

# Because “Mama” Said So: A Counselor–Parent Commentary on Counseling Children With Disabilities



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**This article, written by a parent of an adult child with spina bifida, invites counselors into the life experiences of children with handicaps and their families. The description of these experiences highlights current problems with the stigma this population experiences. The author describes the varying disability identities and orientations that have evolved within the disability culture and wider society. Counselors are encouraged to use unbiased terminology in both research and clinical work with children with disabilities. Solutions are offered for counselors to implement in practice and research to further overcome stereotypes, develop disability awareness and provide helpful counseling. The author provides practical interventions for a variety of challenges where counselors may be useful to children with disabilities and their families.**

**Keywords:** children, disabilities, stereotypes, stigma, handicaps

I am a counselor, a life coach and the parent of an individual with a disability. Since entering the disability community 28 years ago with the birth of my daughter, I have attended both workshops and seminars designed to assist parents concerning children with disabilities or chronic illness. In 2005, I attended eight monthly sessions of Partners in Policymaking, a national leadership training program for people with developmental disorders and family members of young children with disabilities, designed to achieve productive partnerships between people needing and using services and those who make public policy and laws. In this article, I provide information about children with disabilities and their family systems and offer recommendations for counselors working with children with disabilities and their families.

## Disability Identity and Orientation

I use the term *disability* in this article, while the preferable word to describe differences is *variation*, a more neutral term that lacks negative connotations for children in society. Variations provide richness and diversity in life that can be noted without being denigrated or overemphasized. Depending on how children or adults identify with and orient themselves to the impact of their disabilities, both personally and with respect to society at large, they may have varying preferences for acceptable terms. The reader can consult Gilson and DePoy (2004) for a discussion on disability identities and orientations.

The saying “Nothing about us without us” is an informal one within the disability community. Hahn (1993), a social scientist with over 10 years of research experience in the disability field and personal experience using crutches and a wheelchair since the age of 6, has spoken of a minority model of disability that has its origins in a sociopolitical model. This model arose when individuals with non-transient or lifelong disabilities stated that research using prior models did not seem relevant to their lived experience. Thus, policies and services that arose from these models did not result in meaningful life improvements. Attitudinal variation has arisen

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within the disability subculture regarding identities and orientations toward disabilities. A sociological ideology for conceptualizing individuals with disabilities and their families has emerged, which varies from the older entrenched medical model that regards disability as illness, tragedy or a negative situation requiring treatment and rehabilitation. Using the medical model, people with disabilities and their families are conceptualized based on their acceptance of and adaptation to disabilities. The sociological model focuses on the larger society or system and its reaction to the individual, rather than examining the person with the disability as the identified patient. Impairment and dysfunction are conceptualized as part of the larger system, with its handicapping environment and public attitudinal barriers, rather than within the individual who has varying abilities and is referred to by this larger system as a person with a disability.

A wide range of models have evolved to the point that Darling (2003) proposed an exploration of disability orientations that include normalization, crusadership, affirmation, isolated affirmation, situational identification, resignation and apathy. Familiarity with these orientations will help counselors understand the disability identities and orientations of their clients and their family members. It is beneficial to acquire a clearer understanding of disabilities and their actual rather than imagined impact on clients in order to improve one's diversity awareness.

### **Eliminating Ableism and Pity**

Professionals entering the multilayered maze of counseling children with disabilities must honestly explore their positive and negative preconceptions about people with disabilities. Counselors should understand and confront *ableism*, defined as “the discrimination or prejudice against individuals with disabilities” (Ableism, 2015). Furthermore, counselors should examine and challenge their own disability stereotypes prior to entering the counseling room with clients impacted by disability. Scope (2014), a disability-related charity in the United Kingdom, challenges *ableism* in the initiative “End the Awkward” found on their website (<http://www.scope.org.uk/awkward>). This site allows readers to take an informal quiz to see if they are an “ambassador of cool” or a “captain awkward” around people with disabilities and also a link to watch short television advertisements designed to decrease awkwardness around individuals with disabilities. Helping professionals need to internally clarify the distinction between empathy and sympathy. Counselors can invite open discussion about the disability, as they would invite clients to share information about any subculture, so they feel free to clarify pertinent aspects of their lives and disability in counseling that might otherwise go unaddressed.

Helping professionals also should use non-handicapping language to affirm the individuality and personhood of clients. The *Publication Manual of the American Psychological Association* (American Psychological Association, 2010) has provided the following recommendations for unbiased terminology in research and academic writing:

The overall principle for “nonhandicapping language” is to maintain the integrity (worth) of all individuals as human beings. Avoid language that objectifies a person by her or his condition (e.g., *autistic, neurotic*), that uses pictorial metaphors (e.g., *wheelchair bound* or *confined to a wheelchair*), that uses excessive and negative labels (e.g., *AIDS victim, brain damaged*), or that can be regarded as a slur (e.g., *cripple, invalid*). Use people-first language, and do not focus on the individual's disabling or chronic condition (e.g., *person with paraplegia, youth with autism*). Also use people-first language to describe groups of people with disabilities. For instance, say *people with intellectual disabilities* in contrast to *the retarded* (University of Kansas, Research and Training Center on Independent Living, 2008).

Avoid euphemisms that are condescending when describing individuals with disabilities (e.g., *special, physically challenged, handi-capable*). Some people with disabilities consider these terms patronizing

and offensive. When writing about populations with disabilities or participants, emphasize both capabilities and concerns to avoid reducing them to a “bundle of deficiencies” (Rappaport, 1977). Do not refer to individuals with disabilities as *patients* or *cases* unless the context is within a hospital or clinical setting. (p. 76)

## **Children with Disabilities and the Family System**

The family of a newborn diagnosed with a disability attempts to become acquainted with the infant and gain parenting skills, while still in a bustling neonatal intensive care unit. The family may be experiencing what McHugh (1968) called *anomie*, which is the idea that life is no longer normal, does not make sense, and is out of one’s control. The family’s experience may include focusing on the physician’s words, hearing the startling news that their child is receiving the diagnosis of lifelong disability, and considering what impact the disability will have on their child and family. Simultaneously, numerous specialists and nurses may be verbally giving the parents large amounts of vital, unfamiliar information in complex medical terminology, while evaluating how the parents are adjusting. The parents may be asked to make urgent life-altering medical decisions about surgeries that will affect their child’s well-being. Helping professionals must realize that parents need time to adapt to this life-changing situation.

### **Normalization**

Parents who have not lived with a disability as a part of their lives need time to absorb the impact of the disability on their child and family as they move through *anomie* into the period that Seligman and Darling (2007) called *normalization* and resume the activities that were punctuated by the adjustment to the disability. Families acclimate to a new normal that contains a member with a disability. Gradually parents become capable of a knowledgeable dialogue with the medical community and may even inform physicians of promising treatments for their child, eventually realizing that they and their child(ren) are capably managing the practicalities of the disability, gaining needed services, and coping when unexpected changes and challenges arise.

During normalization, family members strive to help each other, and they build satisfying experiences and memories as they travel through the family life cycle. This process is neither easy nor quick; it can be gut-wrenchingly painful. However, it can produce much personal growth, the shifting of previously held values and priorities, and the satisfaction of a job well done. The process of normalization is not, as some assume, an insurmountable burden to bear, but rather a growth-producing challenge that can be met, sometimes joyfully. Counselors should beware of assuming that all children with disabilities and their families contain pathology. Many families have the internal and external resources to adapt to the disability over time without the need for professional intervention. Helping professionals should avoid referring to these families and children as *special*, as this term minimizes and unintentionally disrespects the effort required by ordinary people who face extraordinary challenges while meeting the other demands of daily living.

### **Parents’ Adjustment to the Diagnosis**

People assume that parents whose children receive a disability diagnosis at birth are grieving the loss of an ideal perfect child. I suggest that the parents have grown to love the child prenatally and are grieving what their actual child is experiencing or may experience throughout life. The parents may struggle with the pain of relaying the diagnosis to siblings, grandparents and extended family members. Olshansky (1962), one of the initial researchers of families of children who have cognitive disabilities, recommended that chronic grief is an expected reaction of a caring parent to parenting a child with a disability and much more useful than the oversimplified idea of acceptance or rejection.

Some developmental disabilities are discovered prenatally or shortly after birth, or result from premature birth. Some disabilities are diagnosed later in childhood, as parents notice missed developmental milestones or the child loses previously-acquired skills through illness, accident or physical abuse. Other parents may suspect a disability in their child prior to receiving an official diagnosis. Counselors should remember that the pang of sadness a parent may feel when his or her child misses a developmental milestone or experiences social stigma is normal and does not mean that parents are coping poorly.

Parents who are trying to be hopeful are not necessarily denying the disability. Automatically applying diagnoses from the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 2013) to the parent's reaction to an initial diagnosis of disability in their child can add additional stress to the family system. Family members of children with disabilities may be inclined toward mental health difficulties that do not interfere with normal life functioning until the additional stress of the disability and the requirements for managing it overload the person's coping skills, either temporarily or over time. The process of normalization takes time to unfold. Helping professionals should build a caring relationship with the family at the time of diagnosis and be available later if mental health issues begin to interfere with normal functioning. Counselors should use their clinical skills of differential diagnosis to understand and unearth the interplay between the parent's orientation to disability and his or her conceptualization of disability identity to avoid framing a mindset as a mental health disorder.

The child's parents or siblings may have psychiatric diagnoses or relational difficulties that predate the child's disability diagnosis. Such issues may interfere with family resilience and the process of normalizing the disability and promoting healthy child development. Addictions, anxiety, depression, adult attention-deficit/hyperactivity disorder and other diagnoses can impede parental well-being and effective parenting. Thompson and Gustafson (1996) suggested that improved child development and adaptation to chronic childhood illness are associated with parental social support, adjustment and decreased stress. Elman (1991) suggested the need for counseling depressed family members. Crnic and Greenberg (1990) indicated that decreased competence in children is related to parental personal stress that interferes with effective parent-child communication. After many years of counseling families, I have come to believe that the family system can operate more smoothly if the individual members address mental health issues that impede marital satisfaction, family cohesion, conflict resolution, stress management, child rearing, medical management and other positive coping skills.

The birth order of a child with a disability can change the future family structure as the parents contemplate whether to have additional children. If the child with a disability is the parents' firstborn and the disability has a genetic component, additional children may share the same disability, in a milder or more severe form. Parents may consult geneticists to explore the probabilities of a recurrence of the disability while they consider their ability to incorporate various scenarios into their lives. Childhood disabilities have direct and indirect psychosocial and financial costs for families. Seligman and Darling (2007) discussed direct costs of adaptive equipment, therapy and child care, and indirect costs like fees for housing modifications, work absences, and parental difficulty for career advancement. Sometimes one parent chooses not to work outside the home in order to be available for tasks related to managing the disability, a decision that reduces the family's income. Regardless of the counselor's or geneticist's viewpoints, the decision to pursue additional children can be a complex, grueling decision for individuals whose convictions do not give them the option of attempting to conceive and then terminating a life prenatally if a disability is detected, especially for parents who already love a prior child with that or another disability.

### **Self-Concept Development among Children with Disabilities**

The child with the disability develops opinions about the family and himself or herself. Children create a sense of self from the reflections they see in their interactions with others. Unfortunately, people with cognitive,

emotional or physical differences encounter distorted mirrors daily. The communication they have with others often is filtered through an unspoken screen of ableism and stigma. In *Disability Is Natural: Revolutionary Common Sense for Raising Successful Children with Disabilities*, Snow (2001) described the Euro-American history of disability and myths. When the child encounters a person who has not had close friendships with anyone with disabilities, the person may display uncomfortable, awkward behavior around the child. The person may stare, avoid eye contact, treat the child with pity, act like the child is “special,” speak to the parents instead of the child or act in other confusing ways that pose barriers to intimacy. Children with disabilities sometimes do not question the interpretations of others and may begin to believe that anomalies are bad and that they are inherently bad, rather than just different. Children with disabilities also may not realize that the awkwardness in the room arises from discomfort in the other person and may wonder what is wrong with them.

Though people with disabilities are a natural part of society, they continually encounter barriers to full participation in society. In a society containing environmental and attitudinal barriers—for example, the lack of ramps or curb cuts necessary for people in wheelchairs to navigate their community—the simplest of tasks can be continually inconvenient.

Counselors must recognize that the disability is the child’s constant companion, 24 hours a day, 7 days a week, which may include a complex medical condition that affects various parts of the body and its functions, possibly resulting in pain. The vocabularies of children with disabilities may include medical terminology and treatments that are complicated to understand and time consuming to accomplish. The child may have a visible disability that is always on display for others’ comments and stares; alternatively, the child may have a disability that is hidden and misinterpreted by people in the community. Until one accompanies a person with a visible disability in public, one does not even realize what a luxury it is to go about daily tasks without others stopping to look for extended amounts of time with expressions of wide-eyed shock or curiosity. Counselors can teach children without disabilities to react less awkwardly around children who have disabilities.

Counselors should remember that each child and family is unique, but be aware that children with disabilities are more like children without disabilities than they are different. They simply vary in some way. The child may be in counseling because of internal challenges resulting from the disability or external emotional, social, attitudinal, educational or physical barriers to inclusion. However, the child may be in counseling for a difficulty that would arise even if there were no disability. It is helpful for children with disabilities to realize that some of the struggles they encounter are common to all children.

### **The Emotional Toll of Services**

Community services, such as Respite Care and Individual Education Plans, are available to assist children with disabilities and their families with some of the challenges presented by the disability. People are vetted to see if they qualify for services and terms from the medical model of disability are utilized. Unfortunately, in order to receive services designed to maximize potential, children with disabilities must interact with agency staff members who discuss and emphasize deficits and rehabilitation in their presence. Children with disabilities may find the language and terminology insulting and demoralizing, considering that they have not had an accident and do not feel the need to be compared or repaired.

The disability subculture is not homogenous. Developmental disabilities include spina bifida, cerebral palsy, diseases of the muscles and bones, neurological disorders, craniofacial deformities, metabolic disorders, endocrine disorders, seizure disorders, cleft palate, cleft lip, visual impairment and blindness, hearing impairment and deafness, mental retardation, attention-deficit/hyperactivity disorder, learning disabilities, autism, chromosome and genetic disorders, and numerous others, including those that are extremely rare and possibly unnamed. Children and families in these various subgroups have some experiences in common and

other distinct differences due to the various traits, challenges, onset and societal reactions to their particular disabilities.

### **Complex Client Group**

Counseling children with developmental disabilities is like working a complex three-dimensional puzzle. Each individual child is as distinctive as a fingerprint. The child is a member of a family that has its own characteristics, rules and roles. The child and his or her family members' temperaments affect reactions to a disability. Within any given family, there may be varying opinions among members about how to handle the disability or avoid dealing with it, which can impact family interactions. Children with handicaps come from a variety of ethnic cultures and heritages that influence the adjustment of the family members' reactions to the child's differences.

### **Spirituality**

Counselors should not underestimate the benefits that some children with disabilities and their families derive from strong connections to their faith or other forms of spirituality, if they are not part of a religious community. Seligman and Darling (2007) wrote that some religious communities contribute a great deal of support to the families of children with disabilities. Poston and Turnbull (2004) discovered that other families have difficulty finding a religious group that will incorporate their child and family into the faith community. They reported that having a child with a disability, at times, is the precipitating factor to the development of spirituality in family members. Schiele (2000) and Parham (2002) proposed that aspects of the Afrocentric service models are beneficial when working with African Americans since these models incorporate interdependence, collectivity, affect and spirituality. These benefits may be generalizable to other ethnic groups. McCarthy (1995) encouraged counselors to explore and use spiritual ideas and techniques to benefit the physical and mental well-being of clients.

Belief in a benevolent power or ideological concept can sustain exhausted, discouraged individuals when situations are beyond their control despite their sincere proactive efforts. During those moments when they feel that they cannot continue without despair, they can let go and allow God, a higher power or whatever spirituality they cling to for sustenance intervene. For example, when sending their day-old neonate into spinal surgery, religious parents may draw comfort from the belief that a divine being continues with their infant and the surgeon beyond the operating room doors that separate them from their child. Children whom physicians predict will die continue against all scientific evidence to live and thrive; sometimes parents have supernatural theories about these outcomes. Turnbull, Turnbull, Erwin, and Soodak (2006) referred to spirituality as the way that people derive meaning in their lives and interact with the sacred. According to Skinner, Correa, Skinner, and Bailey (2001), spirituality can influence whether a family considers the addition of a member with a disability to be a blessing or retribution for an offense (Chan, 1998; Chan & Lee 2004; Rolland, 2003). Frisco (as cited in Seligman & Darling, 2007) indicated that the majority of the grandparents surveyed reported that religion and belief in God helped them more comfortably accept a disability in their grandchild.

### **Multiple Interconnecting Systems**

The child and his or her family have multiple interconnecting systems to navigate, while attempting to achieve the normal activities of being a family and helping the child accomplish typical developmental tasks, without reducing this goal to a tedious, life-draining behavioral chart that devalues the child's personhood and the spontaneity and freedom of childhood. Nichols (1984) considered an open system to be a group of interconnected parts of a whole that interact with each other and the larger environment around information, material and energy. General systems theory and cybernetics provide concepts that assist counselors in studying the multiple elements that constitute the collective experience of living with a disability. These systems may include physicians, therapists, schools, tutors, insurance companies, respite care services, disability advocacy

and support groups, community activities, neighbors, playmates, extended family, and other groups of people who make up the ever-evolving gears of an interacting environment that contains the child and his or her nuclear family subsystem. Miller (1995) affirmed that a well-functioning psychosocial environment is vital to the child's healthy maturation, and counselors can work with children and their families to reduce feelings of being overwhelmed.

Disabilities are not as inherently stressful as what parents go through while trying to help their child with optimal growth and development. Acquiring adaptive equipment, services, educational accommodations and community participation can be tedious and frustrating. Parents often are required to contact busy physicians, educators, automated insurance provider telephone messages and agency coordinators to get documentation for equipment that they need in order to accomplish simple tasks that the dominant culture takes for granted. Normal activities like comfortable body positioning, eating, toileting, ambulating and being integrated into school classrooms can be prolonged, inordinately exhausting, emotionally draining and time consuming.

Once services and equipment are acquired, the family unit may become part of a large, complex, constantly evolving system including, depending on the particular disability, educators, adapted physical educators, therapists (e.g., physical, occupational, speech, respiratory), tutors, dieticians and medical specialists (e.g., pediatricians, gastroenterologists, orthopedic surgeons, cardiologists, urologists, audiologists). Many disabilities require adaptive equipment that is initially unfamiliar to the family. Medical professionals tell parents and their children about assistive health devices that others with similar disabilities have found helpful. The family may need time to adjust to the reality that their child has to use the device, to examine the risks and benefits of equipment and treatments for the disability, and to find someone who provides the service locally.

Health devices are often expensive and must be paid for through insurance, government programs or private payments. Obtaining the equipment may be a lengthy, convoluted process that involves repeated negotiation with insurance providers and resubmitting payment requests or searching out alternative funding sources if insurance payment is denied. Once the adaptive equipment arrives, there are often therapy appointments to individualize the fit of the equipment to the child, teach the parents and child how to use the product, coax the child to use the aids, and check to see that the product is doing no harm to the child. It can take weeks of trial and error to modify equipment that is problematic. This process may repeat often as the child grows older.

Children may want to participate in activities that are outside the realm of the Americans with Disabilities Act. Parents may find themselves having to reassure and encourage the people who run these programs to include their child. This process may involve educating Scout leaders, religion teachers, preschool staff, parents of the child's classmates, camp staff and others about the disability and how to make modifications to include the child, and also may involve calming fears that it will be too difficult for the staff or the child to manage or too dangerous for the child to participate. Most children with limitations want the same independent adventure opportunities as other children; to try new experiences; risk, fail, try again and succeed; and sometimes surpass others' expectations for them.

It is important to help families see that their child needs to be surrounded by a support system that has challenged negative assumptions about people with disabilities. Children with an observable disability do not have the gift of anonymity that most people take for granted. They need comfortable places to just be themselves, recharge emotionally and exist as a member of the group. They need the enduring support and friendship from others who are easy, normal and natural in their interactions with the children, to inoculate them against assaults to their worth that they can encounter in the larger society. On some level, children may think that their parents are giving them affirmation because of their roles as parents. Children need to know that people other than their parents also acknowledge their skills, temperament, accomplishments and personhood.

Children need interactions with people who allow them to be authentic and respond genuinely and honestly; thus, children learn how to be in healthy relationships.

## **Interventions to Disable Ableism and Promote Friendships**

Parents of children without disabilities sometimes tell their children not to stare at children with disabilities but may not make a suggestion for a replacement behavior, like saying, “hello.” Thus normal opportunities to interact are missed and taboos that encourage shunning and bullying continue. This behavior can contribute to unnecessary adjustment problems in adulthood that Cadman, Boyle, Szatmari, and Offord (1987) and Rutter, Tizard, and Whitmore (1970) have suggested are related to experiencing social rejection early in one’s life. To promote integration and change attitudes, it would be helpful for school counselors to offer diversity training concerning disabilities for students and parents throughout the school population. Informational sheets could be sent home in the beginning of the school year or brief presentations could be included at parent meetings. Some of the child’s classmates may grow up and one day become parents of children with disabilities.

### **Social Skills Development**

Miller (1995) reminded us that the peer social system is the main area where children develop and hone relationship-building and social problem-solving skills. However, some children with disabilities have trouble forming relationships with their peers for a variety of reasons. They may lack the opportunity to socialize with peers in a regular setting or have trouble ambulating to where children are playing. They may have a human aide who impedes normal peer interactions, tagging along to manage a healthcare issue. They may not understand the social mores of others their age because of so much time spent with parents and adult health care providers or due to aspects of their disability. In addition, service providers may talk to parents about the child as if the child is not present. Parents can learn to redirect physicians, nurses and other service providers to speak to the child in age-appropriate language.

Tovray and Wilson-Portuondo (1995) suggested that children may need formal help to learn social skills for developing friendships if they do not notice or understand social cues and nonverbal messages from others. Children with disabilities may struggle with nonverbal learning issues or characteristics on the autism spectrum, making engaging or understanding others difficult. They also may have behavioral disabilities that alienate other children or result in the continual loss of recess privileges. They may have medical therapies after school and daily tasks to complete between visits. Children with disabilities may spend an unreasonable amount of time trying unsuccessfully to complete homework assignments. Counselors can help a child with a disability by making a referral to a neuropsychologist to determine strengths and weaknesses, and then the counselor, parents, neuropsychologist, teachers and tutors can help the child develop more effective study and executive functioning skills that match his or her temperament and learning style. Parents and counselors can work together so that children with disabilities have opportunities to *be* and not just *do* activities.

### **Educating Peers to Reduce Isolation**

Sometimes children ask questions undiplomatically. For example, a preschooler with spina bifida might be asked, “*Why do you walk weird?*” Some parents of children with disabilities visit the school on the child’s first day and speak to the child’s classmates in an attempt to decrease painful queries that can invite social anxiety. Preparing the class as a group also frees peers from being preoccupied with unanswered questions. If professionals help the child and family create and practice an elevator speech, perhaps these unhelpful questions will occur less often. The elevator speech can be a few sentences to explain the disability when meeting new people, which could prevent the disability from becoming a taboo subject. Talking openly can relieve other children’s unrealistic fears of catching the disability.



Returning to the previous example of a preschooler with spina bifida, the child could introduce herself by name and say something to let her classmates know what they have in common, like, *“I am 5 years old. I have a brother and sister, and two dogs. Who else has a brother and sister? Does anyone else have a dog? I like to play, read books and eat ice cream. I am looking forward to being your friend.”* After this joining statement, she could then give a brief age-appropriate description naming her disability and saying how it affects her and others, as follows: *“I have spina bifida, so some of the nerves in my back don’t talk to my legs to tell them to feel or move. The other parts of my legs have to work harder, so I walk differently. I’ll pass around my old braces, like the ones I wear to help me walk. Please don’t mess with my wheelchair unless I ask for help. You can’t catch spina bifida like you do a cold. I don’t run so please walk slower, so I can keep up. Let’s talk and see how we can all play together.”* Sometimes the child may not have the social or cognitive skills for public speaking or may simply prefer that the parent give the elevator speech. However, the child can learn self-advocacy by sharing some part of the elevator talk. After the elevator speech, the parent can ask if anyone has any questions. Parents sometimes ask educators to send a letter home to the parents of their child’s typical classmates with a brief description of the disability so that parents understand and include the child in after-school invitations that are extended to the rest of the class. Then the child and peers can begin the school year ready to focus on getting to know each other, forming friendships and learning classroom content.

This introduction could reduce the isolation of children with disabilities by demystifying their differences and allowing them to assimilate into the group. Children with disabilities, their classmates, school staff and families need practical skills for dealing with bullies. Parents can search for schools that take bullying and violence prevention seriously and have a school strategy in place to discourage bullying. Bullies may try their unacceptable behaviors on various class members; however, they tend to choose people who are alone to be their victims of repetitive bullying. Children with disabilities can learn strategies for standing up to the bully. Classmates of children with disabilities can acquire the information necessary to become friends and allies for the student in areas where there may be less adult supervision such as the lunchroom, bathrooms, hallways, or on the playground. They can help intervene to include the child with a disability in pleasant encounters with children from other classrooms and also speak on behalf of their friend when others ask questions or make nasty comments. Counselors can work with the school staff, parents and children to develop school-wide anti-bullying campaigns that teach children to counteract bullying and become allies for one another.

### **Preventing Isolation by Building Peer Support**

The child and family may share their culture, religion and other signs of unity and cohesion. However, if the child’s exceptionality is not inherited, he or she may have the difficult experience of being the only member of his family with the anomaly. The child may benefit from the support of peers with the same disability to spend time with and compare experiences; or just be with colleagues who are already familiar with the disability and do not require explanations. Counselors can help parents find camps and support groups for both the family and child that include both children with disabilities and typical peers. Children need older, successful role models with disabilities who inspire them to persevere when they are discouraged. They need mentors, with and without disabilities, who challenge them to dream and make continual progress to accomplish their dreams.

### **Recommendations for Counselors**

Counselors can be more aware of areas in which they can be quite helpful. Counselors can intervene in the medical system to provide newborns with disabilities and their parents with natural settings that allow relaxed time together to promote attachment and bonding. Counselors also can operate from a systemic, strengths-based model in order to best respect and support the child and family. Throughout the child’s development, counselors and families can collaborate to promote the development of age-appropriate skill acquisition, protective yet permeable personal boundaries, self-awareness, positive self-esteem, social skills, relationship development, the

ability to be resilient in the face of stigma, and the opportunity to transition to the adult roles of employment, independent living, dating and family formation.

### **Systemic, Strengths-Based Counseling Models**

Allen (1994) indicated that counselors and theorists operating from various individually oriented counseling perspectives assume that the origin of dysfunction and self-destructive behaviors in an individual is an internally defective self, psyche or physiological flaw. Hahn (1993) noted that the medical understanding of disability relates to organic pathology or impairment. Counselors who operate from a family systems model believe that difficult individual behavior is best understood as one piece of a larger interacting whole, such as the family or society, which is greater than the sum of its parts. The behaviors of individual members of the system are considered reflections of what is happening in the larger system. Rather than identifying the individual as a patient to be fixed, Nichols (1984) stated that the system should be explored to identify pathology in the interactions between people. Oliver (1996) did not believe that disabilities are intrinsically bad, and Linton (1998) reported that many people have disability pride. Disability pride refers to recognition that society is enriched by the distinctive positive voices, identities, thoughts, awareness, lifestyle examples and literature produced by individuals with disabilities. Seligman and Darling (2007) suggested that professionals who adopt a medical model of pathology may presume that the birth of a child with a disability will lead to maladaptive family functioning and therefore the implementation of intrusive, undesired interventions from service providers. I advocate the use of a collaborative, systemic, strengths-based counseling model due to the complex interconnected systems that make up the environment of children with disabilities and because it is more respectful of the child and family's disability orientations and ability to prosper within a complicated context. It is erroneous, unkind and disrespectful to label a child who is capably using his resources to the best of his ability as unhealthy simply because he varies from the norm.

A systemic, strengths-based counseling model also respects the inherent worth of the child with a disability by not presuming that he or she is the identified patient. He or she is incredibly resilient in the face of daily challenges that would make many adults cower and yet gets up each day with renewed hope and moves forward into the future. Not only does this child face the same developmental tasks of childhood as his or her peers, but he or she must use additional thought, energy and time to develop and implement strategies to compensate for personal variations that may make the accomplishment of these tasks extremely difficult and time consuming.

One goal of counselors working with children with disabilities is to acknowledge the personhood and accomplishments of the children and their incredible inner fortitude, without categorizing them as more special than any other child. In a society where people are compared to a perceived norm, this child was either born with or acquired a variation that has been characterized as less than the norm, and labeled a disability, impairment, handicap or developmental disorder. The terms are pejorative; the connotations of the words just mentioned are as follows: not able, broken, defective, of lesser quality and developing incorrectly.

Counselors might also wonder how separation experiences impact attachment and bonding from the child's perspective. Does the child experience feelings of abandonment and fear at a time when he or she lacks the ability to conceptualize or express them? A question for counselors and researchers to consider is whether there is an enduring impact from these experiences. Some parents initially reject the child with a disability or fear that they will not be able to manage the infant's medical needs. Family members who have access to each other usually bond. Seligman and Darling (2007) reported that attachment can be difficult for some parents when aspects of the child's disability interfere with the baby responding positively to his or her parents' overtures.

Parents and counselors can help children with disabilities develop a healthy sense of self and determine what behavior is acceptable in others, and under what conditions. With so many people entering and leaving the

child's life, it is helpful for parents and counselors to help children understand different types of relationships and what to expect from them. They need to be protected from physical, sexual and emotional abuse and learn refusal skills in situations where their trust and cooperation are exploited.

### **Promoting Self-Awareness**

Children with disabilities need self-awareness. Counselors have the opportunity to assist parents of young children with disabilities by suggesting that parents play games with their toddlers to help them learn body parts and their functions, including the terms that name their disability since it is also a natural part of them. It is not a defining part, but rather an aspect of themselves that they can become aware of and discuss, such as being adopted or having green eyes. Once the disability is assimilated into the family, family members go about the business of life; their child with a disability is just another member of the family.

### **Helping Children with Disabilities, Siblings and Parents Deal with Stigma**

Siblings can help children with disabilities begin to interact differently with peers by accustoming them to the support, disagreements and jealousy common between brothers and sisters. Children with disabilities encounter people within the larger community who may not be familiar with disabilities or the concept that disabilities occur among regular people. Children with disabilities and their siblings need to be prepared ahead of time for ableism so that they are not surprised or heartbroken by the reactions they receive from people outside their home. At home, no one stares at children with disabilities, mocks their disability-related differences or calls them negative names. Unfortunately, well-adjusted children with disabilities may encounter cruelty from other children whom they meet outside their homes and primary social networks. They need to know that the dysfunction in these interactions does not originate in them, but rather are due to a lack of knowledge in other people. Children, parents and siblings need help interacting with the larger society around issues of being different and educating others about their disabilities. Sibling groups can be helpful for children who sometimes feel torn between conflicting emotions about their sibling with a disability. Goffman (1963) said that family members of children with disabilities sometimes receive courtesy stigma when they are in public with their family member who has a disability. Children have reported feeling embarrassed by their sibling or guilty for excluding them or not defending them. At other times children have been shunned for standing up for their sibling. Siblings may sometimes be jealous of the extra attention their sibling's disability requires, assist with their sibling's care or operate independently.

### **The Importance of Being, While Also Acquiring Skills**

Children need time for unstructured play to develop their imagination, gain independence, explore hobbies and experience leisure. They need opportunities to develop the daily living skills necessary to achieve autonomy by adulthood. In addition to learning to prepare food, clean, do laundry, manage money, monitor appointments and keep a home from dissolving into chaos, they will need to gradually take over the medical management of their disability if they intend to maintain their health. Children with disabilities and their families need extreme time-management skills in order to accomplish this herculean task. Counselors or life coaches can help families develop a long-term family vision. They also can help the child and family develop short-term and long-term goals for the child with the disability and problem-solving skills to overcome obstacles to their vision and goals. Parents and children may find it helpful to learn assertiveness skills so they can coordinate homework tasks assigned by support services and say no to excessive demands from numerous systems that add up to more than a 24-hour day.

### **Helping Adolescents Progress to Adulthood**

When a disability is added to the list of difficulties Haley (1997) described, one may discover additional requirements for launching a young adult with disabilities. Some states require adolescents with disabilities to be evaluated before they can apply for a driver's license, and their vehicles may need costly accommodations.

Some people with disabilities are refused the opportunity to obtain a driver's license and must make other plans for transportation. A young person with a disability needs a plan for vocational career development, job training, higher education or some means of financial support. Plans for independent living, a group home, or a nursing home, must be made prior to leaving the family home. Such plans often include meetings with a team to develop an individual education transition plan during secondary school, and meetings with rehabilitation counselors after high school to plan for college, vocational training or employment. Parents and students spend additional time and energy to acquire the documentation required to obtain these services. Counselors and life coaches can help the family members prioritize the various activities competing for their time, energy and financial resources. Professionals may encourage creativity around informal methods of achieving formal goals that do not require the child and family to expend more energy acquiring and maintaining the services than warranted by the potential relief obtained from the services.

### **Other Counseling Services**

Counselors have so many tools to offer children with disabilities and their families throughout the family life cycle. They can offer concepts and techniques to deal with grief and anomie at the initial diagnosis of a disability, the chronic grief that emerges when a developmental milestone is missed, repeated encounters with ableism, or unsuccessful operations and physical therapy. Some childhood disabilities and chronic illnesses end in death at an early age. Counselors and hospice staff can help families prepare for this untimely departure.

Relaxation exercises can be helpful to families after a busy day of preoperative medical appointments, immediately prior to a surgery or while waiting for a surgery to end. A child having a painful medical procedure or frightening experience like Magnetic Resonance Imaging also can use relaxation as a method to cope. Cognitive therapy can help children and families reframe complex medical issues and disabilities from seemingly overwhelming tragedies to neutral manageable situations within their capabilities. Reframing can allow parents who regret missing work to spend hours in physician's offices, X-ray labs or therapy appointments to see the experiences as valuable times—opportunities to really get to know the child and bond around lived experiences.

Learning to use communication skills allows parents to request that nonurgent operations and treatments be scheduled at times that do not interrupt other activities, such as birthdays, weddings and exciting field trips with classmates. Counselors can teach communication skills that can be used within the family to explore rigid roles that may not allow members the flexibility to effectively cope with the added chores that accompany a disability without sacrificing the real needs of any one family member.

Counselors can assist families and children in learning vital time-management and decision-making skills. They can help parents see that self-care is useful and that it is fine to ask for help from each other and use resources outside the family to relieve caregiver stress. Counselors can help families learn to develop a stress management plan that utilizes positive rather than negative coping skills during times of extreme stress. If families and children learn assertiveness skills, they may be able to release passivity or aggression. Counselors can help children and families reduce anxiety and depression throughout the lifespan, cultivate humor and gratitude, and juggle a variety of activities and emotions in the pursuit of a balanced life. Counselors may use their own creativity to generate original ideas for assisting children with disabilities and their families.

### **Conclusion**

This article provides significant ideas to consider when working with individuals with disabilities and their families; there is much to learn through exploring relevant research and anecdotal information regarding disability awareness. An understanding of systemic theory is invaluable when working with the complex

interconnecting systems that make up the environment of a child with a disability. Counselors may explore disability identities and orientations within the individual with a disability, the family and society. Professionals can consider interventions concerning identity formation in the person with a disability by promoting self-awareness, boundary development, and the understanding of and externalization of ableism for both the child and family members. Mental health professionals have the opportunity to confront the stigma associated with disabilities and service acquisition. Counselors can use reframing to normalize variations within students and decrease pity. They can partner with the child and his or her parents to educate the child's classmates and their parents, school personnel, and community about the disability and inclusive practices that prevent social isolation and encourage interactions that disarm bullying and myths about people with disabilities. Counselors can offer practical help to children who may struggle with social skills, study skills, communication, assertiveness, stress management, spirituality, transitioning from childhood to adulthood, and the importance of being or experiencing one's humanity rather than just accomplishing tasks. In addition to using the introductory ideas provided in the article, counselors are invited to creatively adapt additional theories and techniques to support children with disabilities and their families.

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## **References**

- Ableism. (2015). In *Merriam-Webster's online dictionary*. Retrieved from <http://www.merriam-webster.com/dictionary/ableism>
- Allen, D. M. (1994). *A family systems approach to individual psychotherapy therapy*. Northvale, NJ: Aronson.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.
- American Psychological Association. (2010). *Publication manual of the American Psychological Association* (6th ed.). Washington, DC: Author.
- Cadman, D., Boyle, M., Szatmari, P., & Offord, D. R. (1987). Chronic illness, disability, and mental and social well-being: Findings of the Ontario Child Health Study. *Pediatrics*, *79*, 805–813.
- Chan, S. (1998). Families with Asian roots. In E. W. Lynch & M. J. Hanson (Eds.), *Developing cross-cultural competence: A guide for working with children and their families* (2nd ed., pp. 251–354). Baltimore, MD: Brookes.
- Chan, S., & Lee, E. (2004). Families with Asian roots. In E. W. Lynch & M. J. Hanson (Eds.), *Developing cross-cultural competence: A guide for working with children and their families* (3rd ed., pp. 219–298). Baltimore, MD: Brookes.
- Crnic, K. A., & Greenberg, M. T. (1990). Minor parenting stresses with young children. *Child Development*, *61*, 1628–1637.
- Darling, R. B. (2003). Toward a model of changing disability identities: A proposed typology and research agenda. *Disability & Society*, *18*, 881–895. doi:10.1080/0968759032000127308
- Elman, N. S. (1991). Family therapy. In M. Seligman (Ed.), *The family with a handicapped child* (2nd ed., pp. 369–406). Boston, MA: Allyn & Bacon.
- Gilson, S. F., & DePoy, E. (2004). Disability, identity, and cultural diversity. *Review of Disability Studies*, *1*, 16–23.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice Hall.

- Hahn, H. (1993). The political implications of disability definitions and data. *Journal of Disability Policy Studies, 4*, 41–52. doi:10.1177/104420739300400203
- Haley, J. (1997). *Leaving home: The therapy of disturbed young people* (2nd ed.). Levittown, PA: Brunner/Mazel.
- Linton, S. (1998). *Claiming disability: Knowledge and identity*. New York, NY: New York University Press.
- McCarthy, H. (1995). Integrating spirituality into rehabilitation in a technocratic society. *Rehabilitation Education, 9*, 87–95.
- McHugh, P. (1968). *Defining the situation: The organization of meaning in social interaction*. Indianapolis, IN: Bobbs-Merrill.
- Miller, B. D. (1995). Promoting healthy function and development in chronically ill children: A primary care approach. *Family Systems Medicine, 13*, 187–200.
- Nichols, M. (1984). *Family therapy: Concepts and methods*. New York, NY: Gardner Press.
- Oliver, M. (1996). *Understanding disability: From theory to practice*. New York, NY: St. Martin's Press.
- Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework, 43*, 190–193.
- Parham, T. A. (2002). Counseling models for African Americans. In T. A. Parham (Ed.), *Counseling persons of African descent: Raising the bar of practitioner competence* (pp. 100–118). Thousand Oaks, CA: Sage.
- Poston, D. J., & Turnbull, A. P. (2004). Role of spirituality and religion in family quality of life for families of children with disabilities. *Education and Training in Developmental Disabilities, 39*, 95–108.
- Rolland, J. S. (2003). Mastering family challenges in illness and disability. In F. Walsh (Ed.), *Normal family processes: Growing diversity and complexity* (3rd ed., pp. 611–630). New York, NY: Guilford Press.
- Rutter, M., Tizard, J., & Whitmore, K. (1970). *Education, health, and behavior*. London, England: Longman.
- Schiele, J. H. (2000). *Human services and the Afrocentric paradigm*. New York, NY: Haworth Press.
- Scope. (2014). *End the awkward*. Retrieved from <http://www.scope.org.uk/awkward>
- Seligman, M., & Darling, R. B. (2007). *Ordinary families, special children: A systems approach to childhood disability* (3rd. ed.). New York, NY: Guilford Press.
- Skinner, D. G., Correa, V., Skinner, M., & Bailey, D. B., Jr. (2001). Role of religion in the lives of Latino families of young children with developmental delays. *American Journal on Mental Retardation, 106*, 297–313.
- Snow, K. (2001). *Disability is natural: Revolutionary common sense for raising successful children with disabilities*. Woodland Park, CO: BraveHeart Press.
- Thompson, R. J., Jr., & Gustafson, K. E. (1996). *Adaptation to chronic childhood illness*. Washington, DC: American Psychological Association.
- Tovray, S., & Wilson-Portuondo, M. (1995). *Helping your special needs child: A practical and reassuring resource guide*. Rocklin, CA: Prima.
- Turnbull, A. P., Turnbull, H. R., Erwin, E. J., & Soodak, L. C. (2006). *Families, professionals, and exceptionality: Positive outcomes through partnerships and trust*. (5th ed.). Upper Saddle River, NJ: Prentice Hall.