Learning objectives

- Understand the definition of developmental disabilities.
- Understand typical developmental and screening indicators for children aged 0-3.
- Identify the four categories of developmental disabilities.
- Understand intellectual disabilities.
- Understand Down syndrome.
- Understand pervasive developmental disorders/autism spectrum disorders.
- Learn about the features, etiology and prevalence of specific developmental disabilities.
- Understand treatments strategies available for developmental disabilities.
- Gain deeper perspective from case stories about how developmental disabilities affect individuals and families.

Introduction

Developmental disabilities are birth defects that cause lifelong problems with how a specific body part or body system works. They are chronic and severe conditions that impact daily living and functioning, and usually originate at birth or during childhood.

Over 6 million people in the United States have a developmental disability (University of Minnesota, 2010). Some examples of developmental disabilities are autism spectrum disorders, brain injury, cerebral palsy, Down syndrome, hypothyroidism and phenylketonuria (PKU), behavior disorders, spina bifida and fetal alcohol syndrome (FAS). There are no cures for developmental disabilities; however, there are many treatment options available to manage specific conditions successfully. Individuals who are diagnosed with developmental disabilities can live a meaningful, more active, productive and comfortable life with comprehensive and long-term interventions (University of Minnesota, 2010).

Developmental disabilities have come a long way in the past 20 years, from near obscurity and a widespread assumption that they were rare to the forefront as a topic of focus among private and governmental organizations. This has mainly come about as a result of recent studies showing that developmental disabilities, specifically autism spectrum disorders, also known as pervasive developmental disorders, are so prevalent that they have been identified as a national health concern by the Centers for Disease Control and Prevention (CDC). The CDC has launched a nationwide campaign called “Act Early. Know the Signs” and offers information and materials free of charge for mental health professionals as well as families on all aspects of infant and child development as well as developmental disabilities (Centers for Disease Control and Prevention, 2005).

Developmental disabilities defined

According to the Developmental Disabilities Act, section 102(8), the term “developmental disability” means a severe, chronic disability of an individual 5 years of age or older that:

1. Is attributable to a mental or physical impairment or combination of mental and physical impairments.
2. Is manifested before the individual attains age 22.
3. Is likely to continue indefinitely.
4. Results in substantial functional limitations in three or more of the following areas of major life activity:
   i. Self-care.
   ii. Receptive and expressive language.
   iii. Learning.
   iv. Mobility.
   v. Self-direction.
   vi. Capacity for independent living.
5. Reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided. (Maryland Developmental Disabilities Council, 2010)

The Individuals with Disabilities Education Act (IDEA), is a special education law stipulating that all children with disabilities should receive appropriate opportunities for education in the least restrictive and most inclusive environment. It is especially encouraged that an individual with an intellectual disability have the opportunity to interact with other peers of their age group (Merck, 2009-2010). IDEA governs how states and public agencies provide early intervention, special education and related services to more than 6.5 million eligible infants, toddlers, children and youth with disabilities. Infants and toddlers ages 0-2 with disabilities and their families receive early intervention services under IDEA Part C. Children and youth ages 3 to 21 receive special education and related services under IDEA Part B (U.S. Department of Education).
Typical developmental patterns and possible delay indicators

To better understand developmental disabilities, a knowledge base in standard child development is needed. Mental health professionals should be aware of the common milestones in infants and children in the areas of cognition, social-emotional skills, motor function, speech and language skills (oral-motor in infants), adaptive (self-help) skills, as well as other indicators for further screening. This awareness may assist in the provision of an early diagnosis of a developmental disability.

Early intervention is the single most important factor in a brighter prognosis for children identified as having a developmental delay or disability. Below is a listing of key milestones in child development for infants up to age 3, along with indicators for further assessment.

1-2 months

Cognitive:
- Pays attention to someone’s face in the direct line of vision.

Social/emotional:
- Smiles and coos with throaty sounds such as “gu.”
- Likes to be held and rocked.
- Quiets when held or picked up, cries to get attention.

(Infant Parent Program, 1993)

3-5 months

Cognitive:
- Has learned behavior can cause others to act in predictable way (if smiles, gets kissed).
- Eyes locate source of sound.
- Has different cries for pain, hunger or anger.
- Knows strangers from family.
- Seeks out objects (looks for bottle).
- Recognizes bottle or nipple.
- Hands open in anticipation of contact.
- Shows different responses to different family members.
- Searches for speaker.
- Cries at angry tone of voice.
- Reaches for and holds objects.
- Stands firmly when held.
- Rotates head freely.
- Able to bear weight on forearms.
- Rolls from tummy to back, to side, by accident.
- Inspects own hands.
- Hands clasped together often.
- Hands partly open.

Oral motor:
- Mouth opens for food.
- Tongue thrust when the spoon is withdrawn, food is spit out.
- Begins eating cereals, fruits and juices.

Language:
- Responds differently to vacuum cleaner, phone, doorbell or barking dog; may cry or whimper, look toward sound, or increase body tension.
- Uses different voice patterns.
- Babbles.
- Recognizes own name.
- Vocalizes in response to singing.
- Takes turn vocalizing.
- Vocalizes to express displeasure.

Self-help:
- Stretches out arms to be picked up.

(Infant Parent Program, 1993)

6-9 months

Cognitive:
- Searches for objects.
- Imitates actions.
- Finds object after watching it disappear.
- Anticipates movement of objects in space (knows ball will go across room when thrown).
- Will repeat an action to get some consequences (will hide over and over to get you to say “peek-a-boo”).
- Laughs at physical games.
- Recognizes names of familiar objects.
- Stops activity when name is called.
- Participates in games with adult.
- Interacts with objects without mouthing or banging.
- Looks at pictures.
- Is content as long as sees parent; if parent leaves room, cries and tries to follow.
- Shows mild to severe separation anxiety.
- Infant-to-infant interactions.
- Lifts arms when asked if wants up.

Motor:
- Wide range of abilities; pulls, turns, pokes.
- Takes feet to mouth.
- Takes hands to feet.
- Able to reach for toy with one or both hands.
- Supports self in sitting (props with arm).
- Increased extension in back.
- Sits by propping forward on arms.
- Protective response when falling forward (arms out to stop fall).
- Able to rotate upper body independently of lower body.
- Pulls string to get toy.
- Increased ability to bear weight on legs.
- Legs spread apart, turned outward when standing.

Social/emotional:
- Knows parents from other adults, shows special dependence on them, wants food, attention, stimulation and approval from them even when others are available.
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● Gets to sitting from lying down.
● Starts climbing.
● May pull to stand at furniture.
● Pulls to stand by kneeling, then lifts one leg at a time.
● Walks sideways while holding on.
● Rotates trunk over lower body.
● Trunk leans when reaching.
● Picks up small objects with several fingers and thumb.
● Object held in palm by fingers and thumb.
● Transfers object from hand to hand.
● Drops one toy when given another.

Oral motor:
● Can drink slowly with cup but cannot control flow with tongue (choke).
● Jaws move up and down.
● True suck (stable jaw).
● Upper lip comes down well on spoon.
● Tongue holds food on biting surface (gums).

Language:
● Responds to own name.
● Recognizes the words “mama,” “dada” and “bye-bye.”
● Recognizes family members’ names.
● Appears to listen to conversations of others.
● Responds to request “come here.”
● Uses vocalizations and gestures to protest.
● Shouts to gain attention.
● Attends to music and singing.
● Maintains attention to speaker.
● Waves bye-bye.
● Has complex babbling of many sounds strung together.
● Vocalizes two syllable combinations, like “mama.”

10-12 months

Cognitive:
● Laughs aloud in play.
● Responds to name with a head turn, eyes, and smiles.
● Responds to verbal requests.
● Begins to understand the meaning of “no.”
● Begins to see relationships between complex actions and consequences (opening doors, putting lids on).
● Functional use of toys (throws ball, pushes car).
● Learns to do something after you show how (rock doll, bat balloon).
● Performs an action to produce a result.
● Combines related objects (puts furniture in dollhouse, plays with animals together).
● Finds hidden toys.
● Can begin putting pegs in holes.
● Plays catch.
● Looks at objects parents are looking at.
● Puts objects in containers and takes them out.
● Examines objects held in hand.
● Plays interactive games (peek-a-boo).
● Gives toys to others.
● Can find an object that is placed under another object.
● Covers and uncovers face during peek-a-boo.
● Identifies two body parts on self.

Social/emotional:
● Vocalizes, smiles, reaches for familiar person.
● Resists removal of toys.
● Fear of strangers usually ends by age 1.
● Increased dependence on parents.
● Resistance to bedtime.
● Shy period passes by age 1.

Self-help:
● Lifts cup with handle.
● Eats dry cereal, meats, vegetables, fruit with fingers.
● Holds, bites, chews food.

Regions for further assessment:
● Cannot sit with help by 6 months.
● Does not actively reach forobjects by 6 to 7 months.
● Does not babble by 8 months.
● Does not bear weight on legs by 7 months.
● Does not follow objects with both eyes at near (1 foot) and far (6 feet) ranges by 7 months.
● Does not laugh or make squealing sounds by 6 months.
● Does not respond to sounds around him or her.
● Does not roll over in either direction (front to back or back to front) by 5 months.
● Does not smile on his or her own by 5 months.
● Does not try to attract attention through actions by 7 months.
● Does not turn head to locate sounds by 4 months.
● Doesn’t seem to enjoy being around people.
● Experiences a dramatic loss of skills he or she once had.
● Has difficulty getting objects to mouth.
● Head still flops back when body is pulled to a sitting position.
● One or both eyes consistently turn in or out.
● Persistent tearing, eye drainage or sensitivity to light.
● Reaches with one hand only.
● Refuses to cuddle.
● Seems impossible to comfort at night after 5 months.
● Seems very floppy, like a rag doll.
● Seems very stiff, with tight muscles.
● Shows no affection for the person who cares for him or her.
● Shows no interest in games of peek-a-boo by 8 months.

(Infant Parent Program, 1993)

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(Centers for Disease Control and Prevention)
Self-help:
- Takes off shoes and socks.
- Cooperates in dressing.
- Stops drooling.
(Infant Parent Program, 1993)

Indicators for further assessment:
- Cannot stand when supported.

13-18 months

Cognitive:
- Imitates other children.
- Starts turn-taking games.
- Feeds others.
- Plays fetching games.
- Shakes head “no.”
- Shows shoes and clothing during play.
- Plays the right way with toys.
- Shows use of object (brushes with comb, sweeps with broom).
- Explores toys.
- Follows one-step requests.
- Maintains attention to pictures.
- Enjoys rhymes and finger plays.
- Identifies three animal sounds.
- Sings independently.
- Identifies objects by category.
- Has favorite toy.
- Turns pages of book.
- Links plans in simple combinations (puts person in car and pushes car).
- Can focus pretend play with toys or people.
- Imitates new movements.
- Uses adult to achieve goal.
- Attempts to start simple machines.
- Rotates and examines all three dimensions of an object.
- Can try new ways to solve a problem.
- Matches object parts with others (round lid on teapot).
- Discriminates circle and square in a puzzle.
- Imitates grown-up reading, sweeping, talking on the phone.

Social/emotional:
- Hugs toys and people.
- Plays away from familiar people.
- Stranger anxiety may return briefly, asks for help.
- Laughs at events that are different from normal.
- Shows anger or frustration.

Motor:
- Imitates scribble.
- Builds two- to five-block tower.
- Squeezes toys.
- Enjoys walking activities, pulling toys, throws and picks up objects.
- By 13 months, walks a few steps without support.
- By 18 months, walks with no support.
- By 18 months, balanced somewhat when walking.
- Likes to climb.
- Likes to take things apart.
- Seats self in small chair.
- By 15 months, able to stop and start walking.
- By 17 months, jumps down from step.
- By 18 months, seldom falls; runs stiffly, eyes on ground.
- Creeps up stairs on hands and knees.
- Holds crayon in fist, thumb up.
- Precise controlled release.

Oral motor:
- Full precise use of cup, no chokes, few drips.
- Begins independent use of spoon.
- Chews most foods well.

Language:
- Vocalizes more when playing.
- Responds to request to say words.
- Responds to “give me.”
- Understands “in” and “out.”
- Says 10-15 words spontaneously.
- Names one object frequently.
- Varies pitch when vocalizing; uses three words with babble.
- Asks to have needs met.
- Uses consonants such as t, d, n and h.
- By 18 months, talks more than gestures.
- Imitates words overheard in conversations.
- Asks, “What’s that?”
- Asks for more names, five or seven objects on request.

Self-help:
- Brushes teeth with assistance.
- Combs or brushes hair.
- Cooperates more when dressing.
- Puts socks on.
- Shows wet or soiled pants.
- Moves about house without adults.
- Hands empty dish when finished eating.
- Unzips zipper.
- Gets into adult chair unaided.
(Infant Parent Program, 1993)

19-24 months

Cognitive:
- Leads parent to desired object.
- Puts away toys on request.
- Pretends to play musical instrument.
- Imitates housework activities.
- Groups objects in play.
- Uses two toys together in pretend play.
- Knows four body parts and clothing items on self.
- Chooses five familiar objects upon request.
- Names pictures when asked.
- Attempts to fix broken toys.
- Stacks and assembles toys and objects.
- Chooses one object from group of five upon request.
- Follows two-step directions.
- Uses both small and large toys.
- Plays for longer periods than before; interested in manipulative and constructive toys.
- Enjoys rhymes and singing.
- Will have inanimate objects perform actions (doll washes self).
- Notices shapes of things.
- Thinks somewhat before acting.
- Uses a tool to obtain a desired object.
- Can foresee effects.

(Infant Parent Program, 1993)
### Social/emotional:
- Parallel play (not with other children, but alongside).
- Loves rough and tumble play.
- Demands nearness of adults.
- Alternates between clinging and resistance to parents.
- Conscious of own acts (acts whether parents approve or disapprove).
- Spends most of group in solitary play, watching other children.
- Interacts by watching, taking turns, and playing roles.

### Motor:
- Pushes a stroller or cart.
- Flies a toy airplane.
- Runs.
- Walks up stairs, one at a time, not alternating feet.
- Squats to play.
- Jumps off floor with both feet.
- Snips paper with scissors.
- Strings two or three beads.
- Crawls backward down stairs.

### Oral motor:
- Drinks from straw.
- Has lip control when cup is moved away from mouth.
- Does sequence of suck-swallow.
- Can drink 1 ounce from a cup without pausing.
- Can stop breathing while swallowing.

### Language:
- Uses adult-like dialogue.
- Uses words during pretend play.

### 2-3 Years

#### Cognitive:
- Pretends to write or type.
- Pretends to talk on telephone.
- Performs many related activities during the day.
- Points to four action words in pictures.
- Understands the concept of “one.”
- Understands size concepts.
- Identifies four objects and what they can do (broom sweeps, clock ticks).
- Understands location phrases (on the table, under the chair).
- Names one color.
- Uses one object to represent many objects (a stick can be a gun, shovel, truck).
- Shows interest in how and why things work.
- Follows three-step unrelated request.
- Identifies parts of an object.
- Counts to three.
- Copies circle.
- Matches four objects to their picture.
- Has increased attention span.
- Can describe actions.
- Relates one experience to another, using logic and knowledge of previous experiences.
- Can plan actions in own mind without acting them out.
- Recognizes self in photo.

#### Social/emotional:
- Shares toys with other children.
- Responds to greetings.
- Takes turns when asked.
- Aggression increase.
- Plays well with two to three in a group.
- Begins to claim and defend ownership of objects (mine).
- Inflexible and rigid.
- Has best friend.
- Recognizes adult standards and corrects self.

#### Motor:
- Runs with whole foot contact, stops and starts.
- Can describe actions.
- Talks more in play with other children.
- Rides tricycle.
- Interacts by watching, taking turns, and playing roles.
- Fails to develop a mature heel-toe walking pattern after several months of walking, or walks only on toes.
- Refers to self by name.
- Understands size concepts.
- Uses sentence-like intonation patterns.
- Imitates two-three word phrases.
- Uses 50 different words by 20 to 21 months.
- Uses new words, often relates personal experiences.
- Refers to self by name.

#### Self-help:
- Indicates pants are wet.
- Gestures to indicate toilet needs.
- Uses spoon to feed self without excessive spilling.
  (Infant Parent Program, 1993)

#### Indicators for further assessment:
- By 15 months, does not seem to know the function of common household objects (brush, telephone, bell).
- Cannot push a wheeled toy by age 2.
- Cannot walk by 18 months.
- Does not follow simple instructions by age 2.
- Does not imitate actions or words by the end of this period.
- Does not speak at least 15 words.
- Does not use two-word sentences by age 2.
- Experiences a dramatic loss of skills he or she once had.
- Fails to develop a mature heel-toe walking pattern after several months of walking, or walks only on toes.
  (Centers for Disease Control and Prevention)
Self-help:
- Wipes hands and face.
- Chooses toys selectively.
- Recognizes family members’ names.
- Asks for help with personal needs.
- Acts out familiar routines.
- Pretends to perform parents’ routines.
- Points to more difficult body parts (elbow, knee).
- Holds crayon in fist, hand turned so crayon points downward.
- Unbuttons large buttons.
- Can snap on line using scissors.
- Initiates own play activities; can entertain self.
- Enjoys role-playing.
- Dries own hands.
- Puts on shoes without tying.
- Pours well from half-full pitcher.
- Unbuttons front buttons by 36 months.
- Undresses completely without help by 36 months.

Indicators for further assessment:
- Cannot build a tower of more than four blocks.
- Cannot communicate in short phrases.
- Cannot copy a circle by age 3.
- Difficulty manipulating small objects.
- Does not understand simple instructions.
- Experiences a dramatic loss of skills he or she once had.
- Extreme difficulty separating from mother or primary caregiver.
- Frequent falling and difficulty with stairs.
- Limited interest in toys.
- Little interest in other children.
- No involvement in “pretend” play.
- Persistent drooling or very unclear speech.
- Poor eye contact.
  (Centers for Disease Control and Prevention)

TYPES OF DEVELOPMENTAL DISABILITIES

Nervous system disabilities

Nervous system disabilities affect the functioning of the brain, nervous system and spinal cord. This can impact intelligence and learning. In addition, these disabilities can cause problems with behavior, speech, language, movement and convulsion disorders. Some of the common nervous system disabilities can include:
- **Intellectual and developmental disabilities** (IDDs) refers to a certain range of scores on an intelligence quotient test (IQ). This type of disability can result from a number of different conditions, such as Down syndrome, fragile X syndrome and autism spectrum disorders.
- **Sensory-related disabilities** are often a key part of complex birth defect patterns. For instance, a child with fragile X syndrome is often very sensitive to loud noises, and may have emotional outbursts or overreact in reaction to certain sounds. A child born with congenital rubella is likely to be deaf and develop cataracts of the eyes.

Metabolic disorders

Metabolic disorders affect an individual’s metabolism. Metabolism is the way the body builds up, breaks down and processes the materials it needs to function. Two of the most common metabolic disorders are:
- **Phenylketonuria (PKU)** – a condition where a specific enzyme that is a protein speeds up chemical reactions and causes intellectual and developmental disabilities.
- **Hypothyroidism** – a hormonal condition that if left untreated as an infant can cause intellectual and developmental disabilities.

Degenerative disorders

Infants born with degenerative disorders sometimes appear normal at birth, but over time, they lose abilities or functions because of the condition. In cases like these, the disability is not detected until an older age when the signs of loss of function start to show. Degenerative disorders are sometimes the results of a metabolic disorder and can cause physical, mental and sensory problems, dependent on the specific type of defect.
- **Rett syndrome** is a degenerative birth defect that most commonly appears in girls, and most often is caused by a specific genetic abnormality (National Institute of Child Health and Human Development, 2010).

Developmental disabilities defined in the Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition (DSM-IV)

Many medical and psychiatric disorders qualify as a developmental disability. This course focuses on those disabilities outlined by or closely associated with the DSM-IV category for pervasive developmental disorders. This course will explore the features, etiology, prevalence, treatment strategies and personal stories from individuals and families living with the disorders of intellectual disabilities, Down syndrome and pervasive developmental disorders (PDD), also known as autism spectrum disorders (ASD), and which further include autistic disorder, Rett’s disorder, childhood disintegrative disorder, Asperger’s disorder, and pervasive developmental disorder, not otherwise specified.

INTELLECTUAL DISABILITY

Features

This disability is characterized by manifestation prior to age 18, and a significant limitation in both intellectual functioning as well as adaptive behavior. Traditionally the focus of an intellectual disability was on cognitive function, but now there is also an emphasis on adaptive and functional behaviors. Intellectual functioning includes activities such as learning, reasoning and problem solving as well as one’s mental capacity. In general, an IQ score in the range of 70 to 75 or lower indicates a limitation in intellectual functioning. Adaptive functioning is measured through standardized testing.
Etiology

Factors that may contribute to intellectual disability can be both genetic and environmental. Contributing factors are much more easily identified in severe cases of intellectual disability. The most common causes for intellectual disability include genetic conditions (such as Down syndrome or fragile X syndrome), problems with pregnancy (such as improper development of the fetus, use of alcohol during pregnancy or infection contracted during pregnancy), problems at birth (complications during labor such as lack of oxygen to the infant), and health problems (diseases like the measles, whooping cough or meningitis, extreme malnutrition, lack of medical care, poison exposure). A lack of the physical, emotional and cognitive support needed and required for growth and development as well as social adaptation during infancy and early childhood can also be a cause of intellectual disability (Merck, 2009-2010).

But in most cases, the cause for intellectual disability is unknown. Determining the potential cause in an individual case can be useful in determining a treatment plan, prognosis for development, and relieve parental guilt. Genetic counseling is an option to help with prevention strategies as well as regular medical treatment and prenatal care. Refraining from alcohol or drug use during pregnancy can be the single most important environmental factor in preventing an intellectual or other disability.

There is no cure for intellectual disability, but most children with this disorder can live happy, functional and rewarding lives; they may just require a little more time and effort to complete or learn an activity (National Dissemination Center for Children with Disabilities).

Prevalence

The prevalence of intellectual disabilities has been estimated at about 1 percent. However, different studies have reported different rates depending on definitions used, populations studied and the method of assessment. An intellectual disability is the most common type of disability in the United States, according to the Centers for Disease Control and Prevention (2005).

CATEGORIES OF INTELLIGENCE DISABILITIES

Mild

About 85 percent of those diagnosed with intellectual disability are categorized in the “mild” group. These children are often not easily distinguished from other children in the way of communication, sensory motor and social skills until a later age. Typically, by the late teens, these individuals can acquire academic skills up to about the sixth grade level. With the right supports in place, an individual diagnosed with a mild intellectual disability can live successfully in a community independently or in a supervised setting (American Psychiatric Association, 1994).

Moderate

About 10 percent of those diagnosed with an intellectual disability are categorized in the “moderate” group. This group of individuals is unlikely to progress past the second grade level of academic skills. Communication skills are acquired during early childhood and under supervision, many can attend to their own personal care. Adolescence may be a difficult time as they may find difficulty in recognizing social conventions for their peer group. The majority of individuals diagnosed with this disability are able to perform work duties that are semiskilled or unskilled. This individual is able to adapt well to community life, but would most likely require a supervised setting (American Psychiatric Association, 1994).

Severe

About 3-4 percent of those diagnosed with an intellectual disability are categorized in the “severe” group. In early childhood, these individuals acquire very little or no communicative speech. However, this may be acquired later when they are school aged. This individual can be trained to provide some elementary self-care skills and can benefit to a limited extent from pre-academic learning of simple counting and the alphabet. As an adult, this individual can also adapt well to community life, but will require close supervision in a group home or with the family (American Psychiatric Association, 1994).
It would have been better if she had told me about these things. It that there was a quiet place that I could go to. She didn’t tell me that there was a chaplain that I could talk to. She didn’t tell me have seen my dad after he died. I didn’t get to say goodbye to my dad. My dad had died the same day. The nurse didn’t tell me that I could “My dad died in December 1999. He died in a hospital in North West My name is Richard West. I work with the Department about what I went through when my dad died. I am hoping that it will Richard’s story

“My article is about what happened to me when my dad was dying and when he died. My name is Richard West. I work with the Department of Health in London on valuing people to make sure that people with intellectual disabilities have rights, choices and independence. I also help the Department of Transport to get transport working better for people with intellectual and physical disabilities. I live in my own flat supported by an outreach team. I get help when I ask them. This is about what I went through when my dad died. I am hoping that it will help others who may go through the same thing as I have.

“My dad died in December 1999. He died in a hospital in North West London. He died from cancer. He had been sick for about 10 months and had been having treatment in hospital. My sister wrote to me because I am not able to use telephones, because I am also deaf. She wrote to tell me that our dad was in hospital. I was able to visit him before he died. I used to visit him on my own.

“This was very hard because I didn’t know about cancer and what it does to people. No one in the hospital told me what was happening to him. I didn’t know that he was going to die. I thought he was going to get better. I only knew he was going to die just before he died because I could see that he was very weak. He wasn’t eating or drinking. No one in my family told me that he was going to die either.

“The last time I went to the hospital to visit him, he wasn’t there. I didn’t know where he was. I asked a nurse what happened to him. She took me to a private room and told me that he had died. She didn’t tell me anything else, and I was too upset to ask her any questions.

“My dad had died the same day. The nurse didn’t tell me that I could have seen my dad after he died. I didn’t get to say goodbye to my dad. The nurse didn’t tell me where they had taken his body. She didn’t tell me that there was a chaplain that I could talk to. She didn’t tell me that there was a quiet place that I could go to. She didn’t tell me about these people that you can talk to when a person dies.

“It would have been better if she had told me about these things. It would have been better if everything was written down in an easy way so that I could have looked at it later. The rest of the family organized my dad’s funeral. They didn’t ask what I wanted.

“I didn’t want to go to the funeral because I was too upset. One of my neighbors, Laura, talked to me for hours, telling me that it would be good for me to go to the funeral. Laura also has intellectual disability. If it wasn’t for her, I wouldn’t have gone. She helped me to decide what to wear for the funeral. She was more supportive than many other people.

“I was too upset to talk to the outreach team and too angry to talk to social services or health. I didn’t have a care manager that I could contact myself. I didn’t really know who to talk to. Laura was the only one who was there.

“I think that it would be better if the health people had talked to me about cancer and radiotherapy and chemotherapy. I think it would have been easier for me to understand what was happening to my dad.

“A few weeks after the funeral, I wanted to talk to someone about how I felt about my dad’s death. I spoke with a member of the outreach team and asked them to get in touch with someone from social services. I was able to talk to a care manager about how I was feeling. I didn’t know that there are special people that you can talk to about death and dying. The care manager didn’t tell me about these special counselors.

“I think that it would be better if care managers tell people about these counselors. I think that people with learning disabilities should be given accessible information about death and dying. We should be told that it is OK to talk to people about death and dying and feelings.

“I don’t know if there is a special group for people with intellectual disabilities who have family members who have cancer or died from cancer. This group could help people to talk to each other about what has happened and how to make it better for them and for other people. Having a group like this would help us to talk about how we feel and to understand what cancer can do and what has happened.

“My friend Laura talked to me about when her dad died. Her dad died in an accident at work. She helped me to think about my dad, the good
thing about him. This was very helpful to me. Because she is also a neighbor, she made sure that I was alright at all hours of the day. She was my main support during this difficult time.

“I want to end with these messages:

- People with intellectual disabilities should be given the same information about death and dying that other people are given.
- Information needs to be accessible, using pictures, photographs, easy words and/or video.
- This information should be given to us by everyone who works with people with intellectual disabilities for example, health, social services, voluntary people, family, etc.

It would be good to plan and work with people with intellectual disabilities who have cancer and talk about how services can make their needs better.

People with intellectual disabilities need support when going through something like this – support can come from family and friends as well as people who work with us.

“I do hope that this article will encourage readers to think about how to help people with intellectual disabilities understand about death and dying” (West, 2003).

## DOWN SYNDROME

### Features

Down syndrome is a chromosomal disorder with the main feature being intellectual disability. The IQ score of an individual with Down syndrome can range from about 25-70. Intellectual disability can range from mild to moderate, and in some cases severe. The common physical traits seen include a small stature, an upward slant of the eyes, low muscle tone, and sometimes a single deep crease across the center of the palm. These traits can vary within each individual in different degrees or not be present at all (National Down Syndrome Society, 2010) (Pinto & Schub, 2010).

### Etiology

Down syndrome is the single most common genetic cause of an intellectual disability. In most cases, the cause of this disability is an abnormal presence of three copies of chromosome 21 instead of two in every cell of the body; this is also known as trisomy 21. This disorder affects almost every organ system and is responsible for cognitive and physical impairments that may include hearing and visual losses, congenital heart defects, autism, attention disorders, celiac disease, depression and early-onset Alzheimer’s disease (Pinto, S. & Schub, T., 2010).

Down syndrome can be diagnosed during pregnancy, and screening is a typical part of pregnancy care. Initial screening for Down syndrome can show a high risk for one in 20 women, which is a much higher rate than women who actually give birth to a child with Down syndrome. If initial screening shows a high risk for Down syndrome, further, more invasive testing can take place; these tests are much more accurate, usually having a 98 percent to 99 percent efficacy rate. Down syndrome is typically suspected at birth if not during pregnancy based on clinical features and then confirmed through cytogenic studies (National Down Syndrome Society, 2010).

### Prevalence

One-third of the cases of moderate to severe intellectual disabilities are accounted for by Down syndrome. This disease is estimated to occur in one per about 733 live births in the United States and affects males slightly more than it does females. Down syndrome is the most commonly occurring genetic disorder, with 400,000 people in the United States currently affected by the disorder (National Down Syndrome Society, 2010). About 75 percent of fetuses with Trisomy 21 identified in utero suffer demise prior to delivery. About 50 percent of those who have Down syndrome also have congenital heart disease. Seizure disorder is present in about 5 percent to 10 percent of those affected. The life expectancy for a person with Down syndrome has increased dramatically in the past two decades from age 25 in 1983 to age 60 and older today.

Maternal age is a high risk factor for Down syndrome because of the higher risk for chromosomal abnormalities associated with older eggs being fertilized. A woman aged 45 and older has a one in-35 chance to give birth to a baby with Down syndrome versus a 35-year-old woman who has a one-in-400 chance. While the rates of Down syndrome per birth increase with the age of the mother, 80 percent of the children born with Down syndrome are born to women younger than 35 years of age because of higher fertility rates in younger women. (National Down Syndrome Society, 2010).

### Treatment strategies

There is not a specific treatment strategy utilized for Down syndrome. There are treatment strategies for the various medical disorders and complications related and for behavioral and psychological issues experienced by the child and his or her family. The child with Down syndrome will likely have a team of medical providers in addition to a pediatrician that includes a pediatric cardiologist, a pediatric gastroenterologist, a pediatric endocrinologist, a developmental pediatrician, an audiologist, a physical therapist, a speech pathologist and an occupational therapist.

Early intervention can help children with Down syndrome and their families better understand what to expect during crucial periods of development and growth, and how to deal with the day-to-day struggles that can occur with the syndrome. Intervention services can begin as early as birth and are a major contributing factor to a better quality of life and realization of full potential for children with the syndrome. The following chart demonstrates developmental milestones for children diagnosed with Down syndrome and those children who have not been diagnosed with Down syndrome:
### Developmental milestones

<table>
<thead>
<tr>
<th>Gross motor</th>
<th>Range for children with Down syndrome</th>
<th>Typical range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sits alone</td>
<td>6 - 30 months</td>
<td>5 - 9 months</td>
</tr>
<tr>
<td>Crawls</td>
<td>8 - 22 months</td>
<td>6 - 12 months</td>
</tr>
<tr>
<td>Stands</td>
<td>1 - 3.25 years</td>
<td>8 - 17 months</td>
</tr>
<tr>
<td>Walks alone</td>
<td>1 - 4 years</td>
<td>9 - 18 months</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Language</th>
<th>Range for children with Down syndrome</th>
<th>Typical range</th>
</tr>
</thead>
<tbody>
<tr>
<td>First word</td>
<td>1 - 4 years</td>
<td>1 - 3 years</td>
</tr>
<tr>
<td>Two-word phrases</td>
<td>2 - 7.5 years</td>
<td>15 - 32 months</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Personal/social</th>
<th>Range for children with Down syndrome</th>
<th>Typical range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Responsive smile</td>
<td>1.5 - 5 months</td>
<td>1 - 3 months</td>
</tr>
<tr>
<td>Finger feeds</td>
<td>10 - 24 months</td>
<td>7 - 14 months</td>
</tr>
<tr>
<td>Drinks from cup</td>
<td>12 - 32 months</td>
<td>9 - 17 months</td>
</tr>
<tr>
<td>unassisted</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uses spoon</td>
<td>13 - 39 months</td>
<td>12 - 20 months</td>
</tr>
<tr>
<td>Bowel control</td>
<td>2 - 7 years</td>
<td>16 - 42 months</td>
</tr>
<tr>
<td>Dresses self</td>
<td>3.5 - 8.5 years</td>
<td>3.25 - 5 years</td>
</tr>
<tr>
<td>unassisted</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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**Gaining perspective**

Below is a motivational story from an individual illustrating her own personal life experiences as a person with Down syndrome.

“My name is Sara Wolff. I am 24 years old, and my great story is about my public speaking.

“I’d first like to share a little bit about myself with you. I definitely have something unique about me – and that is an extra 21st chromosome, called Down syndrome … which, by the way, has never stopped me from doing anything!

“I don’t think of myself as having ‘DOWN’ syndrome but ‘UP’ syndrome, because I am an upbeat and positive person. I have been raised with the motto, ‘Never say never’, and that the words ‘I can’t’ don’t exist.

“Inclusion’ began the moment I was born. My family included me in everything they did. I was fortunate to have parents who believed in me. I was a fully included student from pre-school through high school graduation, and college.

“My biggest accomplishment was organizing a Buddy Walk as my senior graduation project. The event was a huge success, and I was honored for my efforts at the 2002 NDSS Annual Spring Luncheon with Barbara Walters. It was a life-changing experience and one that will be forever etched in my memory. It was my first time speaking in public, and I was excited, not nervous, and loved sharing my experiences.

“I knew from that moment on, public speaking was something I wanted to do. Since then, my speaking experiences have ranged from small groups such as churches, schools and community organizations to large events like the NDSS St. Louis Conference and other buddy walks. Regardless of the size of the audience, I feel good knowing I can inspire people and make a difference.

“Being a part of the 2008 NDSS Buddy Walk PSA with Meredith Vieira was very special. Knowing that my public speaking could have the ability to change hearts and attitudes towards individuals with Down syndrome was really inspiring. Also, it was totally awesome to act with Meredith Vieira. She is an amazing person with a genuine heart.

“I am honored and humbled to be a part of the My Great Story campaign. I felt like a celebrity for a day. I encourage all individuals with Down syndrome to share their story. We all have a great story to tell because we are all unique individuals who should be proud of who we are.” (Wolff, 2010)

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### AUTISM SPECTRUM DISORDERS (ASD)/PERVASIVE DEVELOPMENT DISORDERS (PDD)

#### Features

Pervasive developmental disorders usually become evident in the first years of life and can sometimes be associated with some level of an intellectual disability (American Psychiatric Association, 1994). Symptoms are typically evident by age 3, but can present as early as infancy. This condition will remain with an individual throughout their life span. However, early interventions can lessen the severity of symptoms and improve the individual’s quality of life (Singer, S.S., 2009). There are few physiological signs of ASD, but some believe that head circumference in infancy can be a predictor. Researchers have noted that normal head circumference at birth then a rapid acceleration of growth during the first two years of life indicated later diagnosis with the disorder. This pattern of growth is not fully understood, but it is believed that it reflects an early neurological warning sign (Boyd, et al. 2010).

These types of disorders cause a marked impairment in socialization, communication, and sometimes, sensory integration skills. In addition, these individuals present stereotyped behavior, interests and activities. Typical symptoms might include deficits in the use and understanding of language, difficulty relating to people and events, unusual play with toys and other objects, and difficulty with changes in routine or surroundings. Sometimes children will exhibit repetitive body movements or behavioral patterns. Children may demonstrate sensory integration issues such as having abnormal responses to stimuli like light or sound (Singer, S.S., 2009).

Signs of possible social issues related to ASDs:

- Does not respond to name by 12 months of age.
- Avoids eye contact.
• Prefers to play alone.
• Does not share interests with others.
• Only interacts to achieve a desired goal.
• Has flat or inappropriate facial expressions.
• Does not understand personal space boundaries.
• Avoids or resists physical contact.
• Is not comforted by others during distress.
• Has trouble understanding other people’s feelings or talking about own feelings.

Signs of possible communication issues related to ASDs:
• Delayed speech and language skills.
• Repeats words or phrases over and over (echolalia).
• Reverses pronouns (e.g., says “me” instead of “I”).
• Gives unrelated answers to questions.
• Does not point or respond to pointing.
• Uses few or no gestures (e.g., does not wave goodbye).
• Talks in a flat, robot-like or singsong voice.
• Does not pretend in play (e.g., does not pretend to “feed” a doll).
• Does not understand jokes, sarcasm or teasing.

Examples of unusual interests and behaviors related to ASDs:
• Lines up toys or other objects.
• Plays with toys the same way every time.
• Likes parts of objects (e.g., wheels).
• Is very organized.
• Gets upset by minor changes.
• Has obsessive interests.
• Has to follow certain routines.
• Flaps hands, rocks body or spins self in circles.

Some people with an ASD have other symptoms. These might include:
• Hyperactivity (very active).
• Impulsivity (acting without thinking).
• Short attention span.
• Aggression.
• Causing self-injury.
• Temper tantrums.
• Unusual eating and sleeping habits.
• Unusual mood or emotional reactions.
• Lack of fear or more fear than expected.
• Unusual reactions to the way things sound, smell, taste, look or feel. (Johnson, C.P., 2004)

Etiology

Dr. Leo Kanner, a physician at Johns Hopkins Hospital, first described autism as a unique condition in 1943. Until then, autism had been defined as “a form of childhood schizophrenia characterized by acting out and withdrawal from reality” (Singer, S.S., 2009). Although autism spectrum disorder has been recognized more only in recent modern times, there are many historical accounts pointing to the existence of autism well before the 20th century (Center For Autism and Developmental Disabilities Epidemiology [CADDE]).

Initially it was thought that autism spectrum disorders were a result of poor parenting, more specifically, “cold unloving mothers.” (Autism Speaks, 2005-2010). Kanner perceived autistic children to be victims of an affective disorder caused by highly intellectual, emotionally cold and compulsive parents, specifically mothers. He theorized that these children withdrew from social contact as a result. This unsubstantiated theory was perpetuated among those in the medical community and experts in child development such as Bruno Bettelheim, a renowned professor of child development. This stigma caused guilt and a tremendous burden to bear for the parents of children diagnosed with this disorder during that time. In addition, Kanner’s theories perpetuated the notion that these children came from relatively wealthy, professional families. Research has shown us that this is not the case. Children with this disorder come from families in a wide socioeconomic range (Singer, S.S., 2009). Not until the 1960s and 1970s did these sentiments start to change. Dr. Bernard Rimland helped the medical community understand that autism is not caused by cold parents, but by a biological disorder. Dr. Rimland is the father of a son with autism. He founded the Autism Society of America and the Autism Research Institute (Autism Speaks, 2005-2010).

Modern science and research has shown us that this class of disorders is thought to have a biological basis and has a strong association with genetics. Researchers have found hereditary links and are further investigating combinations of genes that may be responsible for these conditions. One indicator of a genetic factor in this disorder is that siblings of autistic children are 50 times more likely to be diagnosed than children who do not have a sibling with the disorder (Singer, S.S., 2009). Problems that occur during the prenatal or perinatal period have also been implicated in causing PDDs. Premature birth, viral infections while in utero and oxygen deprivation during delivery can increase the likelihood of a pervasive development disorder (Singer, S.S., 2009).

Unfortunately, in 90 to 95 percent of the cases diagnosed, the cause is still unknown. In the remaining cases, the characteristics of the disorder are often secondary to the child’s primary impairment. Some of the most common secondary causes include environmental factors, chromosomal abnormalities and genetic disorders, with the most common associated genetic disorder being fragile X syndrome (Boyd, B., et al., 2010).

In the 1990s, there was a controversial proposal that the onset of these disorders was related to vaccinations. The association was made with the mumps, measles and rubella (MMR) vaccination given at approximately 18 months of age, because the vaccination corresponded with early detection of symptoms of autism. Research into this area has not substantiated this claim (Singer, S.S., 2009).

Prevalence

The Centers for Disease Control and Prevention’s (CDC) most recent Autism and Developmental Disabilities Monitoring (ADDM) Network (2006) data show that between 1 in 80 and 1 in 240 children have autism spectrum disorders. This translates to about 1 in 110 children and an estimated prevalence of about 1 percent. Boys are shown to be at least 50 percent more likely to have autism spectrum disorder than girls; this means one in 70 boys will be diagnosed with an autism spectrum disorder. These numbers were released in 2009 and are based on data collected in 2006 from specific areas of the country. The results were more than alarming, as they reflected a 57 percent increase from the prior data collected in 2002. This is a 600 percent increase in the last 20 years. These results have made the disorders a center of focus for the Centers for Disease Control and Prevention. It is estimated that these disorders affect 1.5 million Americans today.

![Fast Facts]
- One in 110 children will be diagnosed with autism.
- One in 70 of these will be boys.
- The disorder affects 1.5 million Americans today.

According to some experts, the broadening of the definition of autism spectrum disorders to include those with less apparent symptoms has contributed to the increased number of individuals diagnosed. The Centers for Disease Control and Prevention maintains there is not
sufficient evidence to substantiate this as a causal factor, but does maintain that more accurate information gathering within the group being measured over time may be an attributing factor to the increase in quantity of evaluations and ultimately, an increase in diagnoses. The study explores the possibility that increased awareness regarding these disorders likely led to the increased quality of behavioral information in case records of the patients being studied. This type of symptom information is used to solidify a diagnosis, and because of its availability in combination with an increase of knowledge about symptoms by practitioners, may have led to an increase in the number of diagnosed cases (Centers for Disease Control and Prevention, 2010). Communities and awareness organizations have used this increase as an opportunity to gain momentum in their fight for additional funding to promote research and support families who have these disorders (Centers for Disease Control and Prevention, 2010). Why these disorders are increasing at such an alarming rate is unknown, but some think that the increase is related to environmental factors and more accurate diagnoses (Autism Speaks, 2005-2010).

Treatment strategies

There are no medical tests that can diagnose pervasive development disorders. Medical and other professionals must carefully evaluate behavior and developmental milestones in order to provide an accurate diagnosis. Professionals who are experienced in this field can provide a very reliable diagnosis by age 2. Early detection and intervention are key factors in providing the best prognosis for these conditions.

All children should be screened for developmental delays and disabilities during regular well-child doctor visits at:
- 9 months.
- 18 months.
- 24 or 30 months.

Additional screening might be needed if a child is at high risk for developmental problems due to preterm birth, low birth weight or other reasons.

All children should also be screened specifically for autism spectrum disorders during regular well-child doctor visits at:
- 18 months.
- 24 months.

Additional screening might be needed if a child is at high risk for ASD (e.g., having a sister, brother or other family member with an ASD), or if behaviors sometimes associated with an ASD are present (Centers for Disease Control and Prevention, 2010).

Brief screening instruments have been developed to gather information about a child’s social and communicative development during a well-child exam. Some examples are the Checklist of Autism in Toddlers (CHAT), the modified Checklist for Autism in Toddlers (M-CHAT), the Screening Tool for Autism in Two-Year-Olds (STAT), and the Social Communication Questionnaire (SCQ) (for children 4 years of age and older) (National Institute of Mental Health, 2009).

A comprehensive evaluation should include neurologic and genetic assessment, along with in-depth cognitive and language testing. This evaluation should be completed by a multi-disciplinary team that includes a psychologist, a neurologist, a psychiatrist, a speech therapist or other professionals who may be familiar with diagnosing autism spectrum disorders. There are some measures that have been created to specifically test for specific autism traits. These include the Autism Diagnosis Interview-Revised (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS-G). The ADI-R is a structured interview containing more than 100 items and conducted with a caregiver. It consists of four main factors: the child’s communication, social interaction, repetitive behaviors and age-of-onset symptoms.

The ADOS-G is an observational measure used to “press” for socio-communicative behaviors that are often delayed, abnormal or absent in children with ASD. Another instrument often used is the Childhood Autism Rating Scale (CARS). This instrument helps to measure the child’s body movements, adaptation to change, listening response, verbal communication and relationship to people. It is typically used with children over 2 years of age. The individual administering the instrument observes a child’s behavior and uses parent reports of behavior. The child’s behavior is rated on a scale based on a deviation from the typical behavior of children of the same age (National Institute of Mental Health, 2009). Two other medical tests that should be used to assess this disorder and any child with a developmental delay are an audiologic hearing evaluation and a lead screening. Hearing loss can co-occur with ASD, but some children with this disorder may be incorrectly or prematurely diagnosed with hearing loss. Children with an autistic disorder often have elevated blood lead levels (National Institute of Mental Health, 2009).

There is not one set of treatment plans for autism spectrum disorders. In general, it is agreed that early intervention is key, and that highly specialized and structured programs provide the best results. Applied behavior analysis (ABA) is a technique that studies have shown to be very successful in helping individuals with autism and other developmental disabilities learn specific skills. Behavioral techniques can help children learn how to care for themselves, play, communicate more effectively, be more successful in school, and participate more productively in family and community activities. This technique is most effective when it is used early and intensely. These techniques are typically used by trained or certified behavior analysts or therapists. While this technique is intended to be specific to the individual receiving treatment, applied behavioral analysis treatment does have some commonalities. They include:
- Detailed assessment of each learner’s skills as well as learner and family preferences to determine initial treatment goals.
- Selection of goals that are meaningful for the learner and the family.
- Ongoing objective measurement of learner progress.
- Frequent review of progress data by the behavior analyst so that goals and procedures can be fine-tuned as needed.
- Instruction on developmentally appropriate goals in skill areas (e.g. communication, social, self-care, play and leisure, motor and academic skills).
- Skills broken down into small parts or steps that are manageable for the learner, and taught from simple (such as imitating single sounds) to complex (e.g. carrying on conversations).
- An emphasis on skills that will enable learners to be independent and successful in both the short and the long run.
- Use of multiple behavior analytic procedures – both adult-directed and learner-initiated – to promote learning in a variety of ways.
- Many opportunities – specifically planned and naturally occurring – for each learner to acquire and practice skills every day, in structured and unstructured situations.
- Intervention provided consistently for many hours each week.
- Abundant positive reinforcement for useful skills and socially appropriate behaviors.
- An emphasis on positive social interactions, and on making learning fun.
- No reinforcement for behaviors that are harmful or prevent learning.
- Use of techniques to help trained skills carry over to various places, people and times, and to enable learners to acquire new skills in a variety of settings.
- Parent training so family members can teach and support skills during typical family activities.
- Regular meetings between family members and program staff to plan, review progress and make adjustments (Autism Speaks, 2005-2010).
Parents are encouraged to research their options and find the best treatment for their child’s specific needs. State agencies and awareness groups have developed a set of questions that may help parents find the best treatment.

The Autism Society of America suggests the following questions:
- Will the treatment result in harm to my child?
- How will failure of the treatment affect my child and family?
- Has the treatment been validated scientifically?
- Are there assessment procedures specified?
- How will the treatment be integrated into my child’s current program? Do not become so infatuated with a given treatment that functional curriculum, vocational life and social skills are ignored (National Institute of Mental Health, 2009).

The National Institute of Mental Health suggests the following questions:
- How successful has the program been for other children?
- How many children have gone on to placement in a regular school and how have they performed?
- Do staff members have training and experience in working with children and adolescents with autism?
- How are activities planned and organized?

**Autistic disorder**

Autistic disorder, also known as autism, early infantile autism, childhood autism, or Kanner’s autism, is marked by the essential features of abnormal or impaired development and social interaction and communication and a markedly restricted range of activities and interests. The limitations related to communication may include a delay or a total lack of spoken language, inability to initiate or sustain a conversation with others, the repetitive use of language or language that is idiosyncratic, and a lack of the ability to initiate make-believe play.

Restrictive or stereotyped patterns of behavior may be present such as hand flapping our twisting, preoccupation with parts of objects, or inflexibility in adhering to routines that are nonfunctional (Singer, S.S., 2009). Cognitive skills can have a wide range despite IQ. A higher functioning individual with autism may have higher levels of language comprehension (receptive language) than that of language vocabulary (expressive language) (American Psychiatric Association, 1994). Behavioral symptoms can also have a wide range and may include hyperactivity, aggressiveness, self-interest behaviors, short attention span and temper tantrums in young children. Children may demonstrate sensory integration issues such as a high threshold for pain, oversensitivity to being touched, and exaggerated reactions to odors or fascination with certain stimuli.

These children may also demonstrate abnormalities in eating or sleeping patterns and mood or affect. An individual with autism who is intellectually capable of insight into the disorder may show signs of depression during adolescence in response to the realization of his/her impairment (American Psychiatric Association, 1994).

**Below are the diagnostic criteria for autistic disorder, according to the DSM-IV:**

**299.00 Autistic disorder**

A. A total of six (or more) items from 1, 2, and 3, with at least two from 1, and one each from 2 and 3:
1. Qualitative impairment in social interaction, as manifested by a least two of the following:
   a. Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures and gestures to regulate social interaction.
   b. Failure to develop peer relationships appropriate to developmental level.
   c. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, or pointing out objects of interest).
   d. Lack of social or emotional reciprocity.
2. Qualitative impairment in communication as manifested by at least one of the following:
   a. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime).
   b. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others.
   c. Stereotypes and repetitive use of language or idiosyncratic language.
   d. Lack of varied, spontaneous make-believe play or social imitative play if appropriate to developmental level.
3. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by a least one of the following:
   a. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.
   b. Apparently inflexible about specific, nonfunctional routines and rituals.
   c. Stereotyped and repetitive motor manerisms (e.g., hand or finger flapping or twisting, or complex whole body movements).
   d. Persistent preoccupation with parts of objects.

**B. Delays or abnormal functioning and at least one of the following areas, with onset prior to age 3 years:**
1. Social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

**C. The disturbance is not better accounted for by Rett’s disorder or childhood disintegrative disorder (American Psychiatric Association, 1994).**
Rett’s disorder

This disorder is classified as a pervasive developmental disorder, but shows signs of a chromosomal disorder such as fragile X syndrome (Kowalski, G., 2009). Rett’s disorder, also known as Rett syndrome, was first described by the Austrian physician Andreas Rett in 1966. The syndrome was not widely recognized until a second article was published in 1983 by Swedish researcher Dr. Bengt Hagberg. This neurodevelopmental disorder almost exclusively affects girls (National Institute of Neurological Disorders and Stroke, 2010). This occurs because of a mutation in a gene on the X-chromosome, and thus male children with the condition generally do not survive beyond birth (Kowalski, G., 2009).

The main feature of Rett disorder is the development of various but specific deficits following a period of normal growth and functioning after birth. There are no prenatal or perinatal signs of dysfunction, and the infant shows normal signs of psychomotor development to the first five months of their life. Between 5 and 48 months of age, the child’s head growth decelerates and she loses previously acquired hand skills (Range, L., 2009).

Subsequently, the child will develop characteristics of stereotyped hand movements that may look like hand wringing or hand washing. After the first few years of onset, interest in the social environment diminishes, but it is possible to develop social interaction later in the course of the disease (American Psychiatric Association, 1994). Over the course of the next few years, the child will develop severe impairment of expressive and receptive language development and psychomotor retardation, such as showing difficulty with crawling or walking, and in many cases, individuals with this disorder cannot walk or crawl at all.

Eighty percent of the female children who suffer from this condition also suffer from seizures and gastrointestinal disorders. Small hands and feet are one of the main characteristics of Rett syndrome (Kowalski, G., 2009). The most severely debilitating feature of this disorder is apraxia, which is the inability to perform motor functions and which interferes with every body movement, including speech and gaze of the eyes. Early on in the disease, these children demonstrate autistic-like features. Other symptoms that may manifest include cognitive disabilities, a wide-based gait, teeth grinding and difficulty chewing, and breathing problems that may include sleep apnea, hyperventilation and air swallowing (National Institute of Neurological Disorders and Stroke, 2010).

This disorder occurs in four stages according to scientists who study the disease:

- **Stage one (early onset)** – This stage is called early onset and typically begins between 6 and 18 months of age. The symptoms of the disorder at this time are somewhat vague, so sometimes are overlooked by parents and doctors. Some minor indicators are showing less eye contact and showing a reduced interest in toys they used to play with. During this time, there may be delays in gross motor skills, and hand wringing and decreasing head growth may occur but not be prevalent enough to draw attention from parents or a medical doctor. This stage usually lasts for a few months, but can go on for more than a year.

- **Stage two (rapid destructive stage)** – This stage usually begins between ages 1 and 4 years and may last for weeks or months. It is possible that the onset is gradual or rapid and during this time. The child loses purposeful hand skills and spoken language. The stereotypic hand movements will emerge during this time, and can include ringing or washing, clapping or tapping, or repeatedly moving the hands to the mouth. These symptoms should not occur when the child is sleeping. Breathing problems and irregularities will emerge during this time, but can improve during sleep. Females with the disorder start to show autistic-like symptoms during this time, such as minimized social interaction and communication. Slowed head growth is usually noticeable during this time.

- **Stage three (plateau or pseudo-stationary stage)** – This stage usually begins between ages 2 and 10 years and can last for many years. Seizures as well as motor problems and apraxia are very prominent during this time. During this stage, there may be an improvement in social skills and behavior, with the child showing more interest in her surroundings. She may be more alert, have a longer attention span and communicate more effectively. Many girls with this disorder stay in this stage for most of their lives.

- **Stage four (late motor deterioration stage)** – This stage can last for many years or even decades. During this time, prominent features that appear can include curvature of the spine, rigidity and spasticity of the muscles, muscle weakness, reduced mobility and an increased muscle tone with abnormal posturing of an arm, leg or upper part of the body. At this time, females with this disease who were previously able to walk may stop walking. Eye gaze may improve, and repetitive hand movements may decrease. In general, there is not a decline in cognition, communication or acquired hand skills during this stage (National Institute of Neurological Disorders and Stroke, 2010).

Below are the diagnostic criteria for Rett’s disorder, according to the DSM-IV:

**299.80 Rett’s disorder**

A. All of the following:
1. Apparently normal prenatal and perinatal development.
2. Apparently normal cycle motor development through the first five months after birth.
3. Normal head circumference at birth.

B. Onset of all of the following after the period of normal development:
1. Deceleration of head growth between ages 5 and 48 months.
2. Loss of previously acquired purposeful hand skills between ages 5 and 30 months with the subsequent development of stereotyped hand movements (e.g., handwriting or hand washing).
3. Loss of social engagement early in the course (although often social interaction develops later).
4. Appearance of poorly coordinated gate or trunk movements.
5. Severely impaired expressive and receptive language development with severe psychomotor retardation. (American Psychiatric Association, 1994).

The data on prevalence of Rett’s disorder is limited, but from the research available, it is estimated to affect one in every 10,000 to 15,000 live female births and is found in all racial and ethnic groups worldwide. The disorder typically occurs spontaneously in most affected individuals. The risk of a family having a subsequent child with the disorder is less than 1 percent, but because there is this chance, prenatal testing is available for families with an affected daughter (National Institute of Neurological Disorders and Stroke, 2010).

There is currently no known cure for Rett’s syndrome, but researchers are moving forward in finding new information about the disease every day. In 1999, researchers were able to identify the MECP2 gene mutation on the X-chromosome as being responsible for this disorder. Testing in animals has demonstrated the potential to reverse the disease (International Rett Syndrome Foundation, 2008).

Rett’s syndrome is typically diagnosed through observation of the signs and symptoms of the disease. It is recommended that a developmental pediatrician, neurologist or geneticist be consulted when there is a suspicion of this disorder to confirm the diagnosis. Rett’s syndrome is often misdiagnosed as autism, cerebral palsy or nonspecific developmental delay. Due to advances in research, there is now a test available to identify the gene mutation, eliminating the need for extensive testing to eliminate the possibility of other disorders and waiting sometimes years for symptoms to present in order to obtain a diagnosis (International Rett Syndrome Foundation, 2008).
The effect of Rett’s disorder on the family is certainly devastating. Support systems are necessary for families who learn their child is diagnosed with the disorder. There are support systems available in local communities and online. The devastation of the disease on family life cannot be better described by anyone but a family affected. Below is a sample welcome letter to families from a support website, and demonstrates how Rett’s disorder affected one family.

**One family’s story**

“We knew early on that something was amiss with our little granddaughter. At first, the signs were subtle. We chose to believe that she had low muscle tone. We chose to believe that she was developing a little slower than most babies. We chose to believe that it would all be all right. When my daughter called with the diagnosis, we all cried. We wept with sadness and anger and disappointment and fright. We grieved for all the things that were not to be for our beautiful granddaughter. We would never hear her voice, see her play tag with other children, ride a bike, rollerblade, play sports or walk down the aisle at her wedding. In addition, our pain was doubled as we watched our child and her husband try to deal with this monumental, life-altering situation.

“As the days passed, we all found our own ways to cope with and accept this curve ball that life had thrown us. We read and studied and talked with people who knew so much more than we did. Sharing our pain with those who understood somehow made things little easier. As we learned more and more about this devastating disorder, the days passed. We watched little Jillian grow and our love for her grew as well.

“Her little personality began to emerge, and we could see that she has a wonderful sense of humor. Her ability to light up a room with her smile is amazing. She has so much personality, and although she is unable to speak, she says volumes with her beautiful blue eyes. She, along with the other ‘patient angels,’ relies totally on others to meet her every need. She brings joy to all who come in contact with her. She has brought together our family and our community. She has brought out her parents’ strength and courage and sense of advocacy. Every day she teaches us about determination and courage. At 3 years old, Jillian might not be riding a Schwinn bicycle, but she does sit proudly on her own adaptive bike. She might not sing to us, but she entertains us with her love of music. She might not run on the playground, but she enjoys school and her classroom of friends. To see Jilly and her friends with their wheelchairs in a circle is to behold a circle of love.

“All children have special needs teachers and physical and occupational therapists. Our Jilly does, and now we, too, have new special friends in our lives. These are wonderful, caring, nurturing people who we would not know if it weren’t for Jilly. We are richer for these friendships. Yes, there are still moments of sadness, but they are fewer and farther between. We celebrate milestones differently than parents and grandparents of healthy girls, and we do celebrate. Jillian is a blessing in our family. We revel in small milestones, and we get so excited when we hear of new breakthroughs in Rett research. We are happy. We are hopeful. We are blessed. We hope that you and your family find strength and comfort and the ability to live with your patient angel knowing that she is a special gift.” (International Rett’s Syndrome Foundation, 2008)

**Childhood disintegrative disorder (CDD)**

Childhood disintegrative disorder, which can also be known as Heller syndrome or disintegrative psychoses (Van Voorhees, 2010), is a condition that occurs in children who have developed normally until about age 2. Theodore Heller, a special educator, first proposed the term “dementia infantilis” to account for the condition in 1908 (Westphal, 2009). The essential feature of the disorder is a marked deterioration in multiple areas of functioning. Normal development occurs with verbal and nonverbal communication, social relationships, play and adaptive behaviors up to about the first two years of life. The child then starts to show a significant loss of some or all of these previously acquired skills (American Psychiatric Association, 1994). The demonstration of the disease is very similar to autism, but it is differentiated by the age of onset, which must be prior to age 10 with at least two years of normal development. The onset of the disorder can be gradual or abrupt. Some signs that may be a predictor of onset are increased activity levels, irritability and anxiety followed by a loss of speech and other skills (American Psychiatric Association, 1994). Children and many adolescents with this disease have trouble maintaining a regular sleep-wake cycle. This chronic condition can exacerbate behavioral problems. In addition, epileptic seizures are a complication of the disorder and can peak during adolescence (eMedicine, 2010).

Below are the diagnostic criteria for childhood disintegrative disorder, according to the DSM-IV:

**299.10 Childhood disintegrative disorder**

A. Apparently normal development for at least the first two years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior.

B. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:

1. Expressive or receptive language.
2. Social skills or adaptive behavior.
3. Bowel or bladder control.
4. Play.
5. Motor skills.

C. Abnormalities of functioning in at least two of the following areas:

1. Qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity).
2. Qualitative impairments in communication (e.g., delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play).
3. Restricted, repetitive and stereotyped patterns of behavior, interests and activities, including motor stereotypes and mannerisms.

D. The disturbance is not better accounted for by another specific pervasive development disorder or by schizophrenia. (American Psychiatric Association, 1994)

The cause of this disease is still unknown, and as with other autism spectrum disorders, it is suspected to have a genetic link. Early detection plays a key factor because of the unknown origin of this disease. Medical doctors should provide routine screenings, and parents should be aware of developmental milestones and the steps to take if warning signs occur. If symptoms of the disease are suspected during routine medical screenings, an in-depth evaluation should occur involving a neurologist, child psychologist and psychiatrist, a developmental pediatrician, audiologist, speech therapist, and physical and occupational therapist. Professionals will perform the following tests (these tests may also be used to diagnose other disorders on the autism spectrum):

- **Medical history** – This is an extensive birth, development, medical and family health history with special emphasis on when developmental milestones were reached and the age at which previously learned skills were lost. The family will find it helpful to look at baby books, family photo albums and videotapes so they can accurately remember when their child reached specific developmental milestones.

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Neurological exam – A neurologist performs a physical examination to look for abnormalities in the brain and nervous system. A neurologist may order tests including computerized tomography (CT), magnetic resonance imaging (MRI) and an electroencephalogram (EEG). CT and MRI are imaging techniques that provide doctors with pictures of the brain’s anatomy. An EEG is a test that measures the brain’s electrical activity to determine the presence of seizures.

Genetic tests – These tests usually involve a blood test to study the child’s chromosomes and determine whether there’s an inherited family condition or disease.

Communication and language tests – In-depth tests can measure how the child communicates with words and nonverbal gestures (facial expressions, posture, rhythm of speech, gestures) and how the child interacts with others (understanding words, body language, social cues, tone of voice).

Hearing (audiology) test – This is an examination to check for hearing loss or hearing-related problems.

Vision test – This examination checks for vision loss or vision-related problems.

Behavior inventory – Doctors use formal rating scales and checklists to document the occurrence of specific behaviors, such as repetitive movements, oversensitive or undersensitive responses to normal sights, sounds and touch sensations in the environment as well as social interactions and play skills.

Developmental tests – Developmental tests are administered to measure how the child performs skills compared with other children of the same age. These tests will measure the following skills:

- Gross-motor skills – This includes walking, running, jumping, throwing and climbing.

- Fine-motor skills – This is the use of the hands and fingers for the manipulation of small objects such as buttons, pencils and scissors.

- Sensory skills – This is how the brain and body organize and respond to a variety of everyday sounds, sights, smells, tastes and tactile (touch) experiences in the environment.

- Play skills – This involves how the child plays with toys and other objects as well as children and adults. The style and type of play behavior (imaginative, varied, purposeful, goal-directed) are observed.

- Self-care skills – These skills include toileting, feeding, dressing and brushing teeth.

- Cognitive skills – These skills include attention, following directions, thinking, concentration and problem-solving abilities (Mayo Clinic Staff, 2008).

Childhood disintegrative disorder is very rare, occurring in about 2 per 100,000 children, much rarer than autistic disorder (eMedicine, 2010). Prevalence of this disease is the same regardless of race or socioeconomic status, and the disease is somewhat more common in males than females. The average age of diagnosis of the disease is about 4 years old, again very similar to the onset age of autism.

There is no cure for this disease. Due to this and its rarity, the prognosis is poor for those who are diagnosed, especially for those who also have an intellectual disability that is moderate to severe (eMedicine, 2010). The duration of the disorder is life-long, and the associated difficulties remain relatively constant throughout the life cycle (American Psychiatric Association, 1994).

The treatment strategies for childhood disintegrative disorder can be very similar in nature to those for autistic disorder. Treatment strategies include medication to manage the symptoms of the disease, as well as behavioral therapies to assist with maintenance and improvement of self-help, communication and social skills (Mayo Clinic Staff, 2008).

Asperger disorder

Hans Asperger, an Austrian physician, first described the syndrome in 1944 when he saw similarities in behaviors displayed in his young male patients (Mayo Clinic). These findings were not widely recognized until 1981, when Lorna Wing described the disorder in a series of case studies. Not until 1992 was this disease actually formally recognized as a distinct medical diagnosis, and in 1994 it was published in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (National Institute of Neurological Disorders and Stroke, 2010).

The main feature of this disorder is a severe and sustained impairment in social interactions and communications with others. Asperger disorder is often thought to be a milder form of autism, but there are distinct differences between the two disorders. The main difference between autism and Asperger disorder is there are no clinically significant delays in language development or communicative phrases in Asperger disorder. There is also normal development in cognition and development of age-appropriate self-help skills as well as adaptive behavior and curiosity about the environment (American Psychiatric Association, 1994).

Children with Asperger syndrome do have characteristic features in their social interactions, communication skills and interests, outlined as follows:

- Social interaction:
  - Inability to develop friendships that are appropriate to the child’s developmental level.
  - Impairment in non-verbal behavior, such as eye gaze, facial expression and body language to regulate social interactions.
  - A lack of social and emotional reciprocity and empathy.
  - Impaired ability to identify social cues.

- Communication skills:
  - Difficulties with conversation skills and a tendency to be obscure, have an unusual intonation and rhythm in speech, and make literal interpretations.

- Restrictive interests:
  - Special interests that tend to be unusual in their intensity and focus.
  - Preference for routine and consistency. (Attwood, 2005)

Below are the diagnostic criteria for Asperger disorder, according to the DSM-IV:

299.80 Asperger disorder

A. Qualitative impairment in social interaction, as manifested by at least two of the following:

1. Marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body posture and gestures to regulate social interaction.

2. Failure to develop peer relationships appropriate to developmental level.

3. A lack of spontaneous seeking to share enjoyment, interests or achievements with other people (e.g., by a lack of showing, bringing or pointing out objects of interest other people).

B. Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least one of the following:

1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.

2. Apparently inflexible adherence to specific, nonfunctional routines or rituals.

3. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements).
4. Persistent preoccupation with parts of objects.
C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
F. Criteria are not met for another specific pervasive developmental disorder or schizophrenia (American Psychiatric Association, 1994).

Providing a differential diagnosis with any pervasive developmental disorder is crucial, but can sometimes be difficult due to overlapping symptoms. A differential diagnosis between Asperger disorder and autistic disorder will be the key component in providing the proper treatment for the child diagnosed. In differentiating between the two, it is important to remember the following about Asperger disorder: The onset is usually later, the outcome is usually more positive, social and communication issues are less severe, restricted interests are more prominent, verbal IQ is usually higher than performance IQ (in autism, the case is typically the reverse), physical clumsiness is more frequently seen, family history is more frequently related, and a neurological disorder is less common with this disorder (Ozbayrak, 2010).

The incidence of Asperger disorder is not well known at this time, but researchers conservatively estimate that two out of every 10,000 children have the disorder. Boys are three to four times more likely than girls to have the disorder. (National Institute of Neurological Disorders and Stroke, 2010).

Treatment planning for Asperger disorder coordinates therapies that address the main symptoms present: poor social interaction skills, intensity of and preoccupation with restricted patterns of interest, repetitive routines and physical clumsiness. As with other pervasive developmental disorders, early intervention allows for better outcomes. The treatment plan will vary for each child, but in general, should be geared to that child’s interests and engage the child’s interests in very structured activities, with tasks being taught in a series of simple steps. Treatment strategies may include social skills training as well cognitive behavioral therapy, which can assist with the common issues of anxiety, depression, obsessive compulsive and explosive behaviors that can occur as a result of frustration with difficulties in social interactions. Medication management can be helpful for co-morbid conditions such as obsessive-compulsive disorder, anxiety or depression. Occupational and physical therapy can assist children who have poor motor coordination or who have issues with sensory integration. Speech therapy may assist in improving speech patterns and peculiarities.

Parent education and training in how to help a child at home is also a key factor in working with children with Asperger disorder (National Institute of Neurological Disorders and Stroke, 2010). Below is a common example of tips that may be given to parents in order to assist their children in their treatment at home:

- Keep all your speech simple, to a level they understand.
- Keep instructions simple; for complicated jobs, use lists or pictures.
- Try to get confirmation that they understand what you are talking about or asking. Don’t rely on a standard yes or no, which many like to answer with.
- Explain why they should look at you when you speak to them. Encourage them and give lots of praise for any achievement, especially when they use a social skill without prompting.
- In some young children who appear not to listen, the act of “singing” your words can have a beneficial effect.
- Limit any choices to two or three items.
- Limit their “special interest” time to set amounts of time each day if you can.
- Use turn-taking activities as much as possible, not only in games but at home, too.
- Pre-warn them of any changes, and give warning prompts if you want them to finish a task. For example, say: “When you have finished coloring that area, we are going shopping.”
- Try to build in some flexibility into their routine. If they learn early that things do change, and often without warning, it can help.
- Don’t always expect them to “act your age”; they are usually immature, and you should make some allowances for this.
- Try to identify stress triggers and avoid them if possible. Be ready to distract with some alternative phrase such as, “come and see this”.
- Find a way of coping with behavior problems, even trying to ignore it if it’s not too bad. Hugging sometimes can help.
- Promises and threats you make will have to be kept, so try not to make them too lightly.
- Teach them some strategies for coping. Suggest they tell people who are teasing them to “go away,” or to breathe deeply and count to 20 if they feel the urge to cry in public.
- Begin early to teach the difference between private and public places and actions, so they can develop ways of coping with more complex social rules later in life.
- Let them know that you love them and that you are proud of them often. (Attwood, 2005)

Children with Asperger disorder are often described as “little professors.” Having a child with this disease can be very frustrating, because they develop normally with normal cognitive function and sometimes very high intelligence. Parents often have a hard time understanding why their child seemingly disobeys a command or ignores their efforts to engage in a conversation.

**Tyler’s story**

The story below illustrates what it is like to have a child with Asperger disorder from a parent’s perspective.

“Tyler entered an integrated program in pre-school due to developmental delays with speech and processing. His father and I often wondered at that time if we would ever know his thoughts, his dreams, or the ideas running through his mind that were evident to us, but which he could not express with words.

“We saw improvement in Tyler a mere six weeks after he started in the program. It’s hard to remember now what the milestones were, but I do recall commenting that I couldn’t believe how far he had come in just six weeks. Most notable was his improved ability to focus for longer periods in groups, and to interact with his classmates in a more ‘typical’ way. He was growing, the teachers worked very hard to help him improve, and we were noticing.

“His most memorable event occurred a few weeks into kindergarten. Prior to this time, Tyler had a fairly extensive vocabulary, but often struggled to find the right word, or combination of words, to express a thought. Most importantly, Tyler’s responses were limited to repeating the last word of the question put to him. If I asked him what he had for lunch, he would reply, ‘lunch.’ If I asked him if he wanted juice or milk, he would reply ‘milk.’ Similarly, if I asked him if he wanted milk or juice, he would reply ‘juice,’ reiterating the last word of the sentence spoken. I had stopped asking him about his day at school or what he had for lunch because his inability to reply was so heartbreaking, and I could see how desperately he wanted to tell me, but couldn’t. Tyler rarely ever made sentences with more than 2-3 words, saying things like, ‘I me up,’ instead of ‘pick me up’ at the age of 4. Then, one day he came home from kindergarten with a bird feeder he had made. As we hung it on the tree, he proudly announced, ‘I made it at the art table.’ I burst into tears, and called everybody I knew to tell them what he had said.”
“From that point, a whole new world opened up for Tyler, and for the first time, we were able to get to know him. The integrated setting was able to provide one-on-one opportunities for Tyler with speech and occupational therapy. Having ‘typical’ students in class has helped Tyler aspire for improved performance and behaviors, as well as allowed him to make friends and feel accepted. The teaching team was able to adapt to Tyler’s special needs by offering visual learning tools and providing solutions to help him develop better concentration in a group environment. But, as I mentioned, most notably, the class has helped him overcome his considerable communication issues.

Pervasive development disorder, not otherwise specified (PDD-NOS)

This category is to be used when there is a severe, pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills, and stereotyped behavior, interests, and activities are present, but the criteria are not meant for a specific pervasive developmental disorder, schizophrenia, schizotypal personality disorder, or avoidant personality disorder (American Psychiatric Association, 1994).

Conclusion

Developmental disabilities have evolved from obscure, misunderstood, misdiagnosed and seemingly rare conditions to some of the most common childhood disorders recognized today. In the past 20 years, research, funding and legislation have focused on these types of disabilities, and in this short time, origins of these disorders have become better understood. Research has shown that there are genetic as well as environmental links that cause developmental disabilities. Yet we will not be able to specify more clearly the prevalence and specific causal factors of these disorders until they are further studied and more properly diagnosed. To some extent, certain developmental disabilities and their origin will always be difficult to pinpoint because symptoms overlap, and co-morbidity with other medical and mental health disorders can complicate the diagnostic process.

Early intervention plays a key role in the prognosis of children who are affected with these disorders. Regular screenings, beginning at birth, are necessary to properly diagnose and provide necessary treatments for these disorders. All professionals who work with infants and children should be trained in developmental screening as well as warning signs for possible delays or developmental disabilities. Information is readily available for professionals as well as parents from federal, state and local agencies that focus on infant and child development.

Parents rely on professionals for advice and direction; especially those in the medical community. Developmental disabilities are a relatively new focus area for the medical community, and many professionals are still becoming aware of the conditions and the benefits of early screening and diagnosis. At this time, there are still many professionals who advise parents to use the traditional “wait and see” approach until their child is school age. Many disabilities are still not being diagnosed until almost age 5, often too late, because most can be reliably diagnosed by trained professionals at age 2. Waiting until a child reaches school age negatively affects a prognosis for the most positive outcome. When a child enters the school system without a diagnosis and treatment plan already in place, he or she will likely take longer to adjust to the school setting, making a more difficult transition for all involved. We are tasked as mental health professionals to educate ourselves and share our knowledge with parents to advocate for the best and most appropriate care for their family.

Bibliography


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DEVELOPMENTAL DISABILITIES

Final Examination Questions

Select the best answer for each question and then proceed to www.EliteCME.com to complete your final examination.

1. Developmental disabilities are birth defects that cause:
   a. Lifelong problems with how a specific body part or body system works.
   b. Temporary problems with how a specific body works.
   c. Inconsistent problems with how a body system works.
   d. Problems that affect only the brain.

2. Slightly less than:
   a. 3 million people in the United States have a developmental disability.
   b. 4 million people in the United States have a developmental disability.
   c. 1 million people in the United States have a developmental disability.
   d. 6 million people in the United States have a developmental disability.

3. Early intervention:
   a. Does not play a large role in a better prognosis for children with disabilities.
   b. Is not the key to helping children identified with a disability.
   c. Is the single most important factor in a brighter prognosis for children identified as having a developmental delay or disability.
   d. Has no effect on the prognosis for children with disabilities.

4. About 35 percent of those diagnosed with intellectual disability are categorized in the “severe” group.
   a. True.
   b. False.

5. Down syndrome is:
   a. The single most common genetic cause of an intellectual disability.
   b. Not an intellectual disability.
   c. The least common genetic cause of intellectual disability.
   d. Not caused by genetics.

6. Pervasive developmental disorders usually become evident:
   a. After the age of 5 and are associated with physical impairment.
   b. In the first years of life and can sometimes be associated with some level of an intellectual disability.
   c. At age 8 or later.
   d. During pregnancy.

7. Autism spectrum disorders are now considered:
   a. A result of poor parenting.
   b. To be a biological disorder.
   c. To be a problem with children in their mid-teens.
   d. To be caused by vaccines.

8. Autism spectrum disorders affects:
   a. 2.5 million Americans
   b. 17 million Americans
   c. 30 million Americans
   d. 1.5 million Americans

9. The main feature of Rett’s disorder is the development of various but specific deficits:
   a. Immediately following birth.
   b. Following a period of normal growth and functioning after birth.
   c. Identified in utero.
   d. After puberty.

10. The main feature of Asperger’s disorder is severe and sustained impairment in social interactions and communication with others.
    a. True.
    b. False.