

**Human Behavior
and the
Social Environment**

OVERVIEW: HUMAN BEHAVIOR AND THE SOCIAL ENVIRONMENT

Human Behavior and the Social Environment (HBSE) content views human development and behavior from a person in environment perspective and includes theories and knowledge focusing on the interactions between and among individuals, groups, societies and economic systems. Biological, sociological, cultural, psychological, and spiritual concepts are applied through the life span, and social systems are examined in terms of how they promote or deter people in maintaining or achieving health and well-being. (CSWE, 2003)

Content related to developmental disability is easily integrated into this curriculum area. Definitions of disability can be explored from a person-in-environment/social construct perspective, relying upon strengths and the context of social systems. The definitions of disability and models of disabilities included in the introductory section of this manual can be used as introduction to disability relative to HBSE.

This section provides a values clarification exercise targeted toward HBSE, building upon the general values clarification activities found in the previous section. A sample case study is then provided as a framework that can be used to explain the HBSE paradigm related to disabilities. This is followed by handouts explaining developmental milestones and disability, and in turn, brief descriptions of the most common developmental disabilities seen in practice. This section concludes with interdisciplinary tools and content used by professionals such as the multidisciplinary team approach to abuse and neglect, transition planning, Individual Education Plans, and meeting the needs of mothers with disabilities.

DEVELOPMENT AND DISABILITY

Mackelprang and Salsgiver (1999) review human development within the context of disability. The authors state, “we define disability by the meaning the disability carries for the individual. People with disabilities are people in which a disability is part of their lives – not the definition of their lives. Having a disability means difference, not tragedy.” (63) This is a perspective shared by May and Raske (2005) who state several propositions:

- *disability is not a tragedy*
- *disability does not mean dependency*
- *disability does not mean loss of potential, productivity, social contribution, value, capability, ability, and the like*
- *disability is a natural part of life, everyone’s life*
- *there is as much variation between people with disabilities as between people in general*

With that perspective in mind, Mackelprang and Salsgiver (1999) identify various implications of disability in stages of development:

Birth to 3

From the perspective of trust vs. mistrust, painful interventions or separations from family can complicate development of trust. Gaining autonomy and control over their lives can also be complicated if the atypicality constrains ability to explore and gain competence in managing the environment. It is important to provide supportive and adaptive environments and adaptive devices that allow for maximum control over the environment. Parents should be educated about developmental needs and ways to meet these needs and modify environments and be educated about legal protections and supportive services. Professionals should be alert to any tendency to lower expectations that serve to inhibit maximal development and also should be aware of special vulnerabilities children with disabilities may have related to abuse and maltreatment.

3 to 6 years

Language development may be delayed or acquired differently for children with certain disabilities. Supportive environments, use of sign language, and technological devices should be used as appropriate since communication is a significant factor in gaining a sense of autonomy and empowerment. At this age, interaction with peers is also important as is having role models that include people with disabilities. Children should not be isolated from others.

6 to 12 years

Again, interaction with peers and development of social skills and friendships is important. Role models that include people with disabilities help children develop positive self-images. Integration and inclusion are encouraged. Individualized educational plans may be needed for some children. Mackelprang and Salsgiver also note some difference with children who first become disabled at this age versus those who have never known anything different. For those whose onset of disability occurs at this point, a change in self-concept may occur and relationships may change. Families may go through a grieving process and need to readjust their concepts related to their child. Financial stress can occur.

12 to 18 years

This is the time of many physical changes brought on by puberty. Exploration of identity, increasing independence, importance of peer relationships, and interest in intimate relationships are tasks of this stage. Discrimination and stereotypes (as well as over-protection) can hinder development of independence, social relationships, and positive self-concept. Good role models; facilitation of independence, autonomy, and control over one's life; education and support in development of sense of sexuality and positive body-image; and maximization of social interactions are important at this age. Professionals should be alert to increased vulnerability to sexual abuse and to effects of discrimination and stereotypes. Adolescents who previously did not have a disability, may have believed some of those stereotypes themselves and may also experience loss of some social relationships and positive self-identity. Supportive, disability-affirming environments are helpful in overcoming potential obstacles to optimum development.

Young Adulthood

Independence, employment, housing, transportation, and intimate relationships become important at this stage. Independent living services and other community support services can help. These may be especially important for those who acquire a disability at this stage. Mackelprang and Salsgiver make the point that “deprofessionalizing services and redirecting resources to the control of individuals allows people who use attendants to hire and direct their personal attendants rather than being dependent on others to control how and from whom they receive care”. (1999, 71) Young adults can also become advocates and role models for others.

Middle Adulthood

Mackelprang and Salsgiver note that “persons with disabilities in their middle years have been instrumental in developing a burgeoning disability culture and in changing the political and legal landscape for those that follow”. (1999, 72). Middle age is also a time when people may first acquire an age-related disability and may need to understand that it is not tragic or inhibiting to living full, satisfying, and meaningful lives.

Older Adulthood

Most older adults will eventually acquire some type of disability. As with adults who acquire a disability in middle age, continuing opportunities to living full, satisfying and meaningful lives are important. Ageism adds to barriers for older adults.

Reference

Mackelprang, R. and Salsgiver, R. (1999). Disability: A diversity model approach in human service practice. Belmont, CA: Brooks/Cole.

ASPERGER'S SYNDROME: A STORY OF CHARLIE

EARLY CHILDHOOD

Charlie is an 18-year-old male who has been diagnosed with Asperger's Syndrome. He has three other brothers, two older and one younger. Charlie's birth was normal, but labor was short and severe requiring a few seconds of oxygen to be given to him immediately after birth. As an infant Charlie would scream whenever someone attempted to change a diaper or give him a bath.

Although early development proceeded normally, Charlie started with what was termed by doctors as Passive Aggressive Disorder. At eighteen months of age, Charlie started refusing to eat many foods. He limited his diet to dairy and grains, completely refusing to eat meats, fruits, or vegetables. Even though he started to walk before a year old, he suddenly stopped and decided to crawl until fifteen months of age. He had language ability, but refused to talk until four years old, preferring to grunt and point. He would go without something rather than talk or repeat a phrase he had said. Potty training was an issue due to retained bowel syndrome and refusals.

Charlie preferred to play on his own or to sit quietly against a wall or under a piece of furniture. He could remain so quiet and still for extended periods of time that you could walk right past him and not know that he was there. Charlie was fascinated with anything to do with nature (i.e., animals, plants, etc.). He would only allow you to hold him when he initiated the action, which was always of brief duration. When he was upset, you could not hold or comfort him. If the family went out socially, say to a school function, Charlie would often hide under a table or desk and growl at people who went past. At times this growling would be accompanied by his swatting at people, especially if they attempted to engage him in any way.

Charlie was put in preschool programs starting at age 3-1/2. He would often sit outside of the circle, but listened to everything that was said. In kindergarten his teacher noticed that even though he appeared not to be paying any attention, Charlie knew where she was and everything she said no matter where she was in the room. He continued to be a "loner" not engaging socially with classmates. Charlie had to repeat 1st grade due to his refusal to participate in the class for 3/4 of the year. In fact, Charlie had to be dragged to school kicking, biting, and screaming. Once at school he would behave, but I would get panic calls from the school saying that they could not find him. He would be located in a bathroom stall hiding on the toilet or separating wall, or standing quietly against a hallway wall watching people go past looking for him. Until this point, the school system did not think there was a problem and my concerns had gone unheeded. Now they wanted Charlie to have professional evaluations.

Charlie's first official evaluation was at Newington's Children's Hospital in Connecticut. Both Charlie and his mother were interviewed together and separately along with different tests that were administered to him. The results of all this were that they

suspected her of child abuse (something Charlie said while interviewed alone because he didn't understand their question). She was told that Charlie was of low average intelligence*, they diagnosed him with ADHD, and suggested a full psychiatric evaluation/counseling. The mother's opinion was that Charlie was not ADHD. At one point Charlie spent an entire day sitting at the dining room table (except for bathroom breaks and meals) rather than write three sentences for school. He was not disruptive or restless in any manner; he just refused to write more than three words. She felt this was not ADHD behavior and set up the psychiatric evaluation.

Although the psychiatrist could not diagnose Charlie's disability, he did agree that Charlie did not have ADHD. He stated that Charlie did not have Autism, but it would be helpful to read up on the disorder as Charlie exhibited many of the traits.

These behaviors continued with Charlie receiving occupational and speech therapies, and behavior modification services through the school. When Charlie was eight years old, his father shut down with clinical depression. The family was thrown into a crisis mode. A call from the school alerted his mother to the fact that Charlie might be suffering from depression himself. Charlie began exhibiting suicidal ideations and acting out violently. Although psychiatric counseling and medication management were started immediately, Charlie spent his ninth birthday hospitalized due to a thwarted suicide attempt. This was the start of a year and a half of 911 calls due to violent behavior, emergency room visits, and inpatient and outpatient hospitalizations.

Counseling was problematic as Charlie was not cooperative. He often hid under the table and growled. At one point he locked himself in the men's room, refusing to come out until security finally managed to get the door open. The insurance company finally decided to send a counselor out to the house. On his own turf, Charlie finally started to respond.

The family learned a lot through this process. For one, they learned that Charlie was not necessarily ignoring us when we asked him questions and he talked about something to do with nature. Charlie used analogies with nature in an attempt to communicate with others. The counselor taught Charlie to come to us for comfort and to accept hugs. He was also the first person to mention Asperger's syndrome (then still a new diagnosis) and recommend an evaluation for it. Consequently, Charlie was finally diagnosed with Asperger's at nine years of age.

* Standardized testing has rated Charlie from low average intelligence to gifted depending on the mood he was in and external factors at the time of testing.

DISABILITY DISCRIMINATION: THE INSIDIOUS INSPIRATION QUOTIENT

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Background

Approximately 54 million Americans have a disability according to the U.S. Census Bureau's 1996 data. This represents approximately 20% of the U.S. population. As people age, they face a risk for adventitious disability that is roughly proportional to their ageing. For example, by age 85, 84% of Americans have at least one disability.

In a 1998 survey of U.S. households commissioned by the National Organization on Disability (NOD) conducted by Harris and Associates, the pattern and magnitude of poor quality of life indicators was again substantiated. This survey has been conducted periodically over the past several years. In the 1998 survey, the unemployment rate among persons with disabilities was 6%. Secondary students with disabilities were twice as likely to drop out of high school as students without disabilities. Furthermore, the NOD/Harris survey found that persons with disabilities were 1/3 less likely to socialize with friends, less likely to go to a restaurant at least one time weekly, significantly less likely to be registered to vote when compared persons with no disabilities. Households with a disabled member had a 33% higher exposure to poverty than non-disabled households. One third of respondents said that transportation was a major problem in their lives. Finally, persons with disabilities were significantly less likely to report being satisfied with their lives when compared with their non-disabled peers.

This abysmal state of affairs persists, substantial expenditures of money and effort directed toward "helping" persons with disabilities notwithstanding. When asked, most respondents report a very favorable attitude toward persons with disabilities. Public discourse that seems to reflect this overall favorable attitude seems to betray powerful, insidious limiting and perjorative attitudes toward this population however. There seems to be powerful forces that largely go unchallenged that perpetuate second class citizenship for person with disabilities.

Assumptions that Support the Status Quo

In their 2000 article, "Disability Beyond Stigma: Social Interaction and Activism", Fine and Asch assert that 5 pervasive assumptions conspire to perpetuate ongoing marginalization of people with disabilities. The first of these is the assumption that

disability (and disability-related impairment) is located solely in biology, and is therefore immutable. A second assumption is that when a disabled person faces problems, it is the impairment (disability) that causes them. Third, it is assumed that the disabled person is a “victim”. Fourth, disability is thought to be central to the disabled person’s self-concept, self-definition, social comparison, and reference groups. Finally, it is assumed that disability is synonymous with needing help and social support.

These assumptions provide a durable framework and suggest a familiar perspective for understanding persons with disabilities—all without the holder of such assumptions having to identify or claim any animus toward persons with disabilities. The assumptions, if unchallenged, help to “explain” and “understand” the experience of disability. In effect, the assumptions provide all the necessary answers. They also direct behavior.

If the assumption that disability and impairment are immutably linked is accepted, then why look any further than individual mitigation to reduce impairment? If all problems are viewed as consequences of disability, why focus interventions beyond the owner of the disability? Because of the rather sympathetic orientation toward victims, and an expectation for their engagement as passive recipients of the helpful beneficence of others, we tend to have low expectations. Furthermore, if a disabled person has the audacity to express dissatisfaction with the well intentioned, but misguided “helpful” assistance of others, they are deemed overly demanding, unappreciative, and the ultimate defense proffered by Samaritans is, “I was only trying to help”. Good intentions are expected to trump ineffectiveness, a conditions I’ve previously referred to as “beneficent incompetence”.

The power and pervasiveness of these assumptions and the predictability of behavior they drive is found broadly in popular culture. Most notably, the assumptions shape and predict the discourse about disability in America.

The Inspiration Quotient

An example from the June 22, 2004 edition of the Evansville Courier and Press serves to illustrate the circular, pejorative, limiting, stereotypic views about persons with disabilities. The article—a full front page story with predictable color photographs—concerned a 22 year old man who uses a wheelchair. The photos and text depicted this young man engaging in activities that most of us would consider being rather routine, and certainly unremarkable. Activities such as greeting worshipers at church, bowling, visiting with benefactors (folks who had “befriended” this young man through their involvement in the community integration program in which he is enrolled), and similar “normal”, “routine” activities were highlighted. The text was replete with references to the young man’s persistence, sense of humor, aspirations, and pleasantness. Again, none of these characteristics would be deemed noteworthy—and certainly not newsworthy—if exhibited by any other person. The editorial bias, to wit; these things are remarkable—and newsworthy—because this man has a disability and uses a wheelchair. The low

expectations for persons with disabilities betrayed by the newspapers judgment about the interest and value of this man's story both reify and nurture the assumptions discussed in the Fine and Asch article. Such stories highlighting "accomplishments" and implicitly unexpected "normal" behaviors are all too commonplace.

Such articles have prompted me to consider how we might understand their appeal. I'm developing the concept of The Inspiration Quotient (In. Q.) The In. Q. can be understood as the relationship between expectations for and achievements of persons with disabilities. Given the chronic, widespread condition of low expectations, even nominal "achievements", such as depicted in the Courier and Press article, are "extraordinary". Their appeal includes an affirmation that people with disabilities—for whom we have no animus—actually can do "normal" things. They are deemed "inspirational". It makes the non-disabled viewer feel better.

The "average" In. Q. is 100 (a perfect match between expectations and achievement), where the subject does as expected. In. Q.s in excess of 100 occur either because expectations are incredibly low (the usual condition) and achievements are average (such as in the case above), or In. Q. values because achievements exceed the typical low (v. "incredibly low") expectations. Below average In. Q. values occur when the achievements are substantially lower than expectations. Such condition seems most common in educational settings where expectations have to do with compliant school behavior rather than academic performance.

In the absence of "noteworthy" achievements, effort counts in the In. Q. computation. This is reflected in accounts of the "achievements" of Special Olympics participants, where medals are awarded for skills that are of little or no functional value. (For example, the softball toss is scored on distance rather than accuracy or reciprocity. Most folks who throw a softball throw it to another *person*, not just randomly on the field), and every participant is a "winner" just trying. (Effort counts!) Media accounts of these events are replete with effusive, evocative accounts by the dispensers of copious hugs who attest to the affirming effect of dispensing hugs to such "deserving" recipients. (Beneficence rewarded!) No one questions the paradigm that victimizes Olympians thereby creating opportunities for "normals" to express their generosity and love.

Obviously, the In.Q. is very susceptible to the biases and interpretation of the observer. For some, that we disabled folks are able to get out of bed and go to the supermarket is "inspirational", warranting a high In. Q. for us—we should feel good, right? Who knows, the newspaper may even want to a story about our shopping, deeming it newsworthy!

Using us and our lives as inspirational icons that reinforce the very limiting judgments and behaviors that serve to perpetuate our marginalization is duplicitous at best, and cruelly exploitive, at worst. This conspiracy of low expectations, ascribing inspirational value and failure to understand the experience of disability as a dynamic, socially constructed phenomenon, where the quality of our lives is predicted more by what

happens around us than by what are disabilities are, continues to relegate us to second class citizenship.

Assumptions that Challenge the Status Quo

In our textbook, Ending Disability Discrimination: Strategies for Social Workers, my co-editor Martha Raske, and I argue that disability is only reasonably understood in this dynamic framework where the quality of interaction is a more important predictor of achievement and satisfaction than the disability itself. Disability-related impairment is viewed as a consequence of discrimination, not as a consequence of the disability itself. Our book is based on the assumption that disability and impairment are not immutably linked. As a wheelchair user, I'm not usually impaired, but in an environment that has architectural barriers such as steps, I am impaired even though my disability is exactly the same in both circumstances. So, impairment is not predicted by my disability but by the receptiveness of the environments in which I operate.

A second assumption is that disability-related impairment is socially constructed. It's all about the capacity in communities for all citizens to access opportunities to participate, to achieve, to fail and to be held accountable. This suggests a much broader target system for intervention on behalf of people with disabilities. Continuing to focus interventions on mitigation, restoration, and rehabilitation, while continuing to ignore broader systems, prejudices and marginalizing forces, is short sighted and of very limited positive consequence for people with disabilities.

Raske and I contend that "disability" is a nominal state that is accompanied by limiting assumptions, prejudices, and stereotypes only if it suits the observer. In this sense, disability is a name only. It does not in itself suggest inferiority, superiority or anything else. To the degree that such judgments accompany the conceptualization and discourse about disability, they reflect the biases of the holder of such judgments. Clearly, we have made impressive improvements—even though we have work to do—in understanding race and gender relations. We must work to further this understanding of disability.

Disability and pride can coexist. This assumption casts a different light on the perceptions of and about persons with disabilities than is consistent with rash conclusions about our value as icons of inspiration. Pride is an important confounding variable in the In. Q. calculation. How does one assess the influence of pride as a motivator in our living rich, productive lives—not in spite of or because of our disabilities—but with our disabilities? Most folks think disability is anathema to pride. The concept of "Disability Pride" is an oxymoron to them.

Finally, Raske and I assert that helpers/advocates/activists must assume a "working with" rather than a "working on" orientation when interacting with persons with disabilities. This collaborative, consultative role is contrary to the usual stereotypes and expectations concerning persons with disabilities. The evidence that little is at risk if we change our orientation is abundant. It was again validated in the NOD/Harris survey.

The Americans with Disabilities Act was signed into law on July 26, 1990. The U.S. Supreme Court's Olmstead decision was June 22, 1999. These seminal changes in the glacial movement of legislation and litigation involving people with disabilities have not resulted in radical or even significant granular changes in American culture. People with disabilities may well be the last discovered minority group in the U.S. It's up to all of us who are willing to challenge and question the assumptions that support the status quo to insist that changes be made. We need to challenge In. Q. assumptions. We need to challenge popular portrayals of people with disabilities. We need to challenge low expectations. We need to challenge patronizing treatment of and second class citizenship of persons with disabilities. It's imperative that we each make the changes that we can. The stakes are high. The need is great. LET'S GO DO IT! LET'S END DISABILITY DISCRIMINATION!

DEVELOPMENTAL DISABILITIES

The following resource sheets provide brief descriptions of some common developmental disabilities. The attempt is not to compartmentalize these conditions/diagnoses, but rather to give the student some basic information. The instructor should begin by introducing or reviewing the perspective of disability as a social construct (i.e. review the definitions of disability and models of disabilities provided in this resource manual). Viewed in this manner the limitations of the medical model should become salient and the student should be able to recognize the implications of the limitation.

OVERVIEW OF ASPERGER'S SYNDROME

Asperger's Syndrome is a life-long neurobiological disorder. Due to many common characteristics, it is often considered to be an Autism Spectrum disorder although the debate goes on as to whether it should be classified separately. First mentioned by Hans Asperger in 1944, this disorder was not commonly diagnosed until the mid 1990's. Individuals with Asperger's Syndrome are typically on the average to high end of the intellectual scale. According to Dr. R. Kaan Ozbayrak in [A Guide for Parents](#), the prevalence rate for this disorder is 36/10,000, typically affecting males much more frequently than females (4:1). There is current evidence that genetics plays a part in the occurrence of this disorder. Some famous people thought to have Asperger's include Albert Einstein, Thomas Edison, Leonardo da Vinci, and Beethoven.

Individuals with Asperger's vary greatly both in the characteristics of their disorder and in its severity. According to the DSM-IV-TR, criteria for the disorder are qualitative impairments in social interaction and restricted repetitive and stereotyped patterns of behavior, interest, and activities causing significant impairment in social, occupational, or other important areas of functioning with onset occurring before the age of three. It is important to note here that not all individuals consider this to be a disorder. Some refer to those without the disorder as "neuro-typical" individuals and themselves as "Aspies".

Diagnosis is usually made based on a combination of early developmental history, displayed behaviors, and reports from parents, caregivers, and other involved entities. Since diagnosis of this disorder is fairly recent and the first to be diagnosed were children, many adults were either not diagnosed, or misdiagnosed. Criterion for diagnosis in adults is still being developed. It is not uncommon for those with Asperger's to have a dual diagnosis of Depression and/or Anxiety disorders.

Characteristics vary with difficulty with social relationships being a commonality. Children will benefit from Social Skills Training. In addition to problems with social interaction, individuals often have problems reading non-verbal cues, are concrete not abstract thinkers, and are oversensitive to stimuli (i.e.: noise, taste, smell, feel). Stimuli may become overwhelming for the individual resulting in inappropriate behaviors. It is important to have a "safe" spot where the individual may retreat to when they feel

overwhelmed. Making eye contact may be difficult especially in the case of children. Their preoccupation with certain interests/activities may lead to them being considered by others as rude, geeks, or bores. It is through these very same limited interests/activities that many attempt to communicate. These interests/activities may therefore be used as an affective means of “connecting” with the client.

Adults have often learned to use their strengths to mask different aspects of their disorder. Adults often run into problems in understanding emotions (theirs and/or others), in work and intimate relationships, social situations, etc. One individual stated that he “learned” how to appropriately respond in social situations, but could not apply that to close relationships where emotions came into play. Adults’ limited focus of interests/activities often influences their choice of employment. Inability to remain in this general area becomes more of a crisis for these individuals than the majority of the population. As with children, the effort of attempting to appear “normal” may be emotionally and physically exhaustive.

Since this is a neurobiological disorder with individuals ranging from average to gifted intelligence, their disability is not as apparent to most individuals as a physical disability. It is difficult for parents, teachers, and others to understand how someone who is so intelligent and knowledgeable in certain areas has issues/difficulties with others. For example, there may be strengths in areas of verbal ability with weaknesses in non-verbal areas. The important thing to remember is that everyone is an individual with different strengths and weaknesses. Everyone has their own special gifts. Building on these strengths along with Social Skills training are important aspects of working with individuals with Asperger’s.

AUTISM SPECTRUM DISORDERS

Autism is a developmental disability that affects communication, social interaction, and patterns of behavior. Autism is four times more common with males than females. Signs of autism are usually seen by age 3, for some children as early as 18 months. Autism Spectrum disorders (ASD) can range from severe to a milder form (Asperger syndrome). Sometimes the diagnosis of ASD is delayed because teachers or doctors believe the child is just “a little slow” and will catch up.

Children who are diagnosed with ASD demonstrate atypicality in 3 areas: 1) social interaction, 2) verbal and nonverbal communication, 3) repetitive behavior or interests. Each of these atypical behaviors can range from mild to severe. Each child may experience different effects. Children with this disability may follow typical child development patterns for the first year or so and then show less typical patterns. Some children with ASD find it hard to engage in the give and take of everyday social interaction and are not able to play with other children. It can also be hard for some people with ASD to regulate their emotions. Some children do not speak and some become very disturbed if a routine is interrupted in any way. Many children with ASD experience increased sensitivity as the brain seems unable to balance the senses. Facial expression, movements, and gestures may not match verbal communication. Tone of

voice is sometimes high-pitched, or flat and robot-like. Tone of voice may not match emotion. Frustration, anxiety and depression may occur as children become more aware of their difficulties in communicating with others.

Generally, diagnostic evaluation is made by a multidisciplinary team including a psychologist, a neurologist, psychiatrist, a speech therapist, a social worker, or other professionals who diagnose children with ASD. Children with ASD are guaranteed special education and services under the Individuals with Disabilities Education Act (IDEA) and public schools must develop an Individualized Education Program (IEP) to meet the child's needs. Early intervention is important in identifying child and family needs and building on the child's and family's strengths. Intervention can help build communication and social interaction skills. In middle and high school years, services can help address work, living, and recreation activities.

Reference

National Institute of Mental Health
[Http://www.nimh.nih.gov/publicat/autism.cfm](http://www.nimh.nih.gov/publicat/autism.cfm)

BRAIN INJURY

Traumatic brain injury (TBI) is an insult to the brain, not of a degenerative or congenital nature, caused by an external physical force that may produce a diminished or altered state of consciousness, which results in an impairment of cognitive abilities or physical functioning. It can also result in the disturbance of behavioral or emotional functioning.

Acquired brain injury (ABI) is an injury to the brain which is not hereditary, congenital or degenerative. An acquired brain injury is an injury to the brain that has occurred after birth. Causes of ABI include external forces applied to the head and/or neck (traumatic brain injury), anoxic/hypoxic injury (e.g., cardiopulmonary arrest, carbon monoxide poisoning, airway obstruction, and hemorrhage), intracranial surgery, vascular disruption, infectious diseases, intracranial neoplasms, metabolic disorder, seizure disorders and toxic exposure.

According to the Brain Injury Association of West Virginia, TBI is the number one killer of persons under the age of 44 and a major cause of disability. Motor vehicle accidents cause more than one half of all traumatic brain injuries.

Mild brain injury is also known as a concussion. Moderate brain injury results in loss of consciousness lasting from a few minutes to a few hours. Confusion may last from days to weeks and physical, cognitive and/or behavioral impairments may last for months or be permanent. Severe brain injury almost always results in prolonged unconsciousness or coma. It is also sometimes classified into subgroups (i.e., coma, vegetative state,

persistent vegetative state, minimally responsive state, akinetic mutism, and locked-in syndrome). Coma is a state of unconsciousness from which the person cannot be awakened and will not respond to stimuli or initiate voluntary activity.

Reference

Information above taken from the Brain Injury Association of West Virginia website:
<http://www.biausa.org>

CEREBRAL PALSY

Cerebral palsy refers to a group of condition in the motor control centers of the brain which cause problems in movement and motor functioning. These conditions usually are present at birth and may include paralysis, weakness, problems with coordination, or other atypical motor functioning. A child with cerebral palsy generally cannot move his or her muscles in a typical way. There are many possible causes of cerebral palsy including prenatal illness or infection, insufficient oxygen reaching the fetus (i.e. placenta tearing away from the uterus before delivery), prematurity, asphyxia during labor and delivery, blood diseases, server jaundice, other genetic conditions, and post-natal brain injuries (i.e. trauma or brain infection such as meningitis).

Symptoms may range from mild to severe but do not get worse over time. Cerebral palsy is not diagnosed until about age 2 or 3 and generally is based on evaluation of muscle tone and mobility. Another indication may be the presence of reflexes that typically disappear by 6 to 12 months of age. Brain imaging tests may also be used.

The 3 major types of cerebral palsy are:

- spastic – about 70 to 80% of people with cerebral palsy have this type – muscles are stiff and there may be difficulty in walking – arm, mouth, and tongue muscles may also be affected
- athetoid or dyskinetic cerebral palsy – (10%) – this affects the entire body and is characterized by fluctuations in muscle tone (varying from too loose to too tight) and is sometimes associated with uncontrolled movements – also may have difficulty with sucking, swallowing and speech.
- Ataxic cerebral palsy- (5 – 10%) – affects balance and coordination – may have difficulty with writing and may walk at an unsteady gait.

The majority of people with cerebral palsy do not have any cognitive disability. People with cerebral palsy are doctors, lawyers, teachers, social workers, artists, parents, etc..

In many cases, cerebral palsy cannot be prevented. However, some causes can be prevented by pre and post-natal care, vaccinations, nonuse of alcohol and other dangerous or illicit drugs, and prevention of head trauma such as proper use of car seats.

COGNITIVE DISABILITY

The American Association on Mental Retardation defines cognitive disability as a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18. It is not a medical disorder, nor a mental disorder. The AAMR further states that "...mental retardation refers to a particular state of functioning that begins in childhood, has many dimensions, and is affected positively by individualized supports. As a model of functioning, it includes the contexts and environment within which the person functions and interacts and requires a multidimensional and ecological approach that reflects the interaction of the individual with the environment, and the outcomes of that interaction with regards to independence, relationships, societal contributions, participation in school and community, and personal well being."

The AAMR advises professionals to:

- evaluate limitations in present functioning within the context of the individual's age peers and culture;
- take into account the individual's cultural and linguistic differences as well as communication, sensory, motor, and behavioral factors;
- recognize that within an individual limitations often coexist with strengths;
- describe limitations so that an individualized plan of needed supports can be developed; and
- provide appropriate personalized supports to improve the functioning of a person with mental retardation.

Intelligent Quotient (IQ) scores are used as a criterion for diagnosis of cognitive disability. Generally, an IQ test score of 70 or below, significant limitations in adaptive behavior skills and evidence that the disability was present before age 18 are criteria for determination of cognitive disability.

Reference

Source: http://www.aamr.org/Policies/faq_mental_retardation.shtml

Note: The American Association on Mental Retardation has voted to change their name to American Association on Intellectual and Developmental Disabilities.

DEAFNESS/HARD OF HEARING

Hearing loss can be inherited or caused by illness or injury. Hearing loss involves the decreased ability to hear sounds. Early detection of hearing loss is important in order to assist in language and communication development. Deaf and hard-of-hearing people can communicate as effectively as people without hearing loss.

The Individuals with Disabilities Education Act (IDEA) ensures the right of children between birth and 3 to receive interdisciplinary assessment and early intervention services at little or no cost. After age 3, early intervention and special education programs are provided through the public school system.

The type of sign language preferred by most deaf American adults is the American Sign Language (ASL). Many individuals with hearing loss identify with a deaf culture or deaf community and reject the pathological or medical perspective on deafness. The pathological view focuses on deaf people as different in a negative way and sees deaf people as a group of persons whose hearing loss interferes with the normal reception of speech, who have learning and psychological problems due to hearing loss and perceived communication difficulties, and who are not normal because they cannot hear. The deaf culture perspective defines deaf culture as a group of persons who share a common means of communication (sign language) that provides the basis for group cohesion and identity, who share a common culture, and whose primary means of relating to the world is visual and who share a language that is visually received and gesturally produced.

Deaf culture prefers "deaf people", "deaf" or "hard-of-hearing: rather than "people with deafness."

Reference

Sources; <http://deafness.abobut.com/cs/deafculture/a/deafculture101.htm>
<http://www.signmedia.com/index.htm>
http://www.marchofdimes.com/pnhec/4439_1232.asp

DOWN SYNDROME

Down Syndrome is a common genetic variation which usually causes delay in physical, intellectual, and language development. It is the leading cause of developmental delay. Down Syndrome includes characteristic facial features, some degree of cognitive disability, and may also include heart conditions, increased risk of infection, vision and hearing disabilities, and other health problems. The effects vary from individual to individual – each person having his/her own unique personality, capabilities, and talents.

Facial characteristics may include eyes that slant upward, small ears that may fold over at the top, small mouth, small nose with flattened nasal bridge. Some babies with Down Syndrome have short necks, small hands, and less muscle tone.

Almost half of babies with Down Syndrome have heart conditions and more than half have some visual or hearing impairment. Most of the visual impairments can be eliminated with glasses, surgery or other treatments. Screening for hearing loss should be done at birth or by 3 months of age. Children with Down Syndrome can benefit from inclusive education, appropriate medical care, early intervention, and positive public attitudes.

In adulthood, many persons with Down Syndrome are employed, live independently, and contribute to and enjoy community activities. About 15 to 20 percent of adults with Down Syndrome develop Alzheimer's disease in middle age.

Reference

Sources: <http://www.ndscenter.org/>
http://www.marchofdimes.com/pnhec/4439_1214.asp

SEIZURE DISORDER/EPILEPSY

People who have been diagnosed with epilepsy have had more than one seizure and possibly more than one type of seizure. A seizure occurs when certain atypical electrical activity in the brain causes an involuntary change in body movement or function, sensation, awareness, or behavior. Seizure disorders/epilepsy affect about 2.3 million Americans. People of all ages are affected, but it is more common with the young and old. There is some disagreement about the classification of seizure disorder/epilepsy as a developmental disability.

What causes seizure disorders/epilepsy is not always clear but it can result from another condition such as head injury, brain tumor, brain infection, or stroke. Repeated seizures can happen without warning and for no clear reason. The way a seizure manifests itself may vary from person to person. Some people lose muscle control and the body may twitch or jerk. Some people become “trance-like” or unconscious. Not every one who has a seizure has epilepsy.

There are different types of epileptic seizures including generalized seizures and partial seizures. Generalized seizures begin over the entire surface of the brain and may affect the whole body while partial seizures begin in a specific location in the brain and may cause cognitive impairment on one side of the body or the whole body. A useful test in diagnosing seizure disorder/epilepsy is an electroencephalograph (EEG) or an MRI. Seizure disorder/epilepsy can be treated with medication to control seizures as well as with special diet and, in some cases, surgery.

According to the Center for Disease Control, “people with epilepsy often struggle to overcome low self-esteem and the stigma that is attached to having epilepsy. The stigma is due in part to a lack of understanding by people they see every day – family members, schoolmates, colleagues. Some people mistakenly believe that epilepsy is a form of mental illness or mental retardation, that seizures are something to fear, that drastic first aid measures must be taken to help someone having a seizure, or that people with epilepsy cannot be valuable and productive employees. Public education is needed to eliminate these misconceptions”.

References

National Center for Chronic Disease Prevention and Health Promotion
<http://www.cdc.gov/epilepsy/>

Rowette, L. Dan Yahoo!Health Epilepsy
<http://health.yahoo.com/ency/healthwise/hw108148>

FETAL ALCOHOL SYNDROME

Fetal Alcohol Spectrum Disorders (FASD) result from prenatal exposure to alcohol. Fetal Alcohol Syndrome (FAS) is the most severe and results from alcohol passing from the placenta to the fetus in sufficient amounts to have lifelong effects. FAS is one of the most common known causes of mental retardation and is entirely preventable.

Characteristic physical features of FAS may include small eyes, thin upper lip and smooth skin in place of the usual groove between the nose and upper lip, smaller brain, improperly formed heart, and growth deficiencies. Many children with FAS have some degree of learning or cognitive disability, poor coordination, short attention span, and emotional and behavioral problems. Vision and hearing may also be affected. These characteristics are thought to continue throughout the lifespan.

Fetal alcohol effects (FAE) refer to conditions of babies who are born with lesser degrees alcohol related symptoms.

References

Sources: <http://www.nofas.org/>
<http://cdc.gov/ncbddd/fas/>

FRAGILE X SYNDROME

Fragile X syndrome is the most common inherited form of cognitive disability. It is a genetic condition caused by gene changes in the FMRI gene. Females tend to be affected less often than males and less severely.

Children and adults with Fragile X syndrome have varying degrees of cognitive disability and learning disabilities and behavioral and emotional issues. Young children often have developmental delays and may have more frequent tantrums and attention difficulties. They may appear to be highly anxious, easily overwhelmed by activity around them, have speech problems, and engage in behaviors such as hand flapping or hand biting. Tactile defensive responses (negative response to touch), preservative speech (continued repetition of words or phrases), and poor eye contact may be present. Physical features may include large or prominent ears, large testicles, double jointed, Simean crease (single horizontal crease on the palm instead of the usual 2 creases, or Sydney Line (a horizontal crease that goes from edge to edge across the palm). Fragile X syndrome is the most common known cause of autism or autism associated behaviors.

Most children with Fragile X syndrome do not have serious medical problems although about 20% develop seizures, which are generally controlled by medication.

Fragile X syndrome may be diagnosed by blood test. A blood sample is analyzed to determine if the gene variation is present. Most children with fragile X can benefit from individualized intervention plans that may involve speech therapists, physical and occupational therapists, special educators, psychologists and social workers, and pediatricians.

References

Sources: <http://www.fragilex.org/>
http://www.marchofdimes.com/pnhec/4439_9266.asp

LEARNING DISABILITIES

Learning disability generally refers to a neurobiological condition in which a person's brain is structured or works differently from what is considered typical. Information processing is effected. It may result in differences in listening, thinking, speaking, reading, writing, spelling, or mathematical skills. It is different from a cognitive disability although both are considered developmental disabilities. Usually, there is a discrepancy between a child's expected performance according to IQ test results and actual performance. (Zastrow & Kirst-Ashman, 2004).

Attention Deficit/Hyperactivity Disorder (ADHD) and learning disabilities may coexist, but these are separate and distinct conditions. People with learning disabilities have normal or above normal intelligence. Children with learning disabilities can be successful and experience high achievement with proper instruction, adaptations, and support. Unfortunately, children with learning disabilities sometimes experience feelings of low self-esteem, helplessness and frustration, fear of failure, and withdrawal when appropriate support and assistance is not provided.

The Education for All Handicapped Children Act supports the inclusion concept. Social work roles in working with children with learning disabilities include broker and advocate.

References

Zastrow, C. and Kirst-Ashman, K. (2004). Understanding Human Behavior in the Social Environment. Belmont, CA: Brooks/Cole.

<http://www.coping.org/specialneeds/impac.htm>

SPINA BIFIDA

Spina bifida affects the neural tube that develops into the brain and spinal cord. The neural tube does not close completely. There are 3 forms of spina bifida:

- Occulta – mildest – usually no symptoms. There may be a small gap in one or more of the vertebrae of the spine. Usually no treatment is needed.
- Meningocele – the rarest form. In this form, a cyst or sac pokes through the open part of the spine. The cyst is removed surgically and development generally proceeds typically.
- Myelomeningocele – most severe form. The back may be closed surgically, however some degree of leg paralysis and bladder and bowel control problems occur. The higher the cyst on the back, the more severe the paralysis.

Medical problems associated with myelomeningocele include hydrocephalus; tethered spinal cord resulting in leg weakness, scoliosis, pain in back or legs, and changes in bladder function; urinary tract infections; latex allergy; obesity; and digestive tract disorders. At least 80% of children with myelomeningocele have “normal intelligence” although some have learning problems.

Reference

Source: http://www.marchofdimes.com/pnhec/4439_1224.asp

VISUAL IMPAIRMENT

Visual impairment generally refers to blindness or low vision. The extent of visual impairment can vary greatly from individual to individual and can also vary within an individual based on factors such as lighting, glare, or fatigue. The definition of legally blind is 20/200 vision with best correction.

Possible reading:

Jindal-Snape, D (2005). Self-evaluation and Recruitment of Feedback for Enhanced Social Interaction by a Student with Visual Impairment. Journal of Visual Impairment and Blindness, 99 (8), 486-489.

This article (available on EBSCOhost) describes results of training a student who is visually impaired to evaluate his social behavior and get feedback from peers with sight. The results indicate that the student improved his ability to evaluate social skills requiring visual cues. This is an important skill in developing friendships.

Unger, D. D., Rumrill, P. D., & Hennessey, M.L. (2005). Resolutions of ADA Title I cases involving people who are visually impaired: a comparative analysis. Journal of Visual Impairment & Blindness 99 (8), 453-463. (EBSCOhost)

“Abstract: A comparison of American with Disabilities Act (ADA) Title I case resolutions by the Equal Employment Opportunity Commission (EEOC) involving people who are visually impaired with those involving all other people with disabilities between 1993 and 2002 revealed that people who are visually impaired are more likely than are other complainants to receive settlement benefits from their employers, to withdraw their complaints after they receive benefits without intercession from the EEOC, and to receive administrative closures. In addition, they are less likely than other complainants to have charges resolved by the issuance of a right-to-sue letter from the EEOC and to receive other closures. (ABSTRACT FROM AUTHOR)”

NOTE: This article also provides some examples of approaches to helping workers become self-advocates including increasing their knowledge of the law and role-playing/rehearsing conversations with employers.

Southwell, P. (2005). Vision impaired. Counselling & Psychotherapy Journal, 16(5), 34-37.

“ This article is specifically about work with clients who have acquired sight loss later in life.” Research Findings show higher prevalence of depression. Age-related Macular Degeneration(AMD) was the most common cause of blindness and partial sight in older adults. AMD affects central but not peripheral vision. Central vision effects ability to read, differentiate people’s faces, drive, and watch television. Driving and reading are reported as two of the most difficult losses. Driving means independence and control so it is important to help people regain a sense of control. The article summarizes key tasks of

therapy with people with acquired sight loss: “facilitate emotional expression and recognition of what it means to them; help them regain a sense of control of their inner lives and of the possibility of mastering their outer environment, and to work on the meaning to them of their changed life, and their sense of significance and worth in a changed and often more hostile environment, in which expectations also have to undergo major changes.”

Assisting

Don't assume someone needs help – ask (“May I help you?”)

Allow the person with the visual disability to take your arm rather than grabbing their arm. Let the person control his/her own movements.

When giving directions, be specific (“there are 3 steps” or “go 5 feet and turn left”)

When directing to a seat, place the person's hand on the back or arm of the chair and inform them where the hand is (“your hand is on the left arm of the chair”)

A “clock system” can be used to help locate food on a plate (“potatoes are at two o'clock”).

Ask permission before interacting with a guide dog.

When conversing in a group, say the name of the person to whom you are speaking.

When you move, let the person know where you are.

(From: Video Reference Guide)

Information related to ways to assist/include students with visual impairments in classroom activities can be obtained from the following web-site:

www.as.wvu.edu/~scidis/

GENETIC TESTING: YES OR NO?

Yes

Technology is now available to test or screen for many conditions. Prenatal and newborn screening can inform parents regarding various genetic conditions. Some medical professionals may not advise parents or potential parents about this technology because of expense or personal values including fears that identifying certain genetic conditions could lead to abortion decisions. However, this should be the decision/choice of the patient. Doctors routinely inform pregnant women about tests for Down syndrome and cystic fibrosis, but do not provide information about other available testing including testing for Fragile X, the most common inherited form of cognitive disability. Genetic testing can help parents better prepare for the needs of their child and family and newborn screening can lead to early intervention and appropriate adaptations that can improve quality of life.

No

Genetic testing can be expensive and may not be covered by insurance. The identification of a genetic condition may place pressure on parents to consider abortion. Legitimizing genetic testing in order to inform pregnancy decisions serves to devalue the lives of those who are living with those conditions. There are numerous genetic tests and it would not be feasible to test everyone for everything. Researching a patient's background for which test might be appropriate could be time consuming and many doctors are not trained adequately to make a determination..

Discussion Questions

- Should tests be routinely performed for categories of people who may be at greater risk for certain genetic conditions?
- Should tests be routinely performed for certain conditions?
- Should all possible tests be available upon request?
- Who should pay for any of the above? Should public funding be available? Under what circumstances?
- What are the reasons for genetic testing?
- What are the pros and cons of genetic testing?

- Issues to consider: In what ways (positive and negative) does “knowing” effect outcomes? (Earlier medical intervention, parents more prepared, parents may choose to terminate pregnancy or not to have children). What values or ethical dilemmas come into play?
- For each of the following, what plans would you make if you knew ahead of time that you or your partner was going to have a baby who:
 - Was deaf?
 - Had Cystic Fibrosis?
 - Had Down’s Syndrome?
 - Had Spina Bifida?
 - Was blind?
 - Had Cerebral Palsy?
 - Was a girl?
 - Was a boy?

References

Harmon, A. (2004). As gene test menu grows, who gets to choose? The New York Times. July 21, 2004. In: Themes of the times (2005). Pearson Education, Inc.

See also:

Depoy, E. & Gilson, S. (2004). Rethinking disability. Belmont, CA: Brooks/Cole. (pp. 103, 104)

TRANSITION PLANNING FOR STUDENTS WITH DISABILITIES

Transition services for students with disabilities became codified with passage of the Individuals with Disabilities Education Act (IDEA) of 1990. This legislation was in response to studies that revealed poor postsecondary outcomes for students graduating with Individual Education Programs (IEP's) (Baer, 2005).

Transition planning for students with disabilities, who were 16 years of age, and younger if appropriate, would now be incorporated into their annual IEP's. These IEP's have been a requirement for all children and youth receiving special education services since IDEA, formerly known as the Education of All Handicapped Children Act, was implemented in 1975. The essential components of each student IEP contain the following:

- a. statement of the student's present level of educational performance;
 - b. annual goals and short-term objectives for each goal;
 - c. specific special education and related services to be provided, and the extent of participation expected in general education;
 - d. projected dates for initiation and duration of services; and
 - e. criteria and procedures for determining if short term objectives had been met.
- (Individuals with Disabilities Act, P.L. 101-476, 34 CFR, Section 30.18)

As a means to address and strengthen the fundamental purpose of secondary education for preparation for adult living, transition services were incorporated into the IEP's in 1990 (Flexer, 2005). Section 300.18 of IDEA (P.L. 101-476) defined these transition services as in four broad ways:

- a. determining student needs, interests, and preferences in transition planning
 - students and their parents must be notified and encouraged to attend the IEP meeting in which transition is discussed;
- b. outcome-oriented planning
 - transition services should be aimed at the "development of employment and other post-school adult living objectives".
 - These activities may include postsecondary education, vocational training, integrated employment (including supported employment, continuing and adult education, adult services, independent living, or community participating).
- c. coordinated set of activities
 - each student's IEP/transition plan (ITP) is to be coordinated by the school's Transition Coordinator and is to include, if appropriate, a statement of any public agency's responsibilities or linkages, or both'
 - formal, written interagency agreements are encouraged between the state Departments of Education and Vocational Rehabilitation (Lloyd, Cook, Opperman, & Thurman-Urbancic, 2004).

- Each students ITP tea should be comprised of the student, parents/guardians, special education teachers, administrators, related service providers such as speech therapists, guidance counselors as well as community members and service providers who provide health services, employment, leisure/recreational services and residential assistance.
- d. promoting student movement to post-school activities
 - IDEA requires that transition services be designed to successfully move the student towards their identified activities and that they be implemented early enough to ensure success.
 - IDEA of 1997 mandated that a statement of needed *transition services* be incorporated into the students IEP by the age of 16 years, and younger if appropriate.

Relevance to Social Work

The primary purpose of transition services is to prepare students with disabilities for adult life. The coordination of these services is paramount to student success and requires extensive communication among various cooperating agencies. As noted by Brolin & Loyd (2004), this may include:

- a. the Office of Vocational Rehabilitation including its Supported Employment component
- b. the Office of Blindness and Visual Services
- c. State Employment Services
- d. Job Training and Partnership Act (JTPA)
- e. State offices of mental health and mental retardation
- f. Community service organizations such as the Rotary and Lions Clubs
- g. Church organizations
- h. Educational entities such as postsecondary institutions, vocational schools, and trade/proprietary schools

Simmons, Flexer, & Bauder (2005) point out those school personnel need the input and contributions of interagency linkages in order for students to realize their transition goals. Examples of these transition service requirements include:

1. Instruction: tutoring, employability skills training, vocational education, college entrance exam preparation;
2. Community experiences: job shadowing, community work experiences;
3. Development of employment and postschool adult living objectives: career planning, interest inventories, self-determination training
4. Related services: occupational and physical therapy, speech therapy, psychology services
5. Daily living skills training: self-care training, home repair, health training, money management

6. Linkages with adult services: referral to vocational rehabilitation, summer youth employment programs, developmental disability and mental health boards, independent living centers
7. Functional vocational evaluation: situational work assessments, work samples, aptitude tests, job tryouts (pp. 217, 219)

Social workers are often involved in the transition process for clients with disabilities including serving in a case management role. Suggestions on how to assess and appropriately identify which of these agencies may best serve a client includes (Brolin & Loyd, 2004) developing a Community Resource Directory that identifies a whole range of possible client services, determining which needs may best be served by non-school personnel and then providing the appropriate referral for consideration of these services, and establishing personal contact with personnel from these agencies.

References

Baer, R. (2005). Transition planning. In Flexer, R.W., Simmons, T.J., Luft, P., & Baer, R. (Eds.). Transition planning for secondary students with disabilities (pp.305-335). Upper Saddle River, N.J.: Pearson Prentice Hall.

Flexer, R. (2005). History and transition legislation. In Flexer, R.W., Simmons, T.J., Luft, P., & Baer, R. (Eds.). Transition planning for secondary students with disabilities (pp.20-52). Upper Saddle River, N.J.: Pearson Prentice Hall.

Loyd, R.J., Cook, I.P., Opperman, C., & Thurman-Urbancic, M. (2004). Transition planning. In Brolin, D.E. & Loyd, R.J. (Eds.). In Career development and transition services: A functional life skills approach (pp.195-220). Upper Saddle River: Pearson Prentice Hall.

Simmons, T., Flexer, R., & Bauder, D. (2005). Transition services. In Flexer, R.W., Simmons, T.J., Luft, P., & Baer, R. (Eds.). Transition services (pp.211-244). Upper Saddle River: Pearson Prentice Hall.

ABUSE AND NEGLECT

Research has shown that some children are at greater risk for abuse and neglect. Some children can be more demanding and seen as more difficult. There are also situations where a child does not meet a parent's expectations; for example the baby was a girl and the parent was determined that this child would be a boy. This existence of these situations in no way implies that the child deserves punishment. It only implies that some children are at higher risk for child abuse and neglect due to their special circumstances or needs.

Children with disabilities have an increased vulnerability to abuse. Abuse, in turn, causes disabilities. Approximately 18,000 children per year experience a variety of permanent disabilities because of abuse or neglect. Children who have disabilities, due to previous abuse or not, suffer abuse twice as often as children without disabilities.

Many myths create barriers around the issue of child abuse among children with disabilities. These include:

- Belief that children with disabilities are more protected than children without disabilities. This false sense of security can lead to denial that abuse could occur or is occurring.
- Belief that children with disabilities are less important than children without disabilities.
- Belief that children with disabilities are less sensitive to suffering from physical or sexual abuse since they are perceived as infantile or asexual.
- Belief that the victim has provoked the abuse.
- Reluctance to accuse professional caregivers if they are the source of the abuse.
- Belief that children with disabilities are less credible than children without disabilities.

For children with severe disabilities, it might take particularly flagrant signs (death, pregnancy, venereal disease, or a new physical injury) before abuse is noted. This challenge can cause children to be left in danger for many years.

While many of the risk factors for children with and without disabilities are the same, other specific areas of concern that make children with disabilities especially vulnerable include:

- Dependency for care will make a child trusting and unlikely to question.
- Children learn compliance and do not complain.
- Some children with disabilities have a limited social group and fear that if they report the abuse, they will damage or end the relationship with the abuser. They might also fear retribution.

- A child with a disability might never have had the opportunity to learn about personal boundaries and self-protection or have inadequate socialization to understand ‘right’ and ‘wrong’ behavior. They might tolerate, accept, and acquiesce to inappropriate behavior.
- Self-injury will mask the source of abuse.
- Physical disabilities could seriously hamper efforts to flee.
- Communication difficulties prevent children from reporting abuse.
- Communication problems and lower cognitive functioning sometimes make a child appear less credible, and therefore they are not believed.

The consequences of abuse and neglect for children with disabilities are similar to those for children without disabilities. However, due to the nature of certain disabilities and their side effects, these consequences may be more severe. Outcomes can include:

- Mild to severe physical injuries.
- Death.
- Sexually transmitted diseases.
- Pregnancy.
- Emotional distress including anger, anxiety and fearfulness, depression and low self-esteem.
- Social withdrawal.
- Impaired ability to trust.
- Learning difficulties.
- Posttraumatic Stress Disorder.
- Tendency toward re-victimization.

Those who witness or experience abuse may be more likely to abuse others.

Children at increased risk of medical neglect and for who the consequences are serious include children with medically diagnosed diseases or disabilities and children under the care of physician sub-specialists or allied health care specialists, due to a medical diagnosis. Failure to obtain treatment, however, must be considered in light of availability of resources, parents’ financial ability to pay for treatment, parents’ cultural and religious beliefs, and the spectrum of seriousness as to the consequences of failure to obtain needed medical care. Some children with disabilities, as well as those without disabilities, lack knowledge about sexuality and abuse, thereby not discerning that sexual contact is abusive. Sexual abuse is often facilitated by personal care routines, such as dressing, bathing, and toileting.

Children with disabilities, as well as those without disabilities, are most often maltreated by persons they know and trust including parents, family members, and other caregivers. Since children with disabilities are routinely in contact with and dependent upon service providers, the risk of maltreatment, especially sexual abuse by service providers, is increased. In addition, perpetrators who abuse children with disabilities share the following characteristics:

- predominately male
- in a position of authority and control and perceive their victim as powerless and unable to accuse
- often victims of abuse as children or were exposed to abusive environments
- may claim victim provoked the abuse
- emphasize victim's differences rather than similarities to persons without disabilities, lack empathy, and minimize personal responsibility.

Not all perpetrators have these characteristics and some people who exhibit these characteristics are not perpetrators.

Disability or Abuse?

There are often practical problems in identifying maltreatment of children with disabilities because symptoms of abuse may be masked by the disability or characteristics of the disability can mimic child abuse indicators. For example:

- Some children have rare diseases that mimic the symptoms of abuse. Osteogenesis imperfecta, or brittle bones, is unusual, affecting only one in 25,000 people. (Child abuse is more common). If an undiagnosed child presents at the emergency room and multiple healed fractures show on an X-ray, medical staff should rule out the condition before reporting injuries as suspected child abuse.
- Some children with disabilities may be limited in their ability to communicate information about an abusive incident.
- Some children with behavioral impairments or cognitive disability engage in self-abusive behaviors or are prone to accidental injury.
- Some children with physical disabilities require greater assistance with personal care routines such as dressing, bathing and toileting at a later chronological age than peers who are not disabled. Personal care routines may result in occasional touching of sexual parts of the body with resultant difficulty discerning if the touch was accidental, required or exploitive.

Areas of assessment to help discern whether the presenting situation is characteristic of the disability or indicative of abuse or neglect include:

- Observation of the injury.
- The child's statements.
- Consistency of injury with explanation given.
- Consistency of the injury with the child's developmental and/or physical capacities.
- Witnesses to the incident.
- Medical findings.

- The child's behavior.

The best rule of thumb in discerning maltreatment is to know what is typical for that particular child. When assessing the child's behavior, it is important to:

- Examine the history of the behavior.
- Obtain a behavioral "baseline".
- Determine whether there has been a clear behavior change that has taken place during the time frame in question.

The following behaviors, especially when corroborated with other evidence, may indicate sexual abuse:

- Increased masturbation.
- Touching others.
- New and odd behaviors related to child's own genitals, i.e. pulling, punching, rubbing, inserting objects into orifices.
- Irritability with related behaviors.
- Fears.
- Sexual drawings.

Situations of sexual activity between children are reportable to child protective services when:

- The perpetrator is in a care-taking role.
- There is suspected lack of supervision by the parent or adult caregiver, thereby enabling the activity to take place.

The following variables should also be considered when assessing sexual activity between children:

- Whether the activity is considered to be normal sexual curiosity that is developmentally appropriate.
- The age difference between the victim and perpetrator.
- The use of force or violence.
- The nature and frequency of sexual activity.
- The existence of a power differential, knowledge differential, and gratification differential between perpetrator and victim.

Interdisciplinary Teamwork

Investigation of suspected abuse or neglect of children with disabilities should follow the same thorough investigatory principles as required for children without disabilities.

Investigative strategies to help facilitate interdisciplinary teamwork and effective intervention include:

- Specialized knowledge on the part of the law enforcement investigator and child protective services worker about children with disabilities.
- Assistance from a disability specialist either in interviewing or providing advice on how to conduct the interview or interpret the results.
- Interdisciplinary policies and procedures on the management of suspected abuse or neglect of children with disabilities, including identified, trained agency liaisons.

Reference

The preceding information is from *One Child at a Time: A Guide for Professionals in Recognizing and Reporting the Abuse and Neglect of Children with Disabilities* by the TEAM for West Virginia Children (2002) and is printed with their permission. The entire publication can be downloaded from their website: www@teamwv.org

CHILDCARE EQUIPMENT FOR PARENTS/CARETAKERS WITH DISABILITIES

The following items are examples of some of the equipment available to assist parents and caretakers with disabilities in caring for children.

The First Years Easy Read Medicine Dropper (larger numbers, larger size)

EvenFlo Ellipsa Stroller (baby sits far forward and is more stable and least likely to tip backward; offers one hand steering and one hand recline)

Cosco Beginnings Simple Start High Chair “Mansfield” (open bottom-increased access for wheelchairs)

Bassinettes and Play Pens (a portable play pen and bassinette may be the best option for women with decreased mobility or for those seated in a wheelchair. Because it is meant to break down, one side folds down with the press of a button, creating accessibility to the child.)

Wheel chair accessible crib (a typical crib was raised to allow access by the wheelchair rolling under. Two doors allow the parent to access the child no matter where she or he is.

Nursing Assistant (a piece of gray foam is formed to the shape of the wheel chair with attached canvas straps with a quick-release latch. One end of the latch is on the lap tray; the other end is attached to the armrests.

Toddler Seat (attaches to a wheelchair for a toddler. Seat rotates and has a seatbelt.)

Reference

Sexton, Jennifer in partnership with the West Virginia University Center for Excellence in Disabilities. Under the magnifying glass: meeting the needs of mothers with physical disabilities: a workshop for nursing professionals.