

Chapter 36

Developmental Disabilities and Disorders

Developmental Disorders and Disabilities (1 of 4)

- A *disability* is any loss of physical or mental function.
- A *developmental disability* is a permanent disability that a person is born with or that begins before 18 years of age.
- Can be caused by illness, accidents, distress, diseases, or developmental (genetic) disorders e.g., cerebral palsy, Down syndrome.

Developmental Disorders and Disabilities (2 of 4)

- Developmental disorders and disabilities can be mild, moderate, or severe.
- Can be a physical or mental impairment or both.
 - Function is limited in three or more life skills:
 - Self-care
 - Understanding and expressing speech and language
 - Learning
 - Mobility
 - Self-direction
 - Independent living
 - Economic self-sufficiency

Developmental Disorders and Disabilities (3 of 4)

- Most individuals who are developmentally disabled need lifelong assistance, support, and special services.
- Independence to the extent possible is the goal for these individuals.
- The disorder or disability affects the child and family throughout life.

Developmental Disorders and Disabilities (4 of 4)

- Family caregiver may be under great stress:
 - Must balance caregiving and other responsibilities
 - Can lead to burnout
 - Economic or financial burdens—e.g., need for specialized, expensive equipment and self-help devices

Caring For A Client Who Is Living With A Developmental Disability Or Disorder (1 of 4)

- Clients often have complex care needs.
- The support worker must be familiar with special equipment and self-help devices—follow care plan.
- Clients living with developmental disorders or disabilities have the same rights and needs as everyone else.

Caring For A Client Who Is Living With A Developmental Disability Or Disorder (2 of 4)

- Every client is unique.
- Promote DIPPS.
 - See textbook box: *Think About Safety: Caring for Clients Who Are Living With Developmental Disorders and Disabilities*

Caring For A Client Who Is Living With A Developmental Disability Or Disorder (3 of 4)

- Support worker helps child who has a developmental disorder or disability and the child's family in the following ways:
 - Encourage family to maintain consistent daily schedule.
 - Assist client in maintaining regular bedtime.
 - Use lists, charts, memory aids.
 - Encourage regular physical activity.
 - Encourage structured social activities.

Caring For A Client Who Is Living With A Developmental Disability Or Disorder (4 of 4)

- Support worker helps child who has a developmental disorder or disability and the child's family in the following ways:
 - Encourage client to take daily medications consistently.
 - Suggest client study in quiet environments.
 - Suggest counselling for family and client.
 - Encourage client to eat a nutritionally balanced diet.

Types of Developmental Disorders and Disabilities (1 of 2)

- Are usually caused by conditions, illnesses, or accidents that injure the brain.
 - Include (but are not limited to):
 - Attention-deficit/hyperactivity disorder
 - Autism spectrum disorder
 - Cerebral palsy
 - Down syndrome
 - Epilepsy
 - Fetal alcohol spectrum disorders
 - Intellectual disabilities
 - Spina bifida

Types of Developmental Disorders and Disabilities (2 of 2)

- Some children or adults may have more than one condition that causes a disability.
 - See textbook *Table 36.1: Conditions that can cause developmental disabilities*

Attention-Deficit/Hyperactivity Disorders (ADHD)

- Attention-deficit hyperactivity disorders (ADHD) cause inappropriate levels of inattention as well as hyperactive and impulsive behaviour.
 - One of the most common childhood disorders, along with attention-deficit disorder (ADD).
- For adults, ADHD interferes with both work and family functioning.
- Chronic condition with no cure, although a number of treatment options are available.

ADHD (1 of 5)

- Approximately 3-7% of school-aged children have ADHD; in larger cities this may be as high as 10-15%.
- Condition appears during early childhood.
 - May be diagnosed before age 7 years
 - Twice as likely to occur in boys as girls
 - Has a biological component; more likely if a close family has it
- Can impair everyday functioning.

ADHD (2 of 5)

- Children with learning or communication challenges more likely to have ADHD.
- Adults who are newly diagnosed with ADHD likely had the disorder in childhood (but were undiagnosed).

ADHD (3 of 5)

- Symptoms include:
 - Disorganization and difficulty with task completion
 - Inability to sit still
 - Trouble with follow-through on promises or commitments
 - Difficulty structuring time and setting priorities
 - Inappropriate remarks
 - Tendency toward addictive behaviours
 - Craving for excitement and high stimulation

ADHD (4 of 5)

- Symptoms include:
 - Trouble focusing attention, easily distracted
 - Mood swings
 - Easily flustered, tense
 - Short temper, likely with a history of explosive episodes
 - Poor social skills

ADHD (5 of 5)

- Treatment
 - A chronic condition with no cure
 - Encourage client to keep food diary.
 - Medication
 - Psychotherapy
 - Early assistance from health care provider is important.

Autism Spectrum Disorder (ASD)

(1 of 6)

- A neuro-developmental disorder that impairs a person's ability to communicate and interact with others.
- Cause is unknown.
- Genetic and environmental factors may be involved.
- No cure.
- Begins in early childhood, between ages of 18 months and 3 years of age.
- 1 child in 94 is diagnosed with ASD.
- Affects more boys than girls.

Autism Spectrum Disorder (ASD)

(2 of 6)

- Begins in early childhood, between ages of 18 months and 3 years of age.
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Autism Spectrum Disorder (ASD)

(3 of 6)

- Consists of complex neurobiological conditions that can affect, gastrointestinal, immune, hepatic, endocrine, nervous system, and impacts brain function.
 - Difficulty with typical social interactions.
 - Verbal and nonverbal communication challenges—some with this condition are unable to understand the facial expressions of others.
 - Involves repetitive behaviours and routines.
 - Impacts development of fine and gross motor ability.

Autism Spectrum Disorder ASD

(4 of 6)

- Symptoms depend on client, and can range from mild to severe.
- Common symptoms of ASD:
 - Language skills develop slowly, or not at all
 - Repeats words or phrases
 - Cannot start or maintain conversations
 - Makes repetitive body movements (hand flapping, finger flicking, rocking)
 - Has short attention span, avoids eye contact
 - Spends time alone

Autism Spectrum Disorder ASD

(5 of 6)

- Common symptoms of ASD:
 - Shows little reaction to pain
 - Dislikes cuddling
 - Has frequent tantrums for no apparent reason
 - Has strong attachment to single item, idea, person or activity
 - Needs routines; dislikes change
 - Lacks fear

Autism Spectrum Disorder ASD

(6 of 6)

- Common symptoms of ASD:
 - Displays aggressive or violent behaviour
 - Tends to injure self
 - Does not respond to others
 - Too active or too quiet

Supporting a Client Who is Living With Autism Spectrum Disorder (1 of 2)

- Treatment needs to be specific to the client.
- Support workers caring for children or adults with autism should:
 - Maintain strict routines
 - Help the client develop social and work skills
- Children with ASD require careful supervision.

Supporting a Client Who is Living With Autism Spectrum Disorder (2 of 2)

- With therapy, the person can learn to change or control behaviours.
 - Behaviour Modification Therapy
 - Rewarding positive behaviours is used to encourage positive social behaviours.
 - Speech and language therapy
 - Music, auditory, recreation, and sensory therapy

Cerebral Palsy (1 of 6)

- A disorder affecting muscle control
 - The abnormality is in the motor region of the brain (cerebral).
 - One or more of the following may occur:
 - Involuntary movements, poor coordination and posture, muscle weakness, difficulty or inability to walk or speak
 - It occurs before, during, or within a few years after birth.
 - Causes include lack of oxygen to the brain.
 - There is no cure.

Cerebral Palsy (2 of 6)

- Infants at risk include those who:
 - Are premature
 - Have low birth weight
 - Do not cry within the first 5 minutes after birth
 - Need mechanical ventilation
 - Have bleeding in the brain
 - Have heart, kidney, or spinal cord defects
 - Have blood problems
 - Have seizures
- Acquired brain injury in infancy and early childhood also can result in cerebral palsy (CP).

Cerebral Palsy (3 of 6)

- Body movement
 - Spastic cerebral palsy—uncontrolled contractions of skeletal muscles
 - One or both sides of the body may be involved.
 - Posture and balance are affected.
 - Difficulty eating, dressing, completing ADLs, walking, or moving.

Cerebral Palsy (4 of 6)

- Body movement
 - Athetoid cerebral palsy—constant, slow weaving or writhing motions
 - Difficulty reaching for and grasping objects
 - Difficulty remaining upright for sitting or standing
 - May involve tongue and face, causing drooling or facial grimacing.
 - Ataxic cerebral palsy—weak muscle tone, difficulty coordinating movements
 - Appears unsteady and shaky; has trouble keeping balance.

Cerebral Palsy (5 of 6)

- Certain terms describe the body parts involved:
 - Monoplegia—mono means one; paralysis of one limb
 - Hemiplegia (half)—means complete or partial loss of ability to move one side of the body
 - Arm and leg on one side are affected.
 - Diplegia (two)—means loss of ability to move corresponding parts on both sides of the body
 - Both arms or both legs are affected but other areas of body not affected.
 - Quadriplegia (four)
 - Both arms, both legs, and the trunk and neck muscles are affected.
 - Talking and eating may be difficult.

Cerebral Palsy (6 of 6)

- The person with CP can have many other impairments and challenges:
 - Intellectual disability
 - Learning, hearing, speech, vision disability
 - Difficulty swallowing
 - Drooling
 - Bladder and bowel control issues
 - Seizures
 - ADHD
 - Breathing difficulties
 - Pressure injuries from immobility

Supporting a Client Who is Living With Cerebral Palsy (1 of 2)

- Care needs depend on the severity of the CP and clients' needs.
- Disabilities and impairments range from mild to severe.
 - The goal is for the person to be as independent as possible.

Supporting a Client Who is Living With Cerebral Palsy (2 of 2)

- Support workers will assist client with:
 - Range-of-motion exercises (ROM).
 - ADLs—to reduce risk of injury.
- Physiotherapy, occupational therapy, and speech therapy can help.
- Some people need eyeglasses and hearing aids.
- Surgery and medications can help some muscle challenges.

Down Syndrome (1 of 2)

- The most common congenital (*present at birth*) chromosomal disorder in Canada.
- It is caused by an error at fertilization
 - In DS, an extra chromosome is present (47 instead of 46 chromosomes)
 - May cause intellectual disabilities, usually moderate to severe.

Down Syndrome (2 of 2)

- The DS child has certain features caused by the extra chromosome:
 - Small head; flat face; oval-shaped eyes that slant upward; large tongue; short, wide neck; wide, flat nose; small ears, short stature, short wide hands with stubby fingers, weak muscle tone
 - Many children with DS have other health problems
 - Congenital heart defects, vision and hearing disorders, ear infections, respiratory infections and thyroid issues
 - Dementia symptoms may occur after age 35.
 - Alzheimer's may appear in adults with DS in their 40s.

Supporting a Client Who is Living With Down Syndrome (1 of 2)

- Care depends on the severity of the DS and needs of the client.
- The goal is for client to be as independent as possible.
- Good nutrition, adequate physical activity, and consistent mental stimulation can lead to longer life (60s).

Supporting a Client Who is Living With Down Syndrome (2 of 2)

- Care plan may include:
 - Speech–language therapy, physiotherapy, and occupational therapy
 - Assistance in training for self-care skills
 - Health and sex education
 - A well-balanced diet and regular exercise because weight gain and constipation are frequent problems

Epilepsy (1 of 2)

- A condition characterized by recurrent seizures (a brief disturbance in the brain's normal electrical function) that affects awareness, movement, or sensation.
- Having a single seizure does not mean a person has epilepsy.
- This condition can develop at any time in a person's life.
- Affects children and young adults most commonly.

Epilepsy (2 of 2)

- Types of seizures:
 - Generalized seizures
 - Affect whole brain—reactions vary according to area in brain
 - Partial seizures
 - Affect only one part of the brain
 - Tonic–clonic seizures
 - Involve convulsions (violent, sudden contractions, jerking) with loss of consciousness
 - Urinary and bowel incontinence may occur
 - Last 1–7 minutes

Treatment for Epilepsy

- No cure.
- Medications are prescribed by a physician to try to prevent seizures.
 - When controlled, epilepsy usually does not interfere with learning or ADLs.
- Some clients may need brain surgery.
- May have some limitations (e.g., driving, work)
- Increased risk for premature death, higher rates of suicide, sudden unexplained death, or accidental death (especially drowning).

Supporting a Client Who is Living With Epilepsy

- Care depends on severity of epilepsy and needs of client.
 - The goal is to be as independent as possible.
- Support workers should:
 - Observe and report all activity before, during, and after a seizure. Call for help immediately if needed.
 - Clients with frequent or unpredictable seizures may injure themselves—safety measures are required.
 - Close supervision is required at all times when client is swimming, boating, or in hot tub, to prevent drowning
 - Ensure environment is safe, track duration of seizure and affected body parts. If seizure lasts longer than 5 minutes call emergency services. Stay with client until they recover.

Fetal Alcohol Spectrum Disorders (1 of 4)

- Fetal alcohol spectrum disorders (FASD) are a group of physical and mental abnormalities in a child that result from alcohol consumption by the mother during pregnancy.
 - These are the most common preventable developmental disability.

Fetal Alcohol Spectrum Disorders (2 of 4)

- Physical challenges
 - Low birth weight, weak muscle tone, poor weight gain, cardiac disorders, hearing impairment, abnormalities of spine and joints
- Characteristic facial features
 - Small head, small eye opening, thin upper lip, small chin

Fetal Alcohol Spectrum Disorders

(3 of 4)

- May not have outward signs of a disability
- Problems include:
 - Intellectual disability
 - Behavioural, learning, and emotional disorders, poor attention span, hyperactivity, poor motor skills, slow language development

Fetal Alcohol Spectrum Disorders (4 of 4)

- Older children and adults with FASD
 - Memory impairment, poor judgement, difficulties with ADLs, inability to manage anger, poor social skills, mental health challenges
 - Some adults can live and work independently; others may require ongoing support.

Supporting a Client Living with Fetal Alcohol Spectrum Disorders

- This is a lifelong condition
- Care depends on severity of FASD and needs of the client.
 - Goal is for client to be as independent as possible.
- With appropriate support and interventions, a person living with FASD can be successful in many areas of their lives.
- Support workers will:
 - Encourage self-esteem.
 - Encouraging self-awareness.
 - Promote independence.
 - Provide names of programs and supports.

Intellectual Disability (Cognitive Disability) (1 of 6)

- Impaired ability to learn—below average intelligence and limitations in the ability to function in certain areas of client’s daily life.
 - No longer called “mental retardation”.
- Intelligence relates to learning, thinking, and reasoning.
 - Those with intellectual disability often can learn new skills, but at a slower rate.
- Often have difficulties with communication, self-care, and social interactions.

Intellectual Disability (Cognitive Disability) (2 of 6)

- Can be caused by a genetic abnormality, injury, or disease that impairs development of the brain.
 - See textbook *Box 36.1: Causes of Intellectual Disability*
- People with intellectual disability often have other disabilities as well.

Intellectual Disability (Cognitive Disability) (3 of 6)

- Intellectual disabilities range from mild to severe
- IQ test (intelligence quotient) measures intelligence.

Intellectual Disability (Cognitive Disability) (4 of 6)

- An average person without an intellectual disability has an IQ 90-110.
- With an intellectual disability:
 - Mildly intellectually disabled = IQ between 55 and 70
 - Slow to learn but able to attend regular school.
 - Can work and function in society with support.
 - Moderately intellectually disabled = IQ below 55
 - Need daily support at home and at work.
 - Severely intellectually disabled = IQ below 25
 - Need constant support in all areas.

Intellectual Disability (Cognitive Disability) (5 of 6)

- The Canadian Association for Community Living is a national association dedicated to serving people with intellectual disabilities and their families.
- They believe that:
 - Persons with intellectual disabilities must be able to enjoy and maintain a good quality of life.
 - Life must be meaningful and dignified.
 - Children should live in a family.
 - Children who are disabled should learn and play with children without disabilities, and be integrated into regular schools.
 - Adults should control their lives to the greatest extent possible.

Intellectual Disability (Cognitive Disability) (6 of 6)

- People with intellectual disabilities have sexual, emotional, and social needs and desires.
 - Some have life partners and children.
- They have a right to privacy and a right to love and be loved.
- Most people with intellectual disabilities are able to socially control their sexual urges; some cannot.
 - Children and adults with intellectual disabilities are vulnerable to sexual abuse.
 - People with intellectual disabilities need to be educated about sexual abuse, safer sex practices, and other issues related to sexuality.

Supporting a Client Who Is Living With an Intellectual Disability

- Care depends on severity of disability and needs of the client.
 - Goal is for the client to be as independent as possible.
 - Support workers must follow clients' care plan which includes:
 - Assisting the client in developing work, volunteer, and daily life skills
 - Person-directed planning
 - Taking part in community or recreational programs—maintain social skills and physical health
 - Respite is provided for client's family or caregivers.

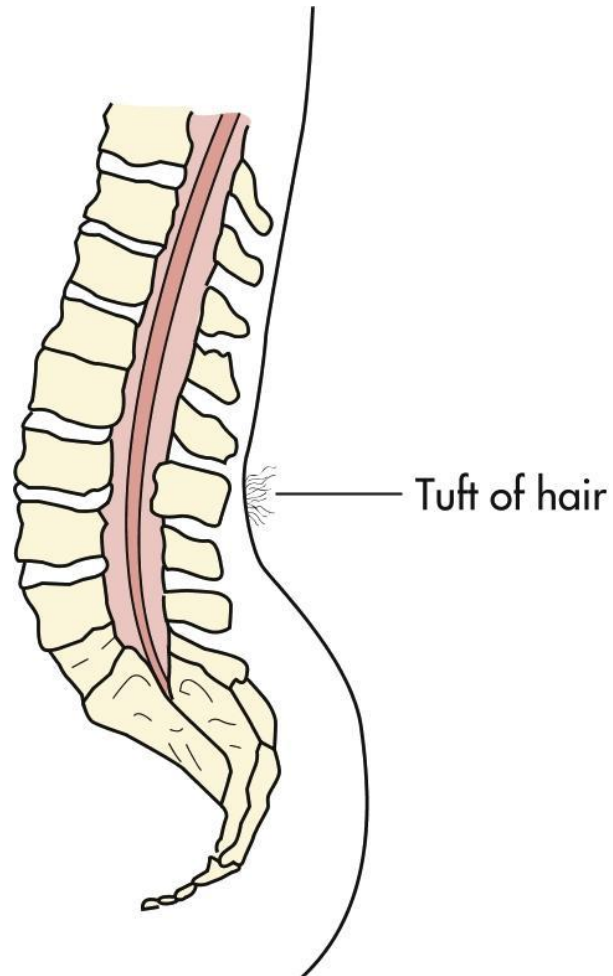
Spina Bifida (1 of 6)

- A congenital disorder involving improper closing of the spine before birth.
 - The *neural tube defect* of the spinal column occurs during the first months of pregnancy
 - Consuming folic acid before conception and during pregnancy reduces the risk
- In spina bifida, vertebrae do not form properly
 - This leaves a split in the vertebrae.
 - The split leaves the spinal cord unprotected.
 - Spina bifida can occur anywhere in the spine.
 - The lower back is the most common site.

Spina Bifida (2 of 6)

- Types of spina bifida:
 - Spina bifida *occulta* (closed)
 - The vertebrae are closed.
 - The spinal cord and nerves are normal.
 - The person has a dimple or tuft of hair on the back.
 - Often there are no symptoms.
 - Foot weakness and bowel and bladder problems can occur.
 - See Figure 36.2 on next slide.

Spina Bifida (3 of 6)



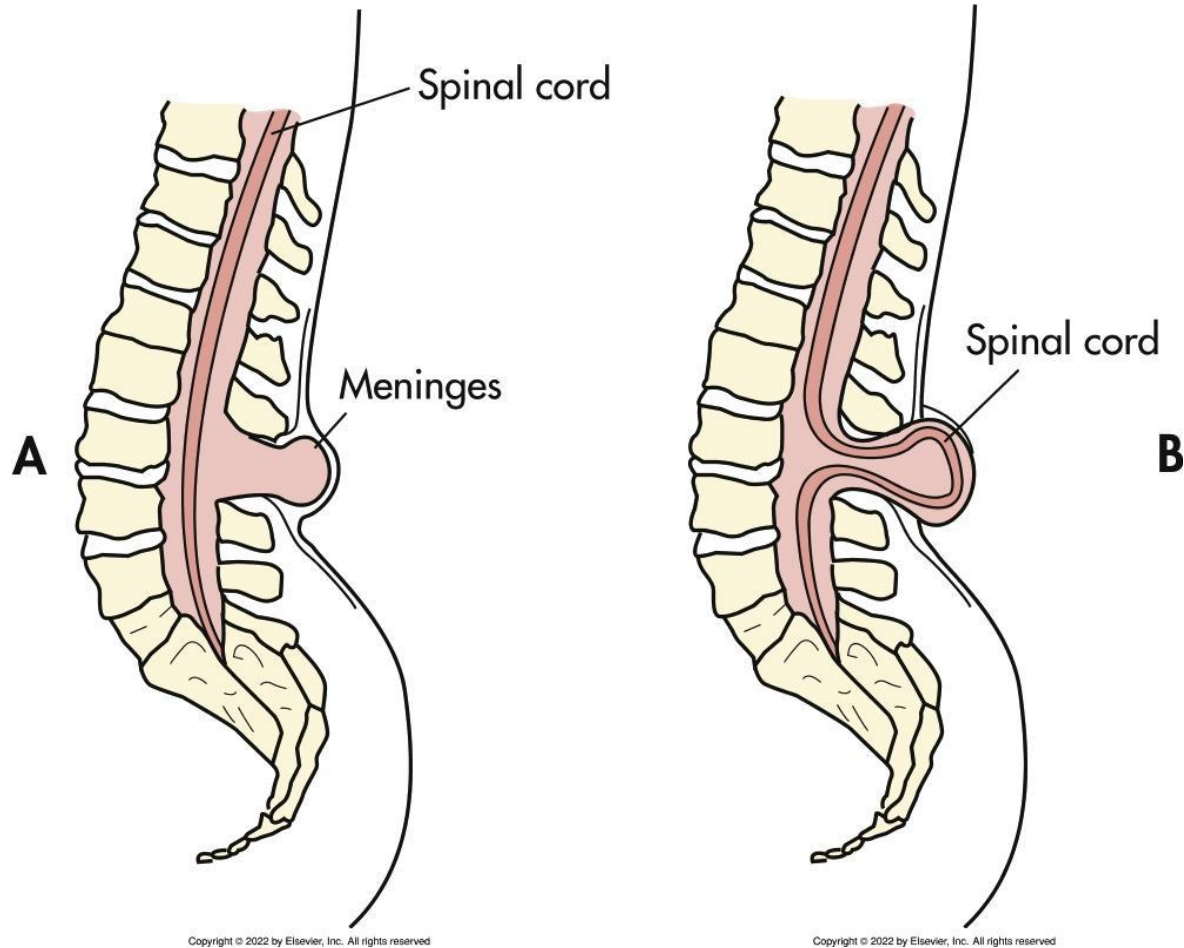
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Spina Bifida (4 of 6)

- Types of spina bifida:
 - Spina bifida *cystica*
 - Part of the spinal column is in a pouch or sac.
 - A membrane or a thin layer of skin covers the sac.
 - The pouch is easily injured.
 - Infection is a threat.
 - There are two types of spina bifida cystica:
 - Meningocele (see Figure 36.3, A on next slide)
 - Myelomeningocele (or meningocele) (see Figure 36.3 B on next slide)

Spina Bifida (5 of 6)



Spina Bifida (6 of 6)

- Types of spina bifida cystica:
 - Meningocele:
 - The sac does not contain nerve tissue.
 - The spinal cord and nerves are usually normal.
 - Nerve damage usually does not occur.
 - Surgery corrects the defect.
 - Myelomeningocele:
 - The pouch contains nerves, spinal cord, meninges, and cerebrospinal fluid.
 - Nerve damage occurs.
 - Loss of function occurs below the level of damage.
 - The defect is closed with surgery.
 - Most common and most serious form

Supporting a Client Who Is Living With Spina Bifida (1 of 2)

- Care depends on type of spina bifida and needs of client.
 - The goal is as much independence as possible.
- No known cure for nerve damage.
- Standard treatment is surgery following birth to prevent further damage and prevent infections.
 - Be careful when working around the sac.

Supporting a Client Who Is Living With Spina Bifida (2 of 2)

- Client may develop health challenges—reduced mobility, infection, bladder and or bowel issues.
- May need involvement of psychologist, occupational therapists, physiotherapists, urologists, neurosurgeons, and orthopedists.

Impact of Developmental Disorders and Disabilities on the Family (1 of 5)

- Families of children who live with developmental disorders and disabilities may face many challenges:
 - Difficulty adjusting to a recent diagnosis
 - Figuring out new roles and routines for everyone in the family—this causes stress
 - Most children with disabilities live with their families at home.

Impact of Developmental Disorders and Disabilities on the Family (2 of 5)

- Primary caregivers experience challenges balancing caregiving with other responsibilities (e.g., job, other children, etc.)
- Parental caregivers worry about the stigma associated with their child's disorder or disability.
- Economic and financial burdens

Impact of Developmental Disorders and Disabilities on the Family (3 of 5)

- Home care and other community agencies provide needed support and services.
- Families in large cities will likely have easier access to support group.
- Many families have to rely on the Internet for information and group supports.

Impact of Developmental Disorders and Disabilities on the Family (4 of 5)

- A support worker will work closely with the family caregivers. Roles may include:
 - Household tasks so parent can spend more time with children
 - Providing respite care
 - Directly assisting the child (e.g., rehabilitation or school)

Impact of Developmental Disorders and Disabilities on the Family (5 of 5)

- Children with severe disabilities may need long-term care in special facilities.
- As children and parents grow older, caring for the adolescent or adult child often becomes physically difficult—they may live in community or residential settings, in their own homes, group homes or in specially licensed long-term care facilities.
- Client's family continues to be involved.
 - Always include family members when appropriate.