assistive technologies are expensive or complicated. Books on tape are often available through book stores or public libraries. Someone with access to a typical tool box and a minimal amount of skills can create technologies that help people use their environment to a greater extent. For instance a fingernail clipper can be mounted on a board to allow someone with mobility limitations to cut his or her own fingernails. Support people need training, guidance and information on how to look creatively at a person's abilities and limitations and make changes or adaptations that increase a person's independence and ability to fully use his or her environment.
- *Access.* Even if people know what they want, finding the right kind of equipment can be difficult. These adaptive devices are very specialized and must conform to the needs of the individual to be of use. The creation and maintenance of resource networks on assistive devices like ABLEDATA available through the World Wide Web (<http://www.abledata.com>), minimize this problem.

While many people are already benefiting from the use of assistive technologies many more are waiting. Coordination of efforts and an increased emphasis on funding for appropriate devices needs to continue. Patience is an asset since many of these items can be funded if the person or their advocates are willing to keep trying and to use the help of family physicians, teachers, and other professionals in obtaining the devices. The outcome for people with disabilities who have access to helpful technologies is an enhanced ability to communicate with others, and to participate in their own care, community activities, employment, and education.

## Culturally Competent Supports

### Fred Sultansade: Supporting Diversity

*“My name is Fred Sultansade. I am 42 years old. I live in the East Orange Group Home. The most important things to me are money, my personal things, having a good time playing baseball and basketball, and going to the mosque to pray.*

*When my father was living he was Islamic. He was from Azerbaijan, on the Caspian Sea. I have pictures of him. My father read Arabic.*

*I used to live in another town. I used to dance with the girls there, exercise, and play checkers. I was thinking about Allah. I had a funny feeling I was going to the mosque when I was there.*

*Now I live at the East Orange Grove Home. When I first came here, I would listen to the "Nation of Islam" on the radio. Reverend Jesse helped me by finding a special mosque for me. Every time he'd be waiting right there for me. I go every Monday, Wednesday, and Friday. If it's nice weather I always go to the mosque. I stay for 15 minutes, 30 minutes or 45 minutes. I listen to the English and Arabic version.*

*I like going to the mosque because I can express myself by saying, "Salam A'lechem, A'lechem Salam." I say blessings in Arabic. Reverend Jesse taught me how you have to "wuudo" or cleansing (my father used to do that). He taught me I have to wash my hands, wash between my toes, on the left and right side, then you make prayers. I wear the white robe that Reverend Jesse bought me. When I go to the mosque, I say, "Salam A'lechem" to the other people and they say, "A'lechem Salam" to me. We talk to each other.*

*Reverend Jesse gave me a new name. My name is Mohammed Rasu. It means "great one." I was called Fridun when I was born. My Dad was mad when I changed it to Fred. When I go to the mosque, people call me Mohammed Rasu. They are happy to see me.*

*I just want to pray for the whole wide world because I think it needs a prayer.”*

*From “Finding a Spiritual Family” by Fred Sultansade (Mohammed Rasu), in IMPACT: Feature Issue on Supporting Diversity Volume. (1996). 9 (3).*

America is a land of great cultural diversity. This diversity has benefits as well as challenges. While most people in the United States enjoy trying and learning about the food, the celebrations, and the history of various ethnic and cultural groups, there are still a number of barriers to having a true multicultural society. For the most part mental retardation and other disabilities affect a similar percentage of people from all cultures, yet in many ways, the services to people with mental retardation and related conditions have been defined by Western European culture and have been slow to make necessary changes which would make services accessible and beneficial to people outside of the dominate culture. Current demographic trends in the United States suggest that the numbers of people from cultural backgrounds, other than Western European, will be growing proportionately to the whole population. It is also estimated that a significant number of these children will grow up in families who do not have enough money and resources to meet all their needs.

Across America, many businesses, schools, churches, social service agencies, and even the branches of the military have provided diversity awareness and sensitivity to their employees, recruits and students. However, to truly be culturally competent, service providers must do more than make employees aware of differences. They must help employees value and understand these differences and give them the tools and training to provide services in a way that is respectful of cultural differences.

Federal legislation typically mandates that assessment and services be provided in a way that takes into account an individual's cultural orientation. However, caution must be used to not use stereotypes or general characteristic of an ethnic group in providing services. In order to provide family and person-centered supports, service providers must have an awareness of the person's cultural upbringing and preferences, as well as their personal circumstances. It is the combination of these components that can help service providers create supports that meet individual needs in a culturally competent way.

Some areas where definitions and preference may differ from the dominate culture include the following:

- *Family.* The dominant Western European culture in America typically defines family in terms of parents and their children, with both parents usually having a comparable say in the choices that affect their child. In some cultures extended family plays a much greater role. Grandparents, aunts, uncles, and cousins, as well as parents and siblings, may make decisions or play a key support role in the family. One parent or the other may be a primary connection to services or a grandparent may be the family decision-maker. By making culturally-biased assumptions about how a family works and who is in a primary role in relationship to the person receiving services, providers can minimize the effectiveness of supports.
- *Disability.* How cultures define disability can vary widely. In some cultures a child with disabilities is seen as a sign of failure on the part of the parents, or as a punishment. Other cultures may see a child with certain disabilities as "blessed" or special. Some cultures simply do not have the same words or concepts for disability. In addition, normal behavior in some cultures, such as talking or interacting during movies or in church services, or not looking at or speaking directly to unfamiliar adults, may be perceived by the dominant culture as potential behavior problems or developmental delays when they are appropriate to the person's family or heritage.
- *Preferences.* People who receive services will have preferences in the food they enjoy or can tolerate, in the music they like, how they prefer to dress, the holidays they observe and how they observe them. These may have little relationship to the food selected by a dietitian working for a regulated facility or the music selected by the direct service staff on the workshop floor. Service Providers may offer options for staff to choose some of their own personal holidays but may not think about the needs of those receiving supports to make those same decisions.
- *Locality.* In the last two decades the trend in service provision has been to offer supports in the community. For people with a heritage outside of the dominant culture "community supports" may not yet be a reality. Many residential services are found in areas where the majority of people have a Western European heritage. The return to the community for people who spent time in regional treatment centers has very rarely been the return to their own communities (home towns, neighborhoods, etc.). Parents in search of family supports may find that they must travel out of their own neighborhoods and receive services from people who lack an understanding of their language, traditions, and beliefs.

Cultural competence in service provision does not happen by accident. It takes a real effort on the part of service providers to examine their own culture and related values and biases. It requires learning about other cultures and having the skills to create individualized services that respect the person's heritage and particular circumstances. In order to become culturally competent a service provider must be able to find ways to remain open to continual learning and exploration of all ethnic backgrounds. They must use or

develop assessment methods that are based on information gathered about people in the individual's ethnic community. Connections with community resources that exist in an individual's own neighborhoods should be nurtured.

Creating a culturally competent service delivery system is more than simply teaching professionals from the dominant culture about other cultures. Active recruitment of people from various ethnic/cultural groups and economic levels into jobs supporting people with mental retardation, onto advisory boards, and at all levels of professional service is essential. This may include the necessity of looking at funding sources earmarked for transportation and financial compensation to make active participation feasible. It will also mean the service delivery system will have to have a real ability for allowing this participation to go beyond "tokenism" and really be prepared to make changes in services based on the input of those who participate. In addition, more work should be done to stimulation and support the development of provider agencies run by people from a variety of cultural backgrounds.

Each State and the communities within them will have different needs. It is important that the States take a look at the local demographics and see how well these populations are being served. When underserved populations are identified an assessment of why they do not use existing services should be done. In addition a look at public awareness materials and the cultural diversity of the service professionals should be compared with the needs of the community to make sure they are reflective of all the ethnic groups which need access to services.

## **Improving Outreach to American Indians**

### **The American Indian Rehabilitation Research and Training Center**

The American Indian Rehabilitation Research and Training Center (AIRRTC) was established in 1983 to improve the quality of life for American Indians/Alaska Natives with disabilities through conducting research and training that: 1) results in culturally appropriate and responsive rehabilitation services; 2) facilitates American Indian access to services; and 3) increases the participation of American Indians in the design and delivery of rehabilitation services. The AIRRTC does not provide direct rehabilitation services to American Indians with disabilities. Instead, it trains providers of rehabilitation services. The training is developed based on information from annual surveys of service providers about their needs in relation to improving services for American Indians with disabilities.

In training for non-Indian providers, the following are presented as some of the outreach strategies to enable them to better serve American Indians:

- Read about the American Indian cultures in your respective States, as well as gather information that provides an overview of lifestyles, sovereignty, treaties, employment, housing, tribal structure, and so forth. Through reading and gathering information, providers can develop an appreciation of the diversity among the American Indian tribes.
- Provide American Indian individuals with clear written and verbal information about rehabilitation services both on and off reservations.
- Consult with a linguist or nearby university that has an American Indian program for assistance in writing the information in the native language or culturally relevant language.
- Develop or obtain a resource list of American Indian Organizations, American Indian Centers, schools, social service agencies, tribal service providers, community health representatives, or Tribal/Indian Health Services public health nurses. By visiting with those on the list or others who are American Indian, assistance can be found in developing an outreach plan.

- Review the organization's written and unwritten policies on outreach services to American Indian tribes to identify flaws that can be corrected. American Indian advisors can assist in recommending outreach strategies that meet their community needs. Some agencies have hired American Indian technicians to serve as liaisons, assist with recruitment of consumers, and assist in developing culturally relevant services. It may also be desirable to subcontract with American Indian tribes to set up satellite offices that are responsible for outreach services. Attend American Indian events that are open to the public such as pow-wows, Indian rodeos, fairs, and American Indian lectures. This facilitates visibility of providers interested in American Indians and helps the providers better understand American Indian pride.

In addition to providing training to service providers, the Center conducts research. A research project focusing on the vocational rehabilitation of American Indian adolescents and adults with fetal alcohol syndrome/fetal alcohol effects (FAS/FAE) began in March, 1996. The purpose of the project is to determine what information and procedures are needed to enhance the ability of counselors to address the rehabilitation needs of American Indian adolescents and adults who have FAS/FAE. The term "counselor" is used to refer collectively to vocational rehabilitation counselors, independent living counselors, school counselors, school psychologists, developmental disability case managers, job coaches, and other rehabilitation professionals.

In all its' work, the AIRRTC recognizes the importance of fully attending to cultural diversity in rehabilitation services. Although American Indian people may represent less than one percent of the total population in this country, they have as much diversity as the remaining combined population (Hodgkinson, et al., 1990). There are 309 federally recognized Tribes and 197 Alaska Native villages. There are over 250 different languages still spoken among Native People. To provide culturally appropriate services for American Indians, providers, researchers, and trainers must involve American Indian consumers in identifying needs and priorities, and in designing, conducting, and evaluating research, training, and services.

*Adapted from "Improving Outreach to American Indians" by Priscilla Sanderson. IMPACT: Feature Issue on Supporting Diversity. (1996). Volume 9 (3). For information on the AIRRTC, a University Affiliated Program, contact The Institute for Human Development, Northern Arizona University, Flagstaff*

## Conclusion

All people receiving services to some extent need "specialized supports." More than ever people are asking for supports that respect their individual preferences and which are provided in the context of their own communities and in keeping with their beliefs. Community providers will need to increase their ability to provide supports to people with challenging behaviors and people who are aging. In addition service providers will need to deal with issues such as cultural competence, often ignored in the past "one-size-fits-all" approach to services, with openness and an ability to learn. As service providers work to meet those needs the use of person-centered planning techniques will become increasingly important.



## Resources

*The Supported Parenting Project (PPP) of Wisconsin.* A three year project (1987-1990) with the purpose of providing intensive in-home services to targeted families and providing information and technical assistance to social service agencies about methods for supporting parents with cognitive limitations. The following publications are products of that project and can be ordered for a minimal charge from The Wisconsin Council on Developmental Disabilities, PO Box 7851, Madison, WI 53707. (608) 266-7826.

*Cultivating Competence.* (1991). D. Ullmer, S.K. Webster & M. McManus. This book is a resource guide to thirty one models of support offered in fifteen States to families headed by parents with cognitive disabilities. \$3.00.

*Helping Parents Parent.* (1992). S. Heighway. This practice guide is useful to anyone providing supports to families headed by parents with cognitive limitations. \$3.00.

*Discovering the Parent's Language of Learning: An Educational Approach to Supporting Parents with Mental Retardation.* (1990). M. Sweet. This booklet describes an approach that can increase the effectiveness of teaching to parents with cognitive supports. \$2.00.

*Facing the Challenge.* (1990). J. Franz. This guide presents an overview of the law and the working of the courts in the context of typical difficulties faced by families headed by parents with cognitive disabilities. \$3.00.

*Building the Foundation: Public Policy Issues In Supported Parenting.* (1992). H. Mandeville, P. Snodgrass, M. Sweet and D. Ullmer. \$3.00.

*IMPACT feature issue, Supporting Parents Who Have Cognitive Limitations.* (1998). This issue provides overview information and profiles of successful programs and supports for parents who have cognitive limitations. Available at the Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Drive, SE, Minneapolis, MN 55455. (612) 624-4512.

*The Clearinghouse on Aging and Developmental Disabilities* at the University of Chicago has a number of resources available for people interested in providing supports to older people with mental retardation and other developmental disabilities. Unless otherwise noted, the following resources can be ordered from: RRTC Clearinghouse on Aging and Developmental Disabilities, Institute on Disability & Human Development M/C 626, 1640 W. Roosevelt Road, Chicago, IL 60608-6904: (312) 413-1860 (V), (312) 413-0453 (TTY), (312) 996-6942 (fax), (800) 996-8845 outside of Chicago.

*Making Choices as We Age: A Peer Training Program.* (1996). A curriculum for training persons with disabilities and their co-trainers on how to teach other adults with mental retardation about: Choice-making, rights and responsibilities, how to make healthy choices, and about things to do in their free-time. Cost: \$45.00.

*Models for Interagency Planning for Long-term Funding of Small-Scale Community Living Options for Older Persons with Developmental Disabilities.* (1992). Cost: \$10.00.

*Belonging and Becoming: What Families Need to Know about Aging and Developmental Disabilities.* (1993). Fact sheets for families on the physical, psychological and social issues related to the aging of individuals with developmental disabilities. Cost per unit: \$3.00.

*Peer Companion Model Implementing Community Integration for Older Persons with Developmental Disabilities.* (1992). Addresses recruitment of non-handicapped senior volunteers to work with older person with developmental disabilities to facilitate access to community activities. Cost: \$10.00.

*The Rehabilitation Research and Training Center on Aging with Mental Retardation.* Check out publications and information at website: <http://www.uic.edu/orgs/rtrcamr/index.html>

*Facilitating Future Planning and Transitions Out of the Home.* (1994). This book offers information on such important topics as aging parents, living outside the system, individual development, planning transitions, community services, and research challenges. Order this book from: The American Association on Mental Retardation (AAMR) publications center, PO Box 25, Annapolis Junction, MD: 20701-0025. (301) 604-1340. Cost: \$35.00 (non-members), \$29.75 (members).

*Autism Society of America.* Check out the Resource listing in the website. This listing has contacts and titles for organizations, books, journals, videos and audio tapes relating to challenging behaviors. <http://www.autism-society.org/packages/challenging-behavior.html#resource>.

*Why Does Samantha Act Like That? A Positive Behavioral Support Story of One Family's Success.* A family tells the story of how challenging behaviors were overcome through positive behavioral support. The book is \$5.25; the video "Samantha" is \$30. Contact: The Family Connection, Beach Center on Families and Disability, University of Kansas, 3111 Haworth Hall, Lawrence, KS 66045, or call (800) 854-4938 for behavioral issues; (913) 864-7600 TTY; (913) 864-7600 FAX; or e-mail [family@dole.lsi.ukans.edu](mailto:family@dole.lsi.ukans.edu).

*Learning to Listen.* This interactive CD-ROM is useful for understanding the reasons why someone might engage in challenging behaviors and helps people begin to understand how to listen to the person and respect their choices. In IBM and Macintosh format. Available at the Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455. (612) 624-4512.

*IMPACT Feature Issue on Challenging Behavior.* (1991). This issue addresses considerations and research findings related to quality of life and community integration of persons with challenging behaviors, as well as areas for future research and training. Available at the Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455. (612) 624-4512.

*Washington Assistive Technology Alliance.* Check out the website at <http://weber.u.washington.edu/~atrc/>. WATA is a project funded by the National Institute of Disability and Rehabilitation Research and mandated by the Technology Related Assistance for Individuals with Disabilities Act (1994). The website has links to further resources and information concerning assistive technologies.

*ABLEDATA* is a nationwide source of information on more than 23,000 assistive technology items available from domestic and international sources. You can reach them at: 8455 Colesville Road, Suite 935, Silver Spring, MD 20910: (800) 227-0216, or (301) 608-8998 (V), (301) 608-8958 (fax), or check out their website at: <http://www.abledata.com/index.htm>.

*Assistive Technology Sourcebook.* (1990). *Assistive Technology: A Funding Workbook.* (1991). Guides to assistive technology including information resources, equipment evaluation, personal care, education, employment, recreation, mobility, computer access, and funding. Available at: RESNA Press, 1101 Connecticut Ave. NW, STE. 700, Washington, DC 20036-4303. (202) 857-1199.

*IMPACT: Feature Issue on Assistive Technologies.* (1995). This issue of IMPACT describes efforts to utilize consumer direction, public policy, creativity, energy, and professional know-how in the pursuit of opportunities for community inclusion, social and economic contribution and self-determination of people who have 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.

*Cultural Competence in Screening and Assessment: Implications for Services to Young Children with Special Needs Ages Birth through Five.* (1991). This booklet discusses implications of cultural diversity on screening and assessment of young children who may have developmental delays or health related needs. Available at: PACER Center, 4826 Chicago Avenue South, Minneapolis, MN 55417-1098: (612) 827-2966 (Voice or TDD), FAX (612) 827-3065.

*Cross Cultural Supports for People with Disabilities and their Families.* (1995). A training curriculum designed to assist people in understanding themselves, embracing difference and in moving toward being culturally competent. To obtain a copy, contact the Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455: (612) 624-4512.

*A Workbook for Your Personal Passport.* (1996). This workbook is designed to assist people with developmental disabilities and facilitators of person-centered planning approaches in developing a person-centered individualized plan. To obtain a copy, contact: Allen, Shea & Associates, 1040 Main Street, Suite 200B, Napa, CA 94559. (707)258-1326.

*Reach for the Dream! Developing Individual Service Plans for Persons with Disabilities.* A manual on integrating the development of individual written plans such as IEPs, ISPs and IWRPs with futures planning processes. Available through: Training Resource Network, PO Box 439, St. Augustine, FL 32085. (904) 823-9800; fax (904) 823-3554.

*Capacity Works: Finding Windows for Change Using Personal Futures Planning.* This book is written for people with disabilities, their families and the people who wish to talk with them toward a more hopeful future. Available through: Training Resource Network, PO Box 439, St. Augustine, FL 32085. (904)823-9800; fax (904)823-3554.

*PATH: A Workbook for Planning Positive Possible Futures.* Uses an eight-step process to help people figure out life goals; build their strengths; include others in a personal support network; and develop a commitment to action. Contact: The Centre for Integrated Education and Community, 24 Thorne Crescent, Toronto, Ontario, Canada M5H 2S5: (416) 658-5363 or fax (416) 658-5067.

*Person Centered Planning: How do we know when we are doing it?* An overview on a variety of approaches to person-centered planning and what is common to all of them. You can obtain a copy from: Oregon Transition Systems Change Project, Oregon Dept. of Education, Office of Special Education, Salem, OR. (503)378-3598.

*It's Never Too Early, It's Never Too Late!* (1988) The goals of Personal Futures Planning are to: help someone develop a picture of what the future will look like for her or him; to build a circle of people who will help support that picture or plan; and, to take some first steps. You can get a copy of this booklet (1988) from the Governor's Planning Council on Developmental Disabilities, 300 Centennial Building, 658 Cedar St., St. Paul, MN 55155. (612)296-4018 or fax (612) 297-7200.

*My Life Planner; Letting Go; Dream Deck.* The Planner and Letting Go provide a variety of activities to assist people with developmental disabilities and family members in planning for the future and figuring out more about their preferred lifestyles, interests and preferences. The Dream Deck is a visual approach to finding out more about preferred activities and interests. For information on purchasing these and other great documents, contact New Hats, Inc., PO Box 57567, Salt Lake City, UT, 84157-7567. (801) 268-9811.

*MAPS (Making Action Plans).* MAPS helps bring together the key people in someone's life to develop a support plan. For more information on how to use the MAPS process, you can find out about available texts, videotapes and training by writing The Centre for Integrated Education and Community, 24 Thorne Crescent, Toronto, Ontario, Canada M6H 2S5. (416) 658-5363 or fax (416) 658-5067.

*Extended Family Support Project.* The 'Homebuilders' project provides assistance to families at risk of having a child placed out of the home and includes families with parents who are mentally retarded or have other developmental delays. Contact the Project Coordinator, Behavioral Sciences Institute, 181 South 333rd Street, Suite 200 Federal Way, WA 98003. (253) 927-1550; fax (253) 838-1670.

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## Glossary

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

**Assistive technology device:** Any item, piece of equipment, product or system, whether acquired commercially, off the shelf, modified or customized, that is used to increase, maintain or improve functional capabilities of an individual.

**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).

**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 as a person who has a problem which needs professional help.

**Culturally competent supports:** Supports which go beyond simply an awareness that there are different cultural perspectives to having a number of sophisticated methods for respecting and infusing preferred cultural references into each person's supports.

**Dominate culture:** In multicultural societies, the cultural practices which are the basis for judging actions and establishing public traditions. Usually the dominate culture is so much a part of the societies' perspective that it is "invisible." Behaviors which are contrary to the perspective of the dominate culture are usually considered inappropriate or wrong, even when they are not harmful.

**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) enhances the capacity of families to provide supports at home, and (d) realizes some cost savings related to promoting care at home over out-of-home options.

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

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

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

**Institution:** Large public or private residential program in which 16 or more people with mental retardation and other developmental disabilities live.

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

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

**Least Restrictive Environment:** A clause in IDEA which mandates that children receive education in the least restrictive settings possible. Frequently referred to as LRE.

**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.

**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.

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

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

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

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

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

## Common Acronyms

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

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



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

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