

## **BEYOND ABUSE: TREATMENT APPROACHES FOR PEOPLE WITH DISABILITIES**

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*Abuse has become a focus of concern in today's society. Historically, signs and symptoms of abuse in people with developmental disabilities have not been effectively recognized, assessed, or treated. Preconceived ideas, institutionalization, lack of creative communication and technologies, and limited self-determination influence the incidence of abuse. These factors impair health care providers' ability to assess, intervene, and treat these people. Development of a supportive culture, education, professional attitudes, and prevention are the tools health care providers may use in partnership with people receiving their services to effectively respond to circumstances of abuse.*

Reports of abuse are prevalent in today's society: Pick up a newspaper. Watch the evening news or an afternoon talk show. People agree that abuse must stop. Are we concerned about abuse for everyone? Historically, individuals labeled developmentally disabled (also known as mentally retarded) have been treated with less concern than most people. Is this because they sometimes behave or communicate differently? Unfortunately, many people have been institutionalized because of these differences. Recent surveys (Baladerian, 1991; Crossmaker, 1991; Enfield, 1992; Sobsey & Doe, 1991) suggest an increased risk of abuse in persons with developmental disabilities, especially if they have been institutionalized. Abuse ranges from overt physical attacks to more insidious forms of intimidation and neglect.

There are various challenges when people with developmental disabilities seek health care or mental health services as a result of abusive experiences. The majority of challenges revolve around communication. Health care providers' preconceived ideas about people with developmental disabilities and what is "normal" behavior may interfere with the assessment, intervention, and treatment process. Determining the cause of behavior changes and presenting symptoms in a person with absent or limited communication skills can be confusing and difficult, but these challenges can be met. It is the varied skills of health care providers that make it possible to assess, intervene, and treat abused persons with developmental disabilities. It is often not

actual experiences, but the label of "developmental disability" that causes people who provide services to quiver at the thought of assessment, intervention, or treatment.

One question often asked is "What is the functioning level of people with developmental disabilities?" This is a very difficult question to answer for some people. Most test results are limited by a person's verbal language or, rather, lack of expression of language. For instance, many years ago, people with cerebral palsy were often institutionalized because they were thought to have a mental incapacity. What many such people really struggled with was a physical disability that made their language unclear. It is the limitations of the tests that label people that cause diminished expectations and beliefs about these people. Abilities and disabilities vary from individual to individual, for all people of all ages, and across physical and mental disabilities and diseases. Ryan's story is an example of confused labeling and the result of persistence by caretakers. Ryan's behavior may well have been the result of an abusive experience:

Ryan was a 25-year-old man with a severe developmental disability. His communication was limited to high-pitched noises that do not resemble words and sign language words for "drink," "eat," and "please." When Ryan was upset, he responded to people around him by pushing, pulling, and hitting himself and others. One time, his self-abusive behavior increased over a 3-day period. Reasons for his behavior were unclear, and his caretakers became frustrated. They asked many questions. Was he hungry, sick, hurt, angry, or sad? Finally, after careful observation, they noticed that Ryan's hitting focused in the area of one ear. An appointment was made with the doctor, and, sure enough, Ryan had an ear infection. Treatment began promptly, and Ryan's behavior improved in a day.

If Ryan had presented for health care services without the careful observations of his caretakers, he might have been treated with more psychotropic medication for self-abusive behavior. It takes thoughtful question-

ing when information is offered to be aware of what is individually normal and then shaking off preconceived ideas for health care providers to assess, intervene, and treat people with developmental disabilities. A deviation from an individual's normal behavior suggests a problem. For Ryan, the problem was an ear infection.

### Settings for Abuse

People with developmental disabilities experience abuse in the same settings as most people—at home, school, and work. Unlike most people, except the elderly and people with mental health problems, they also reside in institutions and group homes. An institution is typically a large building where hundreds of people who have something in common live together. A group home is a smaller building, usually a house, with fewer people. Institutionalization is a dynamic of living in a large facility or group home. People in this kind of setting have little choice or self-determination; a person can be institutionalized anywhere. It can happen in a large building, a community group home, or even in a person's own home.

Institutionalization is an approach whereby one group of people makes decisions for another. Decisions may include when and where a person goes; what is worn; who is visited; what is eaten; and when, how, and by whom health care is received. Parents, teachers, staff, and health care providers hold powerful decision-making responsibilities for the lives of the people they serve, deciding when people receive assessment, intervention and treatment and when they do not. It is the "not" that may contribute to abuse.

### Abuse

Abuse is defined by Baladerian (1991, p. 323) as "non-accidental injury of a person by another or the committing of acts that could result in injury, through acts of commission or omission." Many forms of abuse exist: physical, emotional, psychological, sexual, and financial; acts of negligence; and violation of individual's rights. There have been few data collected and scant literature about the abuse of children and adults with developmental disabilities. In cases of general child abuse, 29% to 70% of children abused have a disability before the abuse occurs (Baladerian, 1991). People with disabilities are perceived to be defenseless and passive, which may lower inhibitions of offenders and thus increase risk of victimization (Sobsey & Doe,

1991). Victims are chosen because they are unlikely to report or resist the event. To compound the risk, institutionalization limits people's ability to make decisions for themselves and exposes people to a large number of caretakers.

Discovery of abuse in people with developmental disabilities, the elderly, children, and people with mental health problems takes a similar path. When people with developmental disabilities report abuse themselves, they are not always believed. Some caretakers devalue the abilities of these people they work with, influencing their acceptance of these reports. Some people with disabilities cannot verbalize their thoughts or feelings completely, confounding the process of discovery. Recognizing signs and symptoms of abuse is complicated when the victim cannot respond verbally to questions. The health care provider must rely on information reported by caretakers and physical evidence. Talk about abuse, injuries of unknown origin, increase in self-abuse, aggressive behaviors toward a specific individual, emotional outbursts when near a particular person, and withdrawal from daily activities or people are some signs of abuse that may be seen singly or in combination. Interpreting these symptoms accurately is a challenge; a number of other events may be attributed to them. The solution is to ask a range of questions to seek a complete picture of contributing factors from as many people as possible. Consider this case of eight young men living in a group home:

All eight men had challenging behaviors and behavior management progress, and all took large doses of psychotropic medications. Four staff persons worked in the house regularly. A nurse routinely reviewed accident reports for patterns of concern. One month she noticed that there were several individuals with facial injuries of unknown origin and numerous bruises. The staff reported that some of the eight men were increasingly aggressive with each other. The staff also stated that several of these housemates were clumsy and were having accidents around the house. The nurse notified an administrator, and an investigation began. After thorough questioning, it was learned that staff members were wrestling and boxing with the men. These men, who in the past had been placed on programs and medications to reduce their aggressive behavior, allowed the wrestling and boxing to occur without resistance. They were intimidated by the staff, who often made decisions for, and reports

about, them. The staff took advantage of the men's silence and hurt them in the process.

Institutionalization experiences are compounded by society's devaluing attitudes, stigmatization, and experiences of maltreatment, all of which lead to greater risk of abuse. Aggressive behaviors, self-abuse, and non-compliance are commonly treated with behavior management plans and psychotropic medications. Frighteningly, these behaviors are often the result of current and past abuse. Plan development and decisions about medications typically occur without the input of the individuals concerned, creating passivity rather than empowering individuals to advocate for themselves. Abuse in the lives of people with developmental disabilities has been well hidden by society (Baladerian, 1991). To add to this problem, caretakers establish a relationship that enhances dependency rather than self-determination, leading to increased vulnerability in people receiving services.

### **Assessment, Intervention, and Treatment Processes**

Assessment, intervention, and treatment of abuse are integrated processes. Each begins at the time of discovery. Health care providers can draw on their existing knowledge and experience for obvious cases of abuse, as well as input from people who can reliably communicate. Challenges to health care providers include abused people with slow neurological pathways, existing physical disabilities, and limited communication abilities; the lack of communication technology; and their own limiting perceptions about people with developmental disabilities. Liz's story, of abuse by a caretaker, is used as an example of assessment, intervention, and treatment in action:

Liz was a 28-year-old woman with developmental disabilities, living in a group home. She had been in an institutionalized setting all her life. Caretakers worked varied schedules and often did not stay with the job long. Liz could sometimes come in contact with 10 or more different staff in a year, making continuity and predictability of meeting her needs and getting to know her a difficult task. A sheltered workshop was where Liz spent her days. In the evening, she helped with household chores, occasionally going to the movies or out to dinner. Left alone, she could not adequately care for herself. Liz had a long history of aggressive behaviors,

hitting and kicking people when frustrated. Although Liz could make several sounds, she did not form words. Infrequent gestures, some sounds, and changes in her facial expression or behavior gave her caretakers clues to feelings and thoughts. A few years ago, Liz's behavior began a subtle change. At first, the staff, who had worked together about a month, did not know why. Then Liz began spurts of crying.

At this point, assessment began by the staff. Liz could not say what was happening. She had a history of problem behaviors with no staff person available who knew her well enough to help interpret these changes. She did not have involved family members, friends, or housemates who could help get or give information. Staff from work were able to talk about Liz from their experiences. People with developmental disabilities have varying abilities to communicate; a lack of verbal communication does not equate a lack of comprehension. Asking Liz about her feelings and thoughts gave her an opportunity to try to communicate in another manner about what was happening.

Impaired neurological pathways slow information processing, but a person can still understand some, if not most information. The assessment process must be slowed to allow for comprehension and response. Enfield (1992) recommends obtaining information from as many sources as possible, and planning several time-limited interviews. Questions should be short and concrete, requiring brief answers. Language used should be familiar to the person and level of development, spoken in a tone of respect. Nonverbal responses are very important and can include facial expressions, posture, body tension, emotional responses (such as crying), tactile defensiveness, activity level, and personal boundaries. Interviewers should also assess for low muscle tone, which decreases intensity in a person's facial expression and body language.

Medical histories and records became a focus for information for Liz. What had happened in the past to cause similar behavior? Who had the most accurate information? When people are institutionalized and change living situations, their records do not always follow them. Histories may be inaccurate, influenced by people's feelings and perceptions at the time of writing. Change in health care providers affects the continuity of information if those providers do not or can-

not communicate with each other. Accurate information is a key element in discovering abusive behavior.

Back to Liz's story:

At the time of Liz's behavior change, the staff reported they were concerned about interactions between Liz and Ralph, a staff person. At times, Liz was aggressive toward Ralph and would hit him. Approaching him with affection later, she sat on his lap laughing. Within a day of the reported staff concerns, Ralph received training about appropriate interactions with Liz and received instructions regarding the agency's abuse policy. Ralph made excuses for Liz's behavior change, saying she had been "aggressive" in the past. Liz's crying increased.

An important aspect of assessment, intervention, and treatment is recognition. Persons who provide care to individuals must be trained to recognize signs and symptoms of abuse. If the cause of changes in a person's behavior is not viewed within the context of the environment, an inaccurate clinical diagnosis may be assigned. People with developmental disabilities may need more time to respond because of impaired information processing. If someone has no means to talk, is feeling afraid, frustrated, angry, or helpless, and is unable to influence others, then it may be necessary for that person to use actions to attract the attention of someone who can help. People may be ignored for "acting out" because they "just want attention." Instead, caretakers should carefully investigate for causes of behavior change. Behavior as a means of communication is often minimized. This could have happened to Liz and probably had in the past.

Sobsey and Doe (1991) recognize a need for independent advocates for people with developmental disabilities. Advocates are important to an individual who does not communicate clearly and whose comprehension level cannot be determined. Advocates are significant contributors in an abuse investigation, especially if they are not affiliated with service providers. Advocates may be family members, friends, staff persons, housemates, fellow employees, employers, consultants, or others, as suggested and agreed upon by the individual. Joyce (1992) states that if a person receiving support requires and/or desires to have someone speak on his or her behalf, because he or she is unable to communicate wishes fully, then one or more advocates could be involved in the process. Advocates should

know their person well enough to understand and discuss his or her needs and should convey the individual's desires clearly, even if those desires differ from what the advocate thinks may be best for the person. Having more than one advocate increases understanding of a person's wishes, needs, and problems. Even when advocates are involved, it is important for others who care about a person to try to understand what the individual is communicating, despite the level of verbal proficiency. Involving several people during assessment, intervention, and treatment increases the reliability of information shared and reduces risks to the person if an "advocate" is also an abuser.

What information is obtained from an advocate? Advocates should be asked questions usually asked of any victimized person. If the abused individual is present during the interview, and he or she should be, respect and tact are required in discussing the person and these very sensitive issues. A written description of what has happened and how present behavior compares with normal behavior is very helpful. Data compiled about behavior change and symptoms of abuse observed over time must be requested when caretakers are involved. Assessments completed by consultants, such as nurses, psychologists, social workers, speech therapists, physical therapists, and occupational therapists, provide valuable interdisciplinary team information. Finally, an assessment is based on observations and questions. Even if the victim does not talk and seems to lack comprehension, staff can trust their observations of a person's behavior to communicate feelings and information.

Liz's story continues:

Along with training, Ralph's supervisor observed his job performance carefully. One day later, Ralph was found with Liz in her bedroom. She was upset and crying again. Liz was in a "compromising" position, with clothes disheveled, and Ralph adjusting his trousers. Ralph was removed from the job site. Staff whisked Liz off to the emergency room for a rape examination. The police were notified and began an investigation.

The staff person who accompanied Liz to the emergency room came prepared with information to communicate to the health care providers and police. Liz was not able to speak for herself. Would the health care providers and police be prepared for Liz and her

challenges? In fact, they were caring and patient, using the information brought by the staff person. Yet their ability to elicit further information was affected by a lack of knowledge about people with developmental disabilities and their limited options for effectively communicating with Liz.

Assessment began at Liz's home when staff researched past problems through medical records and with documented and recalled observations of Liz and Ralph. Intervention began as soon as they felt concern about Ralph's interactions with Liz. Assessment continued in the hospital, and treatment for physical effects began as well.

To determine the best psychological and emotional treatment, health care providers should consider factors that contribute to symptoms and severity of abuse. The TRIADS checklist developed by Burgess, Hartman, and Kelley (1990) assists in determining severity. The TRIADS checklist evaluated types of abuse, the autonomic response of the individual abused, duration of abuse, and style of abuse. Compiled information is used to develop a plan of support.

Now for the end of Liz's story:

The police completed their investigation, and Ralph could not be prosecuted. There was no physical evidence, and Liz could not verbally describe all that had happened. The staff acted as Liz's advocates and helped stop this abusive situation quickly. Liz received minimal (because of her limited communication) counseling for a while afterwards. Ralph was dismissed from his position.

Reliance on "talking therapies" limits treatment of victims with developmental disabilities. Health care providers need to be educated by family members, advocates, staff, and/or speech therapists in other ways to communicate. Conversation is not the only means to provide and receive information. There are several methods of, and technologies for, communication that may help people with developmental disabilities consider and respond to questions. These methods can be crucial in an alleged abuse investigation. Talking may be supplemented by other types of language. Sign language is a commonly used form of communication. However, too few health care providers are fluent in signing. Drawing pictures can be a valuable tool, but many institutionalized people were never taught to

draw. The use of photographs or sketches can help with an individual who uses gestures to communicate. This idea works well when there are predictable questions and answers. Picture boards or books using pictures from magazines, drawings, or photographs also work well. It may take a little extra time to look through the pictures while asking questions, but the results make the method worthwhile.

Facilitated communication (FC) is a newly recognized means of asking and answering questions. FC did not exist when Liz had her experience, but she does use it now. FC involves pointing at letters, words, or pictures with touch resistance of a facilitator. Touch resistance occurs when the person points to a letter, word, or picture, with the facilitator pulling the person's hand away from the communication device, giving time for the person to make their next choice. Some people simply use a piece of cardboard with letters, words, or pictures to communicate a message. Others have hand-held pocket-size keyboards. More sophisticated devices are computerized, with a keyboard, tapes to print messages, and voice output. Bilken (1993) describes FC as physical support that ranges from providing resistance to a person's hand and index finger to periodic taps to the shoulder. Lapos (1993) relates that some people who use FC are becoming independent in typing. Wheeler, Jacobson, Paglieri and Schwartz (1993) note that FC is useful for individuals who have "profound" or "severe" developmental disabilities. They go on to say that research is recent and limited. Further testing and validation are required.

The preceding case displays a variety of challenges. Forms of communication, perceptions of staff and health care providers, interpretations of behavior, and neurological implications are focal points. Individualizing efforts and broadening the scope of observations can resolve many challenges presented in the assessment, intervention, and treatment process.

### **Prevention As Assessment, Intervention, and Treatment**

Prevention is the key element in assessment, intervention, and treatment. Prevention is especially important because 90% of abuse does not result in treatment for individuals (Baladerian, 1991). Baladerian (1991) says that vulnerability to victimization must be addressed in prevention and balance with the opportunity to take

some risks. Always protecting people from experiences does not protect them from abuse. Keeping people out of institutions, however, does reduce the risk of abuse. Teaching people merely to comply with therapeutic interventions and requests of caretakers increases the possibility of abuse. Essentially, people are taught to accept things that are helpful—or potentially hurtful. The key is to teach people to balance compliance with assertiveness in following directions and making decisions for themselves. People should be involved in the development of their own therapeutic interventions. Sobsey and Doe (1991) recommend developing a culture that supports victims, eliminates abuse, and supports those people who report alleged abuse. All people should be educated about abuse and what they may do to stop it.

Creating societal, familial, and organizational cultures that support people with developmental disabilities in advocating for themselves minimizes the effects of institutionalization. As long as such people are perceived in a devalued manner, abuse will persevere. Society, families, and service providers have diversified ideas about how people with disabilities learn to live in the world, some more optimistic than others. Developing a culture that focuses on learning and competence and is influenced by respect for diversity will help these people to resist and, when necessary, report abuse.

Creating a culture that encourages diversity begins with a set of humanizing principles and goals, which are the building blocks of support. Barol (1990) describes goals for professionals in working with the person with developmental disabilities. These goals may be applied in all situations, including school, work, family, and health care settings. Professionals are responsible to provide adequate, proper, humane, and individualized care; planned habilitation and treatment; and respectful consideration of personal dignity and integrity of a participant (Barol, 1990). It is necessary to include care that is sensitive to cultural differences in the least restrictive or intrusive manner, is in line with prevailing community standards, and is designed to encourage individual competencies (Barol, 1990). The first step in accomplishing these goals is to believe that individuals with developmental disabilities have the right to understand and to be treated with as much dignity as all other well-respected persons.

Change in expectations and attitude contributes to success in prevention of abuse.

## Conclusion

Living with a label has dramatic effects on people, especially people who have been or are institutionalized. They are economically deprived, have little credibility, lack opportunity for self-determination, depend on others to meet their needs, have limited access to resources, and are taught to be compliant (Crossmaker, 1991). Keeping people from being institutionalized reduces the risk of abuse. Institutionalization is directly related to being labeled disabled. Consider the word “disability”: The prefix “dis” is defined as an “absence of,” and the word “disability” is defined as an “incapacity” (Webster, 1988). A seemingly more appropriate prefix to the word “ability” is “dys.” Webster (1988) defines “dys” as a difficulty. In persons labeled with developmental disabilities, it is more accurate to define disability as a difficulty with an ability rather than the absence of an ability. When presenting for health care service, such persons have often had labels become the focus of intervention rather than underlying factors or past victimization (Crossmaker, 1991). Labels can be changed.

Consider Jeff's situation:

Jeff was 33-year-old man with developmental disabilities. He often abused himself by pulling his hair. For years, his self-abusive behavior was attributed to chronic anxiety. Jeff did not speak except to repeat other people's words or sing. He had autistic characteristics. A couple of years ago, Jeff tried facilitated communication using a computer. The staff were surprised by the depth of his feelings and observations. At first, he needed a lot of touch resistance, but he gradually became nearly independent in typing, requiring touch to his shoulder only. Over a period of time, Jeff's self-injurious behavior dramatically increased. One day the staff sat with him and asked what was wrong. Jeff said that his back hurt. At first, the doctor diagnosed him with arthritis in his back, possibly because of an injury or blow to the back. Medication was ordered. Jeff persisted in reporting pain using FC. Staff arranged another appointment with his doctor, who ordered further diagnostic tests. Jeff had a kidney dysfunction requiring immediate surgery.

Without Jeff's use of FC, the staff and health care providers could not have made an accurate diagnosis. Anxiety and self-abuse would have continued to be his primary diagnosis until Jeff's medical condition became more serious or even terminal. With his newfound ability to "talk," Jeff became empowered to report accidents, illnesses, and even abuse. He participated in decisions about his care, and the staff and health care providers began to respond to him differently. The difference was that they now recognized his abilities because he could "talk" to them. Jeff had been thinking and feeling all along.

Health care providers have the skills required to assess, intervene, and treat abuse in persons labeled developmentally disabled. Abuse is insidious in its presence in our society. Recognizing signs and symptoms of abuse can influence the discovery of abuse in people with developmental disabilities and allow for quick and germane action. Such people can be taught to "speak" for themselves so they are not dependant on others to interpret their actions. Sometimes referrals are not made for treatment because of a belief that individuals with disabilities do not comprehend their experiences and therefore do not have emotions or thoughts to respond to abuse or other experiences. This is a matter of confusing people with preconceived ideas of health care providers and labels. Underlying cultural beliefs that devalue people are the most difficult to transform, but health care providers do have the capacity to change these beliefs. The ability to treat an abused person with disabilities is limited by perceptions, not skills. As prevention and treatment programs develop, people who receive support services can be empowered to fight abuse through their participation in the development of the programs. Individuals with disabilities must be encouraged to be involved in the development and delivery of the services they receive. These services require attitudes and actions of flexibility, accessibility, and integration.

It is the health care provider who, through his or her own sense of worth, empowers others to take action for themselves. Humanistic principles are the driving force that imparts strength and courage to accomplish these actions. The battle to increase self-determination and decrease victimization is ignited through creative communication, assertiveness skills, increased research, expanded literature, and involvement of advocates. People with a wide range of developmental disabilities

who have been abused can, with the knowledge, support, and respect of their health care providers, be successful in the assessment, intervention and treatment process.



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## Assistive Technology: A Positive Approach for People With Developmental Disabilities

by Diane Nelson Bryen, Ph.D. and Donna DiCasimirro

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*Technology is a lot like freedom. . . . Once it's uncorked, there's no putting it back. Its fruits are there for everyone's enjoyment and benefit. It is often said that assistive technology is liberating [for the individual with a disability] and that is certainly the case. But it is time to be clear that assistive technology is liberating not just for the individual with a disability but indeed for America as a whole.*

—Williams, 1991

### Assistive Technology: A Positive Approach?

Assistive technology is one of the most tangible and accessible, but sadly enough, not always the most obvious of Positive Approaches.

To better appreciate how naturally assistive technology fits into Positive Approaches, both as a philosophy and as an application, consider the purpose of assistive technology. The Technology-Related Assistance for Individuals with Disabilities Act Amendments of 1994 (P.L. 103-218), collectively known as “the Tech Act,” states that assistive technology devices and services can help people with disabilities to:

- a) have greater control over their own lives;
- b) participate in, and contribute more fully, in activities in their homes, schools, and work environments, and in their communities;
- c) interact to a greater extent with people who do not have disabilities; and
- d) otherwise benefit from opportunities that are taken for granted by people who do not have disabilities. (P.L. 102-218, 29 USC 2201)

When you help people help themselves, when you assist a person in finding tools or devices that aid her in being more self-reliant and less dependent upon others, you help create a situation where that person feels more in control and less helpless. What could be more positive?

When reviewing the continuum of positive approach

supports (Barol, 1996) that impact upon a person's well being and self esteem, assistive technology fits into each of the supports as though it were custom-made.

**The Environment.** Do you have control in your home? Can you reach items on high shelves or in the back of the closet? Can you get in and out of your bed or shower without assistance? Do you have to wait for someone else to do those things for you? How frustrated or angry do you feel when your body does not cooperate with your mind and spirit? Most of us have experienced loss of control at some point in our lives. Fortunately, such occasions are usually temporary. When they are not, we ask someone to help; we try to contrive a technique, to rig up some gadget or device, or simply modify the environment to compensate for what we need. We look for an appropriate alternative—a Positive Approach to compensate for some functional limitation that cannot be “fixed” itself.

This same Positive Approach should also be considered for a person who has a developmental disability, especially an individual with challenging behaviors. Simply creating a “friendly environment” can be the first step in helping the person gain (or regain) control of his life. That friendly environment can include a *reacher* for a woman who cannot get to a high shelf. It can include grab bars or a shower chair for the man who cannot get into or out of a tub without support. These assistive devices are not necessarily “high tech”—nor are they necessarily expensive. What they need to be is available to and functional for a particular person in his or her own setting.

**Communication.** Historically, communication is probably the most widely discussed area in the fields of challenging behavior and assistive technology. Sometimes we simply, truly miss what the person is saying, or trying to say. Just about anyone who has supported a person with challenging behaviors has asked herself: “What is he trying to tell me with this behavior?” Those who work with persons who do not use typical spoken communication often try to find an alternate or additional technique for communication. When a successful technique (or device) is found for the person

who has challenging behaviors but does not speak, it is an enormous breakthrough. However, despite good intentions, we sometimes forget that communication is something that happens all the time, day and night. Does the individual have the opportunity to express preferences? To make choices? Do we make sure that the person has access to and actually is encouraged to use that alternative or augmentative device at home, at work, and during leisure? Do we make sure that everyone who supports the person knows how to use the technique or device? Frustration and accompanying expressions of frustration, are almost inevitable if we fail to facilitate the use of the technique or device in all communication settings.

**Assessment.** Ongoing assessment is a “given” when supporting a person with developmental disabilities, especially when that individual has challenging behaviors. We must continually assess whether or not the individual is responding as expected to his environment, her physical state, his emotional life, or her current medication. If not, we look at whether changes in any part of the person’s life could or should occur. When we are supporting a person who uses assistive technology, we ask the same questions. Does the communication device meet the person’s needs? Does the person want or need something more sophisticated or less cumbersome? Are there environmental controls or devices which the person can now benefit from that he may have not needed in the past? Are there possible new assistive technology solutions that may not have been available previously? Has the environment changed? If so, what is the impact? Assessment is an ongoing activity simply because people and circumstances change. Assistive technology can allow a person to gain or regain control over events in his or her life and thereby reduce the potential for frustration and its manifestations.

**Hanging in There.** Change is inevitable. Today’s stellar work or “best practice” can be tomorrow’s average work. A commercial for an investment company talks about “measuring success one investor at a time.” We can take that advertisement quite literally when supporting people with challenging behaviors. We invest in one person at a time—the whole person—and look at what he or she wants and needs to feel in control of his or her life. The answer may be a person to talk to or an assistive communication device to help that individual communicate. It probably won’t happen

overnight. It will require commitment and patience on the part of the person and his or her support team. But the investment is worth it.

Most people would fully agree with the Congressional findings supporting the 1997 reauthorization of the “Tech Act” presented in the beginning of this article. However, many providers and advocates still do not fully appreciate assistive technology as a *Positive Approach* for people with mental retardation or other developmental disabilities.

The purpose of this article is to begin to highlight the role of various assistive technology devices and service in improving the lives of children and adults with mental retardation.

### **Benefits of Assistive Technology for Children and Adults With Disabilities**

Clearly assistive technology has made a difference in the lives of many children and adults with disabilities. In 1993, the National Council on Disability conducted a 19-month survey to better determine the cost/benefits of assistive technology devices and services. The following are some of this study’s findings:

- Almost three-quarters of school age children with disabilities were able to remain in a regular classroom and 45% were able to reduce school related services.
- Sixty-two percent of working-age persons were able to reduce dependence on family members, 58% were able to reduce dependence on paid assistance, and 37% were able to increase earnings.
- Eighty percent of elderly persons studied were able to reduce dependence on others, half were able to reduce dependence on paid persons, and half were able to avoid entering a nursing home.
- Almost one-third of assistive technology users indicated that their family saved money, averaging around \$1,110 per month, with assistive technology. At the same time, one-quarter of the users indicated that they experienced additional equipment related expenses that averaged around \$287 per month.

- Of the 42 users of assistive technology who reported having paid jobs, 92% reported that the assistive technology enabled them to work faster or better, 83% indicated that they earned more money, 81% reported working more hours, and 67% reported that the equipment had enabled them to obtain employment. 15% indicated that the equipment enabled them to keep their jobs.
- When asked to estimate the impact of equipment on their quality of life, assistive technology users reported that without the equipment, their quality of life on a scale of 1 to 10 was about 3; as a result of the equipment, it jumped to approximately 8.4 points (National Council on Disability, 1993, 1-2).

The results of this study certainly underscore Williams's (1991) position—that assistive technology is liberating not just for the individual with a disability but indeed for America as a whole. Let us now turn to the use, needs, and experiences of Pennsylvanians with disabilities.

**Assistive Technology and the Lives of Pennsylvanians With Disabilities**

In 1994, Pennsylvania's Initiative on Assistive Technology (PIAT)—Pennsylvania's "Tech Act" Program—conducted a statewide consumer survey. More than 1,000 surveys were disseminated; 372 (51% person with a disability, 15% a parent or family member, 22% a friend or representative, and 11% other) were completed and returned to PIAT. Of the respondents, 72% were adults with disabilities and 44% had a developmental disability.

When asked, "During the past 2 years, how has assistive technology equipment or services helped you?" the following responses were obtained:

Helped me:

Be included in school	38%
Be included in the community	56%
Become more independent	72%
Get a job	23%
Get a better job	14%
Decrease reliance on personal assistant	52%
Increase quality of life	75%

Based on this data, assistive technology is certainly a Positive Approach for many Pennsylvanians with disabilities. Assistive technology devices used and/or needed by these 361 Pennsylvanians included:

Assistive Technology Device for	Used	Needed
Communication (electronic or manual boards)	32%	10%
Mobility (wheelchairs, walkers, crutches)	74%	4%
Hearing or seeing (hearing aids, reading machines)	30%	11%
Writing/reading (books on tape, computers)	38%	17%
Doing things at home (switches, adapted appliances)	35%	22%
Recreation (remote controls, adapted equipment)	32%	22%
Personal Care (adapted toilets, shower bars)	54%	14%
Transportation (modified cars, bus lifts, ramps)	60%	10%
Help do a job (adapted work equipment)	33%	17%
Help with school (tape recorders, computers)	36%	14%

The results of the 1994 Consumer Survey for Pennsylvanians include three major findings:

- 1) Assistive technology has had a positive impact on the lives of Pennsylvanians with disabilities. It has enhanced quality of life (75%), allowed greater independence (72%), and resulted in more inclusion in the community (56%).
- 2) While a large percentage of people have obtained assistive technology that is helpful to them, 68% of those responding to the survey still do not have the assistive technology that they need.
- 3) There are two main reasons for not having the needed assistive technology: (1) expense and (2) difficulty in determining what specific technology is needed.

Based on the data provided nationally by the National Council on Disability (1993) and the data provided for Pennsylvania by PIAT (1995), assistive technology devices and services is no longer just a promising approach. For many people with disabilities, including those with mental retardation and other developmental disabilities, assistive technology is clearly a *Positive Approach*. The key is to clearly identify the problem and to seek the answer to the question—Is there an assistive technology device or service that can help?



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For more information about assistive technology devices and services, call Pennsylvania's Initiative on Technology (PIAT) at 1-800-204-PIAT.

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## Helping People With Mental Retardation and Mental Illness— An Interwoven Fabric

by Terrence McNelis

My drive home takes me west from Philadelphia along the Pennsylvania Turnpike for approximately 12 miles. On crystal-clear winter evenings I can see a series of twinkling lights that trails across the sky from the horizon to directly overhead. They are definitely not stars: They are too close, and they move. The first time I saw this phenomenon I was puzzled. After a few minutes the simple explanation for this apparition came to me. I was observing the lights of incoming planes in holding patterns near Philadelphia International Airport.

Subsequent to unraveling the mystery of the skies I began to think about the process involved in figuring it out. First, the problem could only present itself after dark. Planes fly in holding patterns all day, but I only saw their running and landing lights when contrasted against the sky. Perhaps more importantly, I needed a *construct* that allowed me to place the sighting of the planes within some *understanding*. I needed to know that there are such things as planes and that they fly. I needed to know that they fly at night with lights on, and I needed to know there was a thing called an airport where planes land. I also needed to know about holding patterns. There are probably many more things that I needed to know about, but I think the point is now clear: Before we can begin to understand a relatively simple concept we must be able to place it within a frame of reference.

As we attempt to help people with mental retardation who are also afflicted with mental illness we must also put our approach within a frame of reference—within a context. Singular approaches not only don't assist in revealing the pattern, they may obscure it. Over the last two decades we have come to recognize that persons with mental retardation may also have a mental illness. This is a major change from earlier notions that suggested that people with mental retardation were immune to mental illness or lacked the depth of feeling necessary to experience it. Behavior that might be attributed to mental illness was said to be a function of mental retardation. As anyone who has worked with individuals with mental retardation knows, most can lead healthy emotional lives. We also know that they are subject to the same ups and downs as we are.

Recent epidemiological studies indicate that 20 to 33% of persons with mental retardation will suffer from some form of mental illness during their life. This recent conceptual breakthrough has helped some people, but not as many and not as much as had been hoped. My sense is that this is because we have not woven the cloth. This primary recognition is only one thread in the total pattern. We must develop a design that will allow us to weave a cloth.

### Values and Principles

Independent of whether the person has mental retardation, mental illness, or both, we must bring to the situation a set of values and principles: They form the foundation of our construct. Services and supports have grown dramatically in the past twenty years. Despite this significant growth, persons with dual diagnosis have seldom been fully supported. Quality must be built in from the onset. The essence of excellent supports is based on the identification of and adherence to a set of values and central principles. Adopting this core of beliefs greatly increases the level of quality. The person with disabilities is worthwhile; that person's power is important: these are the values that must be embraced. We must respect that person's family and commit ourselves to work with them.

The first core principle is *informed choice*. The essence of true choice comes from having a variety of options. In addition, the individual supported should have an understanding of the ramification of the choices that are being made. The viability of our support may very well hinge on our ability to develop choices for the people we are trying to assist. The second principle is that of *empowerment*. Empowerment is not something we can grant to individuals with mental retardation and mental illness; rather, it is their inherent right. It is our role to encourage the use of this inherent power and remove any impediments to its use. As a third principle, *inclusion is a right of all people*. It is important for people with mental retardation and mental illness to be integrated in the community to maximize their opportunity for growth. The fourth principle is that of *responsive and flexible support*. The supports need to be comprehensive and as intensive as the person needs.

### Assessment Skills

We need to develop a good set of assessment skills if we are to effectively support persons with mental retardation and mental illness: This is our second thread. We need to expand our concept of functional analysis. This expansion needs to be biopsychosocial in breadth and contextual and functional in depth. When assessing people we must be willing to look for the biological causes of behavior before all else. We must ask ourselves if there is a medical reason for what we see. Does the person have a chronic stomach problem that irritates them to the point of aggression? Is there a neuropsychiatric reason why we see the behavior? Is the behavior we see in the person related to pre or post seizure time frames? Does the person have an underlying affective disorder? Are they depressed? Is what we are seeing a function of their depression rather than manipulative behavior? Is what we are seeing a function of the individual's medications? These are examples of a biological basis of behavior. We must first look at these causes of behavior, and only then can we investigate psychological and socio-environmental influences. As part of the assessment we must look at how the person communicates with their environment in the here and now. It is important to know the "history" so that we do not commit mistakes over and over again, but we should not let it predict our present evaluation. We should be aware of any psychological vulnerabilities that may be present. Was the person subject to any deprivation or abuse that would make them more vulnerable to an emotional disorder? Have there been any recent or traumatic losses in their lives? Are there any other life events that may increase this person's vulnerability? Finally, we should look at the socio-environmental factors that could be stressors on the person's life. Have we looked at the physical environment in which they spend their days? Do they have friends? Do they like who they live with? Do they get along with the staff? Is the staff able to support the individual? If the person is in a program, does he or she like it? Does it match their needs? All these questions and many more must be answered to perform an accurate assessment and allow us to work together as a support team. To recapitulate: The assessment must focus on the person and highlight the person's capabilities. It must also search for natural supports and recognize and seek out family cooperation. And, lastly, the assessment must embody hope and be open ended.

### Viable Treatment Approach

The treatment approach should reflect the assessment plan. It must be comprehensive in nature and involve all the transdisciplinary players. It must involve the individual and must never lose its consumer focus. Recent advances in medicine and neuropharmacology have brought the team to rely too heavily on the medicines being prescribed. There are substantial gains in the arena of biological psychiatry, but there is no silver bullet that will cure a person independent of all the other components of the support plan. There certainly have been dramatic advances in the medical treatment for mental illness, but these advances require an increased use of effective treatment techniques, not a reduction. Prescription of medications is a science; it is also an art. There is no "one size fits all" treatment that is effective for every person with both mental illness and mental retardation. There still remain many unknown parameters regarding how people process medications, how their ethnicity affects metabolism, and how particular medications interact with different body systems. It is essential that members of the support team be able to communicate effectively with the treating psychiatrist to insure accurate description of symptoms, which in turn ought to assure correct diagnosis and correct prescription of medication. Persons with poor verbal communication skills depend on staff and family to communicate. Positive Approaches and a person-centered philosophy have helped individuals immensely in enjoying a wider life: These, in concert with a biopsychosocial approach, bode well for the people we serve.

### Consumer and Staff Oriented

The thrust toward a person-centered orientation has greatly enhanced our ability to support persons with poor reputations in the community. Careful analysis suggests that there is a correlation of staff centering that must also be in place. A recent article published in the AAMR Journal, found that the turnover rate for community residential facilities was 65% and 73% for homes serving people with "challenging behaviors." This statistic strongly suggests that although we may want to be consumer focused, we need to come a long way to realize our dream. To provide supports to the people with dual diagnosis we must also provide supports to the staff providing that support. As we carefully analyze challenging behaviors of persons with disabilities, we must just as carefully pay attention to the

needs of staff. Most often, direct care staff who are energetic and dedicated are placed with the most challenging persons. What sort of biopsychosocial approach is taken to support these personnel? Do they have the physical ability to handle the most challenging behaviors? Do the administrators offer a planned respite for the staff? Have the most basic needs of staff who are working double shifts in extraordinary situations been met? And, have we considered the maturity level of these personnel? Are they seasoned professionals trained and skilled in dealing with mental illness? Or do they consist of good intentions and concern, and an inability to discern between mental illness and grumpiness? Finally, we must consider the social matters. A 73% turnover rate suggests that challenging behavior flows into the social sphere of the staff. Can residential staff plan special occasions with their families when life runs amuck in the residence? What safeguards and backup systems can we build into programs to assure that challenging behaviors will be handled appropriately, aggressively, and via the correct process?

As science advances with synthesizing specific medications for particular disorders, the rest of the field must reassess and re-design specific staff programs for staff who work with individuals with mental illness and mental retardation who also display challenging behaviors. We must provide competency-based training and consultation along the way. We must pay attention to other psychosocial needs of staff and be prepared to meet them with flexible work schedules, respite assistance and non-blaming perspectives.

Mental illness is an equal-opportunity affliction, and we must be prepared to assist persons with disabilities and staff with precepts of prevention. We must assure that state of the art diagnosis and treatment exists for the person and state of the art administrative support exists for the staff. The field of dual-diagnosis is only 15 years old; it is in its adolescence and many bumps have occurred along the way. At this point, we know that the most effective approach is biopsychosocial in nature and that the overarching paradigm is person-centered.

### **Diversion and Acute Capacity**

Our ability to provide support to individuals in crisis is the final thread in our therapeutic tapestry. This capacity, known as "diversion," involves supporting the person in their own home. This can be accomplished

through counseling, support to staff, and, if necessary, by assisting the individual by bringing in more specially trained staff. If this is unsuccessful, one must be able to provide out-of-home respite if this is indicated. All of these resources must be preplanned, and the individual served must be part of this preplanning. Often respite is in response to a crisis. This not only significantly reduces the success of the plan: It may actually increase the person's anxiety and exacerbate the challenging behavior. The goal of these "diversions" must be zero inpatient hospitalizations. If all of this fails then our goal must be to make the hospitalization as effective as possible while reducing the stay to the minimum. This requires increased expertise on the inpatient side and better capacity on the community side.

### **Summary**

The cloth is now woven and we can begin to see the pattern. The best practices for supporting people with dual diagnosis derive from a value system that forms a foundation. We must be willing to spend the time necessary to accurately assess the individual. Don't accept the working diagnosis unless it is working. Much of the information is there if we ask the right questions. Based on an accurate assessment, plan the treatment supports. Do not design the treatment plan and then make the assessment fit the plan. Maintain the focus on the person being supported. Part of that focus must be on the people that are most important to the success of the plan: These are the direct care staff, who must also be supported in order for there to be success. Lastly, the ability to offer respite and a hospital unit must be based on the needs of the individuals we are attempting to serve.

All of this must occur on the provider, county, and region level. There have been some advances in the western part of our state, and of this we should be proud. We need to see growth across the state so that more of our citizens can enjoy fuller and richer lives.



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- ▲ Anyone involved in supporting people with developmental disabilities and/or mental retardation is encouraged to submit case studies and highlights of specific practices or tools that promote or describe Positive Approaches. Administrators or programs (private, state, county, local) are also encouraged to submit manuscripts discussing regulations and their implications and interpretations as they apply and impact upon Positive Approaches.
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