

Developmental Disability Chapter

Introduction

Developmental disabilities are distinguished from other disabilities as imparting a level of cognitive impairment unlike other impairments. This is formally defined as “a diverse group of severe chronic conditions that include cognitive and/or physical impairments. People with developmental disabilities have problems with activities such as language, mobility, learning, self-help, and independent living. Developmental disabilities begin anytime during development up to 22 years of age and usually last a person’s lifetime,” (National Center on Birth Defects and Developmental Disabilities, 2005). Since developmental disabilities affect children at such young ages, early identification is critical. Healthcare providers in 2002 screened 86 percent of insured children and 71 percent of uninsured children, thus offering them a better chance at a healthy life (White 2005).

The services, funding streams and even quality of life can be very different for people with developmental disabilities, hence the separate chapter. The Maricopa Association of Governments makes recommendations to the Department of Economic Security for Social Service Block Grant funding in this area as well. Since the money available for these services has not increased and indeed has been reduced over the past years, strategic planning takes on new importance. The needs are many, the dollars are few, and the choices are painstaking. This planning process helps to allocate funds in the most responsive and responsible way possible.

The development of this chapter includes extensive research in the field, consultation with local experts and community input from people with developmental

disabilities, their families and the agencies who provide them services. Two focus groups were conducted at the Marc Center in Tempe and at United Cerebral Palsy in northern Phoenix with a total of 30 people. Their feedback, along with other factors, has helped to shape this discussion. We owe a debt of thanks to the providers and funders who help to improve the lives of people with developmental disabilities. We also owe the focus group participants many thanks as well for sharing their experiences for the benefit of all.

This chapter will first offer profiles for the four groups included in the category of developmental disabilities as defined by the state of Arizona: autism, mental retardation, cerebral palsy and epilepsy. Next, a discussion of the history of institutionalization and integration into the community will follow. The strengths, challenges and solutions as identified particularly by people in the MAG Region will be offered next. The conclusion will summarize the main points and close the discussion.

Profile

Autism Spectrum Disorders (ASD): This is actually a grouping of developmental disorders that cause brain abnormalities. These conditions, autistic disorder, pervasive developmental and Asperger disorder, all exhibit the same symptoms but in varying degrees. Symptoms include difficulties with social skills when people don't necessarily want to interact with others or have trouble expressing their feelings. These disorders will also manifest in speech, language and communication difficulties. This includes repeating back something that has been said, volume control and not understanding gestures. Repeated behaviors and routines are commonly associated with these disorders as well. Children exhibiting these symptoms will develop differently from other children while

also sharing similar progress in other areas (National Center on Birth Defects and Developmental Disabilities, 2005).

Rates of autism are increasing, but researchers are unclear if this is the result of more prevalence or simply better diagnosis. Nationally, two to six individuals per 1,000 have ASD, or about 500,000 people aged 0 to 21. In Arizona, there were 1,213 children enrolled in special education classes in the 2000-1 school year. This is roughly 14 percent of all children enrolled in special education classes. While this rate is lower than the rate for mental retardation, it is higher than the rate for children with cerebral palsy, making it the tenth most common form of developmental disability. (National Center on Birth Defects and Developmental Disabilities, 2005).

While genetic and environmental factors are cited as causes, scientists have yet to confirm this through research (National Center on Birth Defects and Developmental Disabilities, 2005). The Southwest Autism Research and Resource Center (SARRC) and the Translational Genomics Research Institute (TGen) in Phoenix have embarked on a partnership to further this research. Currently, all healthcare professionals and pediatricians in Arizona receive a screening kit for use with all 18-month and 24-month well-child exams. Early treatment can have tremendously positive long lasting effects (Melmed, 2005).

Mental Retardation: This cognitive disability is identified by below average test scores and a limited ability to function in every day life. People with mental retardation will struggle with communication, self-care, school and socialization. Symptoms will range from being mild to profound. A child can develop mental retardation anytime before reaching 18 years of age. While the cause is not known, it is often associated with

an injury, illness or brain abnormality. It can be caused before birth by conditions like Down's Syndrome and fetal alcohol syndrome. Other conditions can cause mental retardation directly after birth, like a baby being too jaundiced, or having kernicterus (National Center on Birth Defects and Developmental Disabilities, 2005).

Mental retardation is one of the most common developmental disabilities, affecting over 1.5 million children nationally. The mild forms are three times more likely to occur than severe mental retardation. Especially in the severe range, people with mental retardation will need long-term services and assistance. In 2003, it cost \$1,014,000 to care for just one person with mental retardation. Lifetime costs for all people with mental retardation is estimated in 2003 dollars to be \$51.5 billion (National Center on Birth Defects and Developmental Disabilities, 2005).

Cerebral Palsy: This refers to a group of disorders affecting one's ability to control posture and balance. While this is caused by a non-progressive brain abnormality, meaning it will not worsen over time, symptoms may change over time. There are four main kinds of cerebral palsy. Spastic cerebral palsy is the most common and affects 70 to 80 percent of people with this disorder. This kind makes movements awkward as the result of increased muscle tone. Athetoid or dyskinetic cerebral palsy gives one uncontrollable slow, writhing movements in the face, arms and hands. People have the most problems with balance when they have ataxic cerebral palsy. Some people have more than one kind and are diagnosed with mixed cerebral palsy (National Center on Birth Defects and Developmental Disabilities, 2005).

Similar to other developmental disabilities, it is unclear if the prevalence of cerebral palsy is actually increasing or if increased awareness and diagnoses are

responsible for higher numbers. Studies have shown that 23 out of every 10,000 children had cerebral palsy. Of this number, 75 percent had other disabilities as well. Causes vary from prenatal events in the first six months and low birth weight to the most common causes: meningitis, child abuse and stroke. The average lifetime cost for care in 2003 for one person totaled \$921,000. While there is no cure, early diagnosis and intervention can alleviate the affects and in some cases, all symptoms disappear by the time the child enters school (National Center on Birth Defects and Developmental Disabilities, 2005).

Epilepsy: Also known as a seizure disorder, this condition affects the nervous system and is diagnosed after a person has at least two seizures that were not caused by another medical condition. Some risk factors for epilepsy include brain abnormalities, tumors or injuries, cerebral palsy, babies born small for their age, strokes, mental handicaps and use of illegal drugs. The following factors can bring on a seizure: missed medication, lack of sleep, stress, heavy use of alcohol or drugs, and nutritional deficiencies (Epilepsy.com 2005).

Epilepsy has a long and turbulent history. Throughout time, people with epilepsy have born the attacks and misunderstanding of others. In 1494, a book about witches cited seizures as a sign of the craft and authorized the killing of thousands of people with epilepsy. Later in the 19th century, people with epilepsy were kept in asylums apart from other patients for fear the condition was contagious. Just one hundred years ago, some states permitted people with epilepsy to be sterilized and forbade them from marrying or having children (Epilepsy.com, 2005).

While society has made tremendous progress in the treatment of people with epilepsy, misunderstanding and misinformation are still common. The seizures do affect

the brain, but they do not always cause brain damage. Most people also are not mentally handicapped, although in rare circumstances this does happen. Those who misunderstand seizures will at times mistake them for violent aggression or for non-compliance, which it is not. Many also assume that epilepsy is a lifelong condition, but very often people will grow out of it. Once a person is seizure free for one to three years, the person can be weaned off medication.

The next section will continue the discussion started in this section about institutionalization.

The History of Institutionalization

For years, society was ill equipped to provide proper care for people with developmental disabilities. According to local experts, this population more than any other has suffered from inappropriate institutionalization. In the early 1900's, people with developmental disabilities were forced to either live in institutions with usually atrocious environments, or live with their families with no financial support from the government. In both cases, people with developmental disabilities most often did not receive the appropriate treatment and opportunities we have come to expect today (Davis et. al. 1999).

Lawsuits in the 1960's brought much needed attention to the poor living conditions suffered by people with developmental disabilities. These class action suits coupled with an emerging advocacy movement increased the community's awareness and improved the settings in which people lived. These efforts did not however address the need for more service and housing options and did nothing to make service delivery more individually appropriate. This emphasis began in the 1970's as institutions were

challenged to release people who could live on their own with support and treatment (Davis et. al. 1999).

Many complied and there has been a 78 percent decrease since 1967 in the number of people with developmental disabilities living in institutions. People have transitioned into community settings in large numbers. Over a thirty-year period, the number of people receiving services in the community increased 26 times. States began closing institutions and began investing in community-based care. Only 56 percent of the institutions operating in 1960 remain open today (Lakin 2001). In 1999, advocates and people with developmental disabilities won an important case that would cement the future direction of integrating people with disabilities into the community (Donlin 2005).

The Olmstead case built on the progress initiated by the Americans with Disability Act (ADA). Congress affirmed in the ADA the responsibility of society to “assure equality of opportunity, full participation, independent living, economic self-sufficiency” for people with disabilities. Similar to Brown versus the Board of Education, the ADA asserted that separate is not equal. Two women with mental illness and mental retardation in Georgia brought suit against the state for restricting them to an institutional setting. Their doctors agreed they could live safely and productively in the community but the state refused to release them. The Supreme Court ruled in favor of the two women and set the course for the de-institutionalization movement (Lakin 2004).

This ruling requires states to provide community based care when the individual chooses this option. It does not require states to close down institutions, nor does it require that people be moved to community based settings when these settings are either

unavailable or cost prohibitive. States are expected to make “reasonable accommodations” and to ensure wait lists are not unduly long (Dolin 2005).

Change has been slow. Congress has authorized home and community based waivers through Medicaid so people can choose to receive services either at home or in the community instead of in an institution, thereby providing other treatment options for people with disabilities. Medicaid is still seen as having a bias toward institutional settings however and in 1999, over 75 percent of their funding supported institutions. While Arizona operates an institution that houses people with developmental disabilities, some states have closed all their institutions and rely exclusively on treatment models located within the community. The majority of states continue to place some people in institutions, even though the majority of resources now support community and home based supports (Donlin 2005).

The shift from institutions to community based care has challenged states across the country. Many have already committed funding for their institutions and even if they plan to close them and start community-based programs, they must run parallel programs for a time. Securing the funding to make this transition has been a barrier. When states plan to keep their institutions open and offer additional services in the community, there is seldom money to support both options. The institutions that currently receive funding lobby hard to protect their source of support. In addition, the technical expertise and commitment to make this transition may not exist. The 30 percent of states slowest to close their institutions now house 57 percent of the disability population in their institutions (Lakin 2004).

The de-institutionalization trend has placed more strain on community-based services to work with more people than ever before. Parents of children with developmental disabilities in focus groups conducted by MAG cited a critical lack of therapists. Research echoes this need as well. The wait lists for such services is typically quite long and as a result, some people living at home with developmental disabilities go without the assistance they need (The Arc 2005).

Despite these challenges, many people with developmental disabilities are receiving the care that is most appropriate for their needs and preferences. In the MAG focus groups, some people with developmental disabilities reported needing the support and structure of living in an institution. Others enjoyed the independence of living in the community. People also valued being able to live in smaller institutions with 15 or fewer people. In 1998, over 290,000 people nationally lived in facilities that housed 16 or more people. Today, less than 50,000 live in that kind of facility (Donlin 2005). This accumulates significant savings as services in community-based settings only cost about 27 percent of what institutions cost (The Arc 2005). The next section will continue looking at such strengths.

Strengths

In the focus groups, people with developmental disabilities commented enthusiastically about the strengths they saw in the local disability community. In doing so, they focused on three main areas: opportunities for self-sufficiency, caring people and the services they received- which often helped them to be self-sufficient and were provided by people who cared for them. Clearly, the support they received from the good people in their lives and the ability to support themselves made an indelible impact.

The chance to be self-sufficient often rests on at least two factors- the ability to make a living and the safety of one's home. Both were incredibly important to the focus group participants. No one asked for an increase in benefits or a fancier house. All wanted to maintain a job and to remain in their own homes. Many lived with aging parents and expressed concern about what would happen when their parents passed away or would no longer be able to care for them. Poignantly, many of the developmentally disabled adults are helping to care for their elderly parents. Due to this mutual support, both the developmentally disabled and the elderly are able to stay in their home longer because of each other.

Services often make this wish possible. Were it not for the job coaching they received, many of the people with developmental disabilities would not be able to secure or keep their employment. Residential services like therapy are also a critical element in ensuring their needs are met appropriately. Services received through the Marc Center and United Cerebral Palsy, like those offered at so many other agencies, make a significant impact on the lives for their clients and their ability to achieve their potential.

People with developmental disabilities specifically cited in-home and center based speech, occupational and physical therapy as being critical to success. Day treatment programs for children from birth to three years of age provided important socialization opportunities for children who are often not wanted at mainstream day care programs. Programs like the Division of Developmental Disabilities, Vocational Rehabilitation Services, Medicaid, Arizona Health Care Cost Containment System (AHCCS), and Arizona Long Term Care System (ALTCSS) were offered as some of the best practices.

At the center, caring people make services work well and offer people with developmental disabilities the opportunity to become fully integrated into their community. Focus group participants told countless stories of staff who worked for little pay but gave generously of themselves, the random stranger who assisted them in times of trouble and the bus driver who took the extra time to help them find their way. Such treatment helped people with developmental disabilities to feel better about their community and their place in it. In the next section, some of the challenges faced by people with developmental disabilities will be addressed.

Challenges

As much as strengths sustain them, the people with developmental disabilities that participated in the focus groups shared information about needs as well. These challenges include lack of funding for services, transportation, discrimination and intensifying needs. As important as the services are, they cannot be maintained without adequate levels of funding. For example, some cited the need for more one-on-one workforce training to help them transition from a sheltered work environment to a mainstream job. Others pointed to the lack of therapists and high staff turnover as contributing to the need. The older clients wanted to have more services tailored to their experience. As people age, their needs change and they need to services to evolve as well.

Good transportation helps people with developmental disabilities access available services. When transportation is not available or adequate, this leaves people isolated with unmet needs. Many simply need more instruction on how to use the bus. Others need Dial-A-Ride but struggle when crossing municipal boundaries that don't coordinate

schedules. This is frustrating for high functioning people, but can be dangerous for lower functioning people with limited resources.

As much as focus group participants found people who cared about them, they found just as many who ignored, excluded or harassed them. Sometimes discrimination offered opportunities for personal growth, but many times it made people with developmental disabilities question their identity as full people, doubt their abilities and withdraw from their environment. Parents of children with developmental disabilities recounted how some day cares and play groups would refuse their children or not know how to provide appropriate care, thereby increasing the need for socialization programs. Parents pointed out that children are taught discrimination, knowing the pain this had caused their own children with developmental disabilities. Others experienced discrimination in their own families. Older children shared how their parents took their “normal” children on vacation, leaving them at home with paid care providers. People learn a tremendous amount through observation, participation and engagement. When people with developmental disabilities are denied these opportunities, this affects their growth and sense of self.

Intensifying needs loom ominously in the future while affecting people with developmental disabilities today. This increased need is the result of a few different factors. First, many people with developmental disabilities are living longer but will require more care as a result. Their parents are aging as well and will not be able to offer this support in the future. With de-institutionalization, people want to remain in their own homes, creating a challenge when many states are still funding institutions (Donlin 2005). Local people with developmental disabilities cited stricter eligibility guidelines and

reduced funding for critical services as contributing to the intensification of need. Standardized system of care and funders with conflicting requirements fail to base services on individual needs and instead mandate services that may be inappropriate. When people cannot get the help they need when they need it, their needs fester and worsen. The next section will discuss solutions to resolve these needs.

Solutions

Constructive solutions exist and in some cases, are already in motion to resolve these needs. Companies like TGen conduct research that will be vital to improving the quality of life for people with developmental disabilities. Assistive technologies as discussed in the Disability Chapter help people to achieve normal levels of function and to interact more fully within their community. Medicine prolongs and improves the quality of life for people that never would have survived years ago. As a nation, we are implementing laws like ADA that provide protections for people against discrimination. Locally, programs and agencies offer services and supportive environments that embrace and assist people with developmental disabilities. Fundamentally, people are making a paradigm shift from relying on a cure to building a life. The solutions offered in the Disability Chapter are relevant for people with developmental disabilities as well. The focus for both populations is to break down the barriers that prevent people with any kind of disability from participating fully in society.

Conclusion

Whether one has autism, epilepsy, cerebral palsy or mental retardation, the need to belong to society as a valued person is the same for anyone who does not face life with disabilities. People with developmental disabilities reported many strengths, needs and

opportunities present here in the MAG Region. The challenge of the upcoming years will be to identify how we will care for people with developmental disabilities as they age, become more independent and are faced with more severe needs. Many agencies, both public and private, are dedicated now to this purpose. Many people, staff, private citizens and elected officials, have committed themselves to this goal. Working together, we can ensure everyone has a positive place in society.