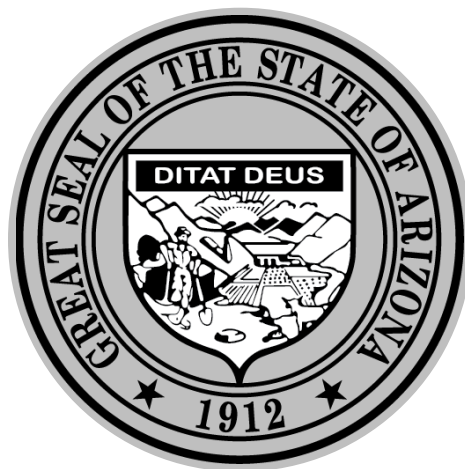


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# Introduction to the Four Developmental Disabilities

Division of Developmental Disabilities

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DEPARTMENT OF ECONOMIC SECURITY

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*Your Partner For A Stronger Arizona*

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**Participant Guide**

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# DEPARTMENT OF ECONOMIC SECURITY

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*Your Partner For A Stronger Arizona*

## **Equal Opportunity Employer/Program**

Equal Opportunity Employer/Program under Titles VI and VII of the Civil Rights Act of 1964 (Title VI & VII), and the Americans with Disabilities Act of 1990 (ADA), Section 504 of the Rehabilitation Act of 1973, the Age Discrimination Act of 1975, and Title II of the Genetic Information Nondiscrimination Act (GINA) of 2008, the Department prohibits discrimination in admissions, programs, services, activities, or employment based on race, color, religion, sex, national origin, age, disability, genetics, and retaliation. The Department must make a reasonable accommodation to allow a person with a disability to take part in a program, service, or activity. For example, this means if necessary, the Department must provide sign language interpreters for people who are deaf, a wheelchair accessible location, or enlarged print materials. It also means that the Department will take any other reasonable action that allows you to take part in and understand a program or activity, including making reasonable changes to an activity. If you believe that you will not be able to understand or take part in a program or activity because of your disability, please let us know of your disability needs in advance if at all possible. To request this document in alternative format or for further information about this policy, contact: 602-542-6825 TTY/TDD Services: 7-1-1. Free language assistance for DES services is available upon request.

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## **Instructor Information**

Date of Training

**Instructor Name**

Phone

Email

**Instructor Name**

Phone

Email

**Instructor Name**

Phone

Email

# Table of Contents

Welcome .....	1
Course Objectives .....	2
Lesson 1: The 4 DDs .....	3
Lesson 2: Intellectual Disability.....	11
Lesson 3: Epilepsy .....	16
Lesson 4: Autism / Spectrum Disorder .....	26
Lesson 5: Cerebral Palsy .....	38

# Welcome

## Introductions

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Please share with the class the following information:

1. Your Name
2. The area you work in
3. Role
4. Supervisor
5. Which, if any, of the 4 developmental disabilities you are most familiar with.

## VALUES & PHILOSOPHY



# Introduction to the Four Developmental Disabilities

## COURSE GOAL

including Autism / Autism Spectrum Disorder, Epilepsy, Cerebral Palsy, Intellectual Disability, and "at-risk" categories.

## COURSE OBJECTIVES

By the end of today's class, you will be able to:

- Define developmental disability
- Distinguish between the four qualifying developmental disabilities
- Explain the difference between the seven functional limitations
- Recognize the symptoms for all four of the developmental disabilities



# LESSON

## The 4 DDs

# 1

"Developmental disability" is defined in A.R.S. § 36-551(18) as a severe, chronic disability which is attributable to disability, cerebral Palsy, epilepsy or autism; is manifest before age eighteen; is likely to continue indefinitely; and results in substantial functional limitations in three or more of the following areas of major life activity:



- Self-care
- Receptive and expressive language
- Learning
- Mobility
- Self-direction
- Capacity for independent living
- Economic self-sufficiency



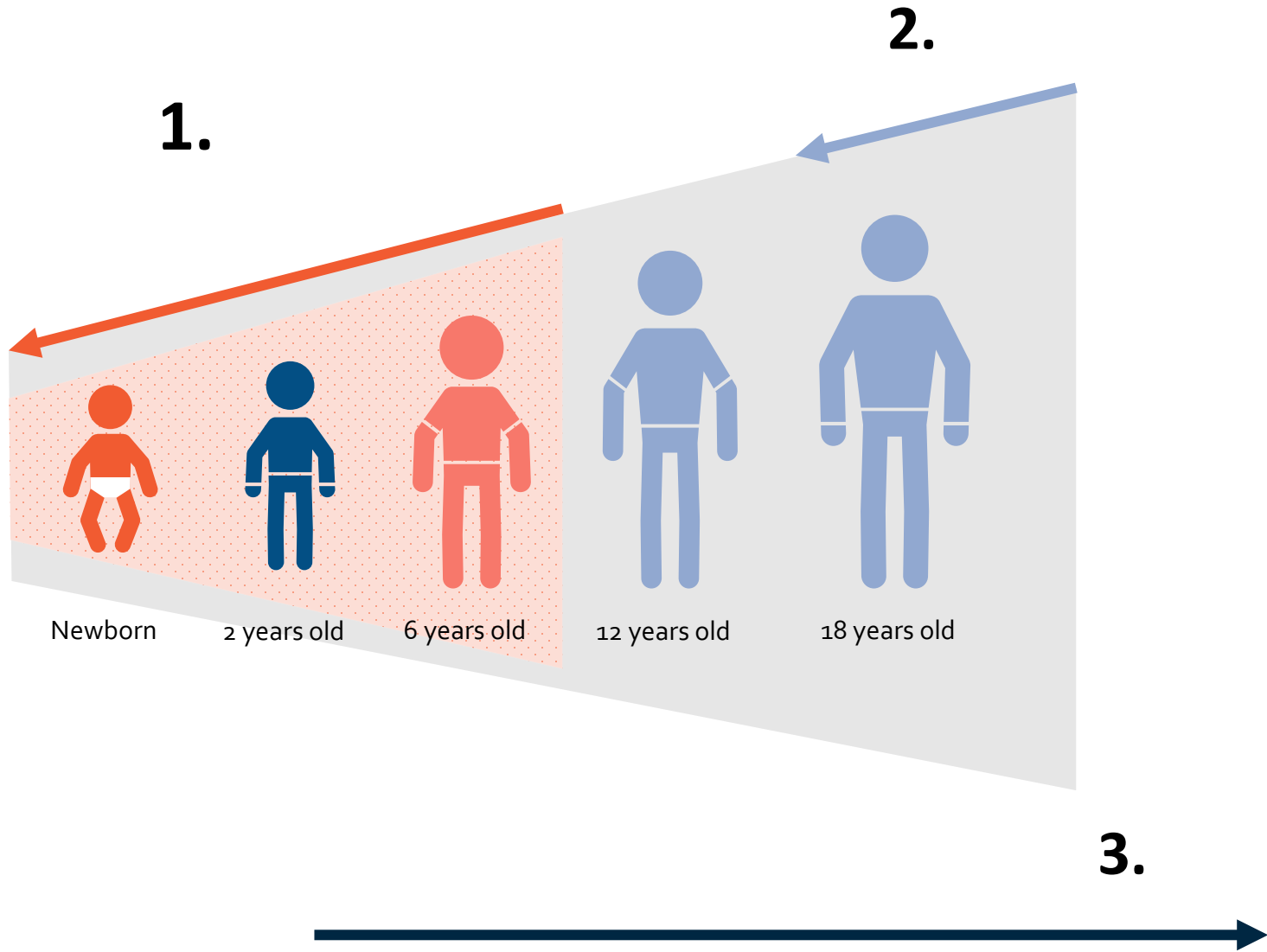
# The Four Developmental Disabilities

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# AGE REQUIREMENTS OF THE 4D'S

1. Prior to the age of 6, a child may be “at risk” for one of the four developmental disabilities
2. Disability manifests itself prior to the age of 18
3. Disability is likely to continue indefinitely



## Review Question

A 26 year old individual calls to apply for services after experiencing his first seizure 2 weeks ago, would this individual qualify for service?

**Yes**    or    **No**

# SUBSTANTIAL FUNCTIONAL LIMITATIONS

In addition to a diagnosis of Intellectual Disability, Cerebral Palsy, Epilepsy, or Autism / Autism Spectrum Disorder before age 18, the person must have substantial functional limitations in at least three (3) of the seven (7) life areas.

**Self-Care:** When a person requires significant assistance in performing eating, hygiene, grooming or health care skills, or when the time required for a person to perform these skills is so extreme it may affect the ability to retain employment or conduct other daily living activities.

Example(s): \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Receptive and Expressive Language:** When a person is unable to communicate with others, or is unable to communicate successfully without the aid of a third person, a person with special skills, or without a mechanical device.

Example(s): \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Learning:** When cognitive or other factors related to obtaining and processing of new information (such as attention factors, acquisition strategies, storage and recovery), are weakened to the extent that the person is unable to participate in age-appropriate learning activities without using of additional resources.

Example(s): \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Mobility:** When motor skills are impaired to the extent that the assistance of another person or mechanical device is required for movement from place to place. Or when the effort required to move from place to place is so extreme it may affect the ability to retain employment or conduct other daily living activities.

Example(s): \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Self - Direction:** When a person requires assistance in managing personal finances, protecting self- interest, or making independent decisions which may affect well-being.

Example(s): \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Capacity for Independent Living:** When, for a person's own safety or well-being, supervision or assistance is needed on a daily basis, in the performing health maintenance and housekeeping.

Example(s): \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Economic Self-Sufficiency:** When a person is unable to perform the tasks necessary for regular employment or is limited in productive ability to the extent that earned annual income is below the poverty level.

Example(s): \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

# CAUSES OF DEVELOPMENTAL DISABILITIES

“Most developmental disabilities are thought to be caused by a complex mix of factors. These factors include genetics; parental health and behaviors (such as smoking and drinking) during pregnancy; complications during birth; infections the mother might have during pregnancy or the baby might have very early in life; and exposure of the mother or child to high levels of environmental toxins, such as lead. For some developmental disabilities, such as fetal alcohol syndrome, which is caused by drinking alcohol during pregnancy, we know the cause”.

*Centers for Disease Control (CDC)*

From a Division standpoint, we are not concerned with the cause. Our role is to focus on supporting the family in finding the best way to support the person with the diagnosis or the person at risk. When the parents and families that you work with ARE concerned about the cause, it is important to empathize while still encouraging them to look to the future.

**There are many different causes of developmental disabilities, including, but not limited to:**

-  Toxins
-  Disease or infection
-  Genetic factors
-  Complications during birth
-  Environmental factors
-  Trauma or injury
-  Medical issues
-  Metabolic disorders

**The #1 preventable cause of developmental disabilities is exposure to alcohol and drugs.**

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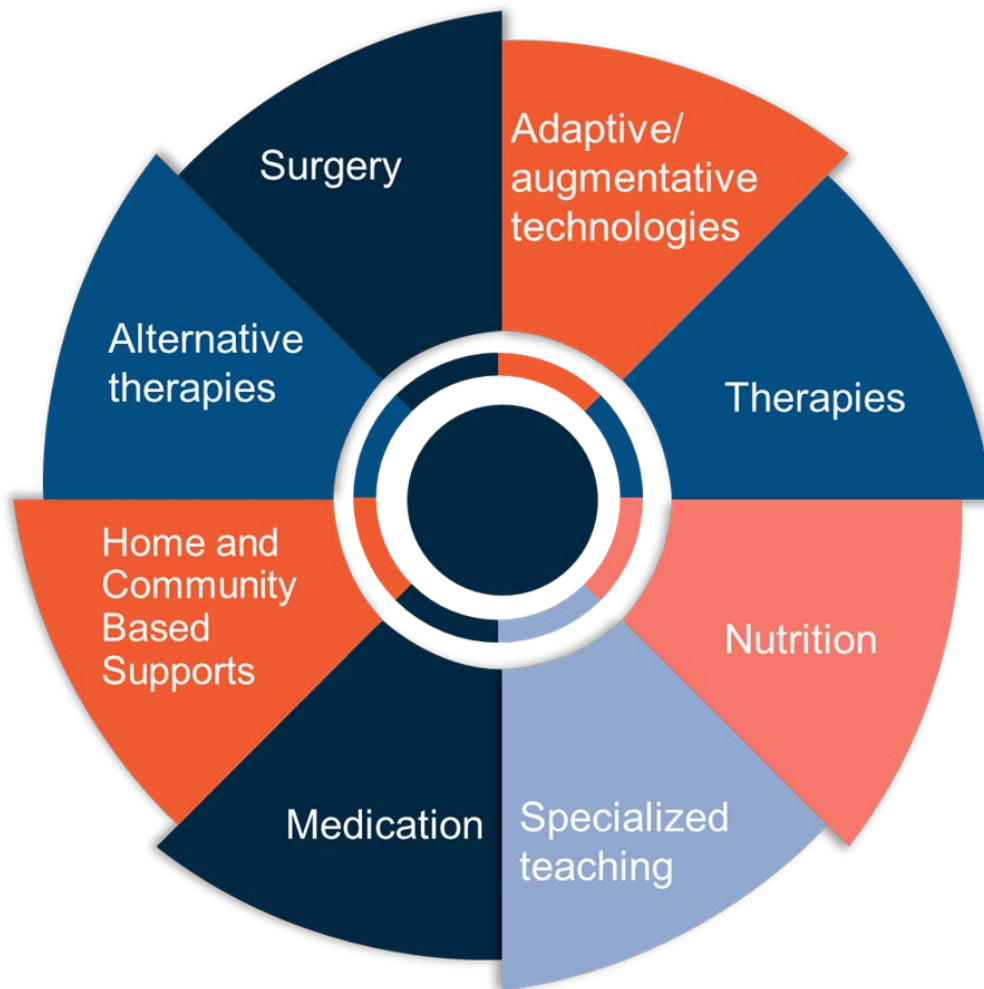
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# TREATMENT AND INTERVENTIONS



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*While Early Intervention is not a separate category of supports and interventions, studies consistently show the more supports we can put in place to give the primary caregivers tools to support the child, and the earlier those supports are put in place, the better the outcome.*

## Review

**Instructions:** Decide if the following statements are true or false. Circle the appropriate response.

1. A developmental disability is the same as a mental illness. True OR False
2. When diagnosing a person's functional limitations, age and cultural factors are considered. True OR False
3. Some developmental disabilities are contagious diseases. True OR False
4. There are no cures for any developmental disabilities. True OR False
5. Educational and vocational training will not help people who have developmental disabilities. True OR False
6. It is safe to assume the physical limitations of people with developmental disabilities based on their diagnosis. True OR False
7. At DDD, we only support people with developmental disabilities if they were diagnosed prior to the age of 18. True OR False

# LESSON Intellectual Disability



## Intellectual Disability

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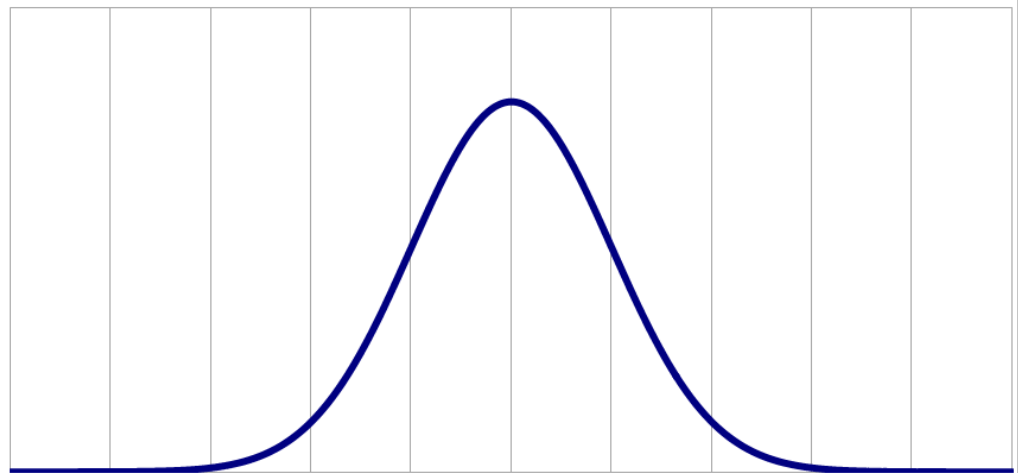
### Arizona Statutory Definition

"Cognitive disability" means a condition that involves sub-average general intellectual functioning, that exists concurrently with deficits in adaptive behavior manifested before the age of eighteen and that is sometimes referred to as intellectual disability.

### Arizona Considerations:

- Adaptive Behavior
- Intellectual Functioning (IQ less than 70)

**IQ Normal Curve**



Standard Deviation	-4	-3	-2	-1	0	1	2	3	4
<b>Wechsler IQ</b>	40	55	70	85	100	115	130	145	160
<b>Stanford-Binet IQ</b>	36	52	68	84	100	116	132	148	164
<b>Cumulative %</b>	0.003	0.135	2.275	15.866	50	84.134	97.725	99.865	99.997



# Facts About Intellectual Disability

## What is intellectual disability?

Intellectual disability, also known as mental retardation, is a term used when there are limits to a person's ability to learn at an expected level and function in daily life. Levels of intellectual disability vary greatly in children – from a very slight problem to a very severe problem. Children with intellectual disability might have a hard time letting others know their wants and needs, and taking care of themselves. Intellectual disability could cause a child to learn and develop more slowly than other children of the same age. It could take longer for a child with intellectual disability to learn to speak, walk, dress, or eat without help, and they could have trouble learning in school.

Intellectual disability can be caused by a problem that starts any time before a child turns 18 years old – even before birth. It can be caused by injury, disease, or a problem in the brain. For many children, the cause of their intellectual disability is not known. Some of the most common known causes of intellectual disability – like Down syndrome, fetal alcohol syndrome, fragile X syndrome, genetic conditions, birth defects, and infections – happen before birth. Others happen while a baby is being born or soon after birth. Still other causes of intellectual disability do not occur until a child is older; these might include serious head injury, stroke, or certain infections.

## What are some of the signs of intellectual disability?

Usually, the more severe the degree of intellectual disability, the earlier the signs can be noticed. However, it might still be hard to tell how young children will be affected later in life.

There are many signs of intellectual disability. For example, children with intellectual disability may:

- sit up, crawl, or walk later than other children
- learn to talk later, or have trouble speaking
- find it hard to remember things
- have trouble understanding social rules
- have trouble seeing the results of their actions
- have trouble solving problems

## What can I do if I think my child may have intellectual disability?

Talk with your child's doctor or nurse. If you or your doctor think there could be a problem, you can take your child to see a developmental pediatrician or other specialist, and you can contact your local early intervention agency (for children under 3) or public school (for children 3 and older). To find out who to speak to in your area, you can contact the National Dissemination Center for Children with Disabilities by logging on to [www.nichcy.org/states.htm](http://www.nichcy.org/states.htm).

To help your child reach his or her full potential, it is very important to get help for him or her as early as possible!

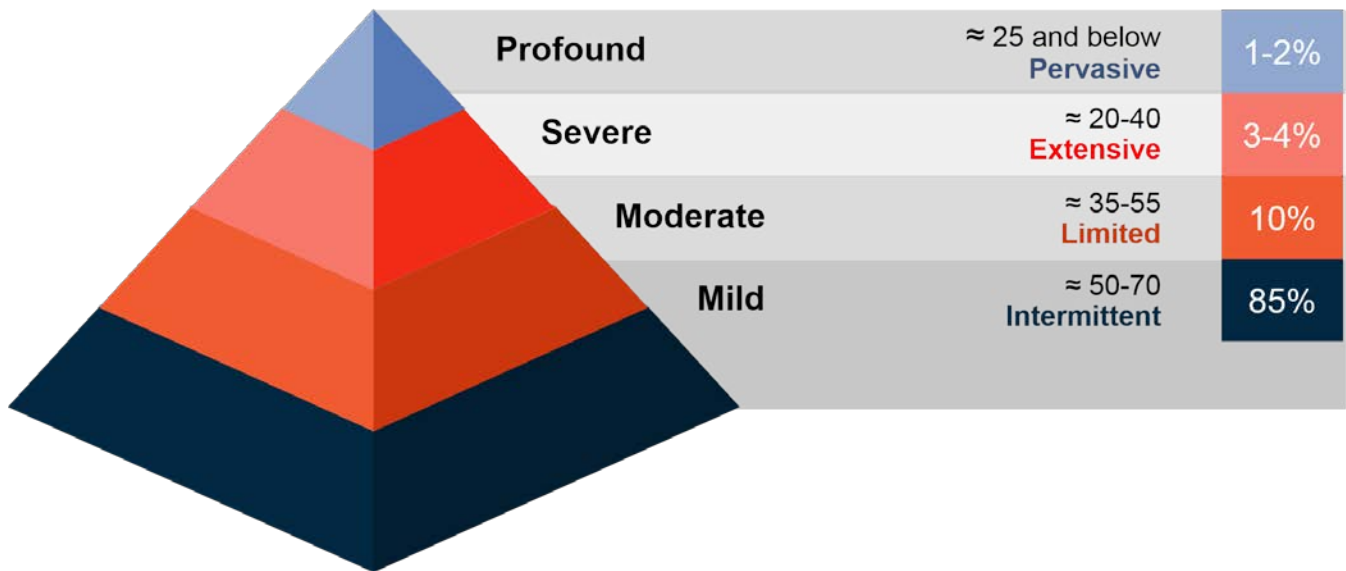
**1-800-CDC-INFO | [www.cdc.gov/ncbddd](http://www.cdc.gov/ncbddd)**



# SEVERITY OF INTELLECTUAL DISABILITY

If you hear the terms mild, moderate, severe, or profound, you are hearing people talk about the severity of the Intellectual Disability.

It is important to remember that every person is unique, regardless of their IQ score. Everyone has their own personality, strengths, and weaknesses.



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# SOME CAUSES OF INTELLECTUAL DISABILITY

- Alterations in embryonic development, such as those caused by chromosomal abnormalities or fetal exposure to drugs and toxins
- Problems of pregnancy and the perinatal period, such as fetal malnutrition, hypoxia, infection, trauma or prematurity
- Genetic causes, such as inborn errors of metabolism or chromosomal aberrations
- Examples:
  - Down Syndrome,
  - Fragile X Syndrome
  - Phenylketonuria (PKU)
  - Tuberous Sclerosis
  
- Medical Conditions of infancy or childhood, such as central nervous system trauma or infection, or lead poisoning
- Physical malformations such as hydrocephalus (fluid accumulation in the brain) and craniostenosis (premature ossification of the sutures of the skull) sometimes result in an intellectual / cognitive disability.

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# Resources

Many resources are available online and in the community to learn more about Intellectual Disabilities. The following are three resources that provide links to many additional community resources / services:

## **Center for Parent Information and Resources**

[www.parentcenterhub.org](http://www.parentcenterhub.org)

## **American Association on Intellectual and Developmental Disabilities**

[www.aaid.org](http://www.aaid.org)

“AAIDD promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities.”

## **The ARC**

[www.thearc.org](http://www.thearc.org)

“The ARC promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.”

# LESSON

## Epilepsy

# 3

### Arizona's Definition of Epilepsy

"...a neurological condition characterized by abnormal electrical-chemical discharge in the brain. This discharge is manifested in various forms of physical activity called seizures."



### CDC Definition

**Epilepsy is a disorder of the brain that causes seizures.** These seizures are not caused by a temporary underlying medical condition such as a high fever.

**Epilepsy can affect people in very different ways.** This is because there are many causes and many different kinds of seizures. Some people may have multiple types of seizures or other medical conditions in addition to epilepsy. These factors play a major role in determining both the severity of the person's condition and the impact it has on his or her life.



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**The way a seizure looks depends on the type of seizure a person is experiencing.** Some seizures can look like staring spells. Other seizures can cause a person to collapse, shake, and become unaware of what's going on around them.

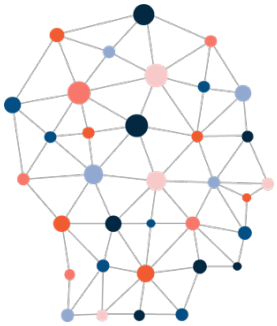
# EPILEPSY VS. SEIZURES

Epilepsy

Seizure

## VIDEO

### **Understanding and Assisting People with Epilepsy**



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### Who Has Epilepsy?

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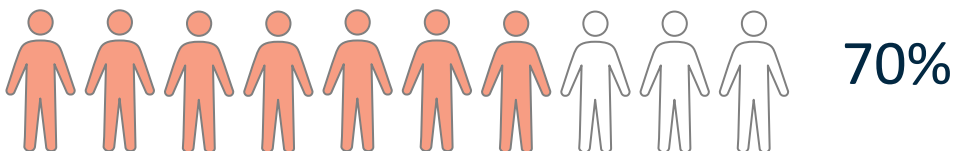
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# CAUSES OF EPILEPSY

In about 70% of people with epilepsy, the cause is not known.



In the remaining 30% of people with epilepsy, the most common causes are:



- Head trauma
- Prenatal brain development
- Brain tumor
- Lead poisoning
- Heredity
- Brain tissue infection
- Stroke

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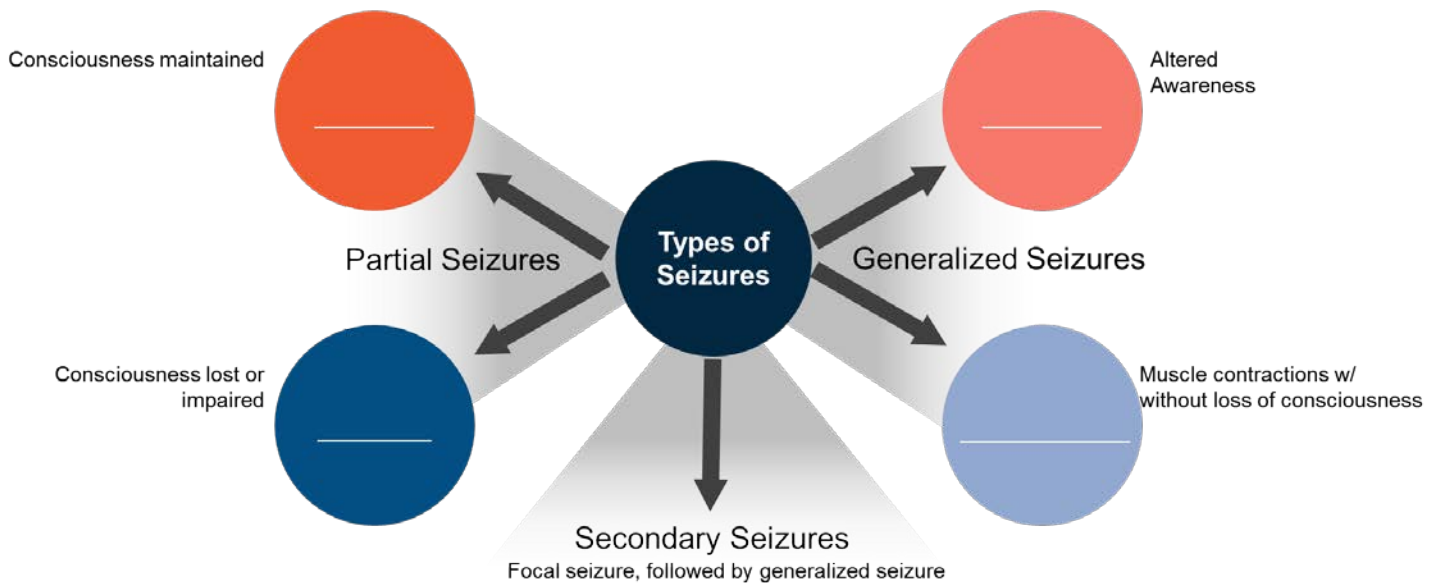
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# TYPES OF SEIZURES AND SEVERITY OF EPILEPSY

Classifying epilepsy involves more than just seizure type, it also encompasses the severity of the seizures as well.



**Epilepsy and seizures can have a variety of degrees of severity:**

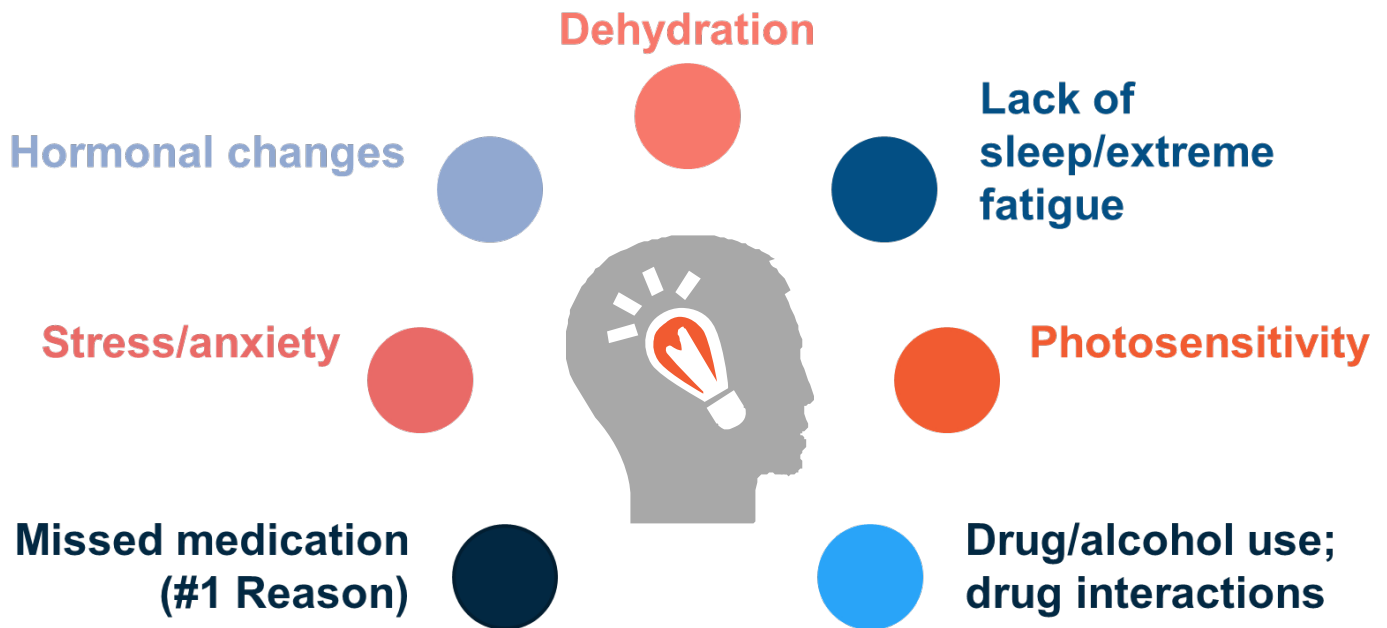
- 1** Uncomplicated epilepsy, seizures controlled with medication
- 2** Seizures not completely controlled by treatment; epilepsy lowers standard of living due to social, emotional, and educational problems
- 3** Seizures resistant to treatment; epilepsy is disabling due to frequent seizures and other problems



# SYMPTOMS INDICATING A SEIZURE DISORDER

- Periods of blackout or confused memory
- Occasional “fainting spells”
- Episodes of blank staring in children
- Sudden falls for no apparent reason
- Episodes of blinking or chewing at inappropriate times
- A convulsion, with or without fever
- Clusters of swift jerking movements in babies

# SEIZURE TRIGGERS



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# FIRST AID FOR SEIZURES

- Stay calm and track time
- Help to avoid hazards without restraining the individual
- Protect head, remove glasses, loosen tight neckwear
- Remove anything hard or sharp out of the way
- Turn person on one side, position mouth to ground
- Check for epilepsy or seizure disorder ID
- Understand that verbal instructions may not be obeyed
- Stay until person is fully aware and help reorient them
- Call ambulance if seizure lasts more than 5 minutes or if it is unknown whether the person has had prior seizures



- Put anything in the person's mouth
- Try to hold down or restrain the person
- Attempt to give oral anti-seizure medication (excluding dissolvable medicine designed to be given during a seizure)
- Keep the person on their back face up throughout convulsion

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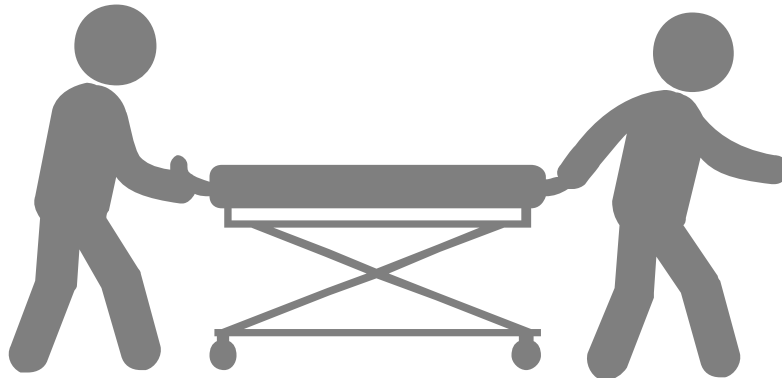
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# WHEN TO CALL 911 EMERGENCY SERVICES

- A convulsive seizure occurs in a person not known to have seizures or lasts more than 5 minutes
- A complex partial seizure lasts more than 5 minutes BEYOND its usual duration for the individual
- Another seizure begins before the person regains consciousness
- Also call if the person:
  - Is injured or pregnant
  - Has diabetes/other medical condition
  - Recovers slowly
  - Does not resume normal breathing



## **Documentation:**

**Risk Assessment:** Details about the types of seizures a person has, including what the seizure looks like, how often, how long they last, and what people around the person should do during a seizure

**Team Assessment Summary**

**Medication Listing:** List all medications and support information

# TYPES OF TREATMENTS



## Medication

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## Surgery



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## Non-pharmacologic

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# SAFETY CONSIDERATIONS

## Personal Safety

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Activities such as bike riding, swimming, fitness, etc.



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## Medical Alert Bracelet

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## Driving

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## A d d i t i o n a l   R e s o u r c e s

### **The Epilepsy Foundation**

[www.Epilepsyfoundation.org](http://www.Epilepsyfoundation.org)

“The Epilepsy Foundation of America® is the national voluntary agency dedicated solely to the welfare of the almost 3 million people with Epilepsy in the U.S. and their families. The organization works to ensure that people with seizures are able to participate in all life experiences; to improve how people with epilepsy are perceived, accepted and valued in society; and to promote research for a cure. In addition to programs conducted at the national level, epilepsy clients throughout the United States are served by more than 50 Epilepsy Foundation affiliates around the country.”

### **Center for Parent Information and Resources**

[www.parentcenterhub.org](http://www.parentcenterhub.org)

### **Epilepsy.com**

[www.Epilepsy.com](http://www.Epilepsy.com)

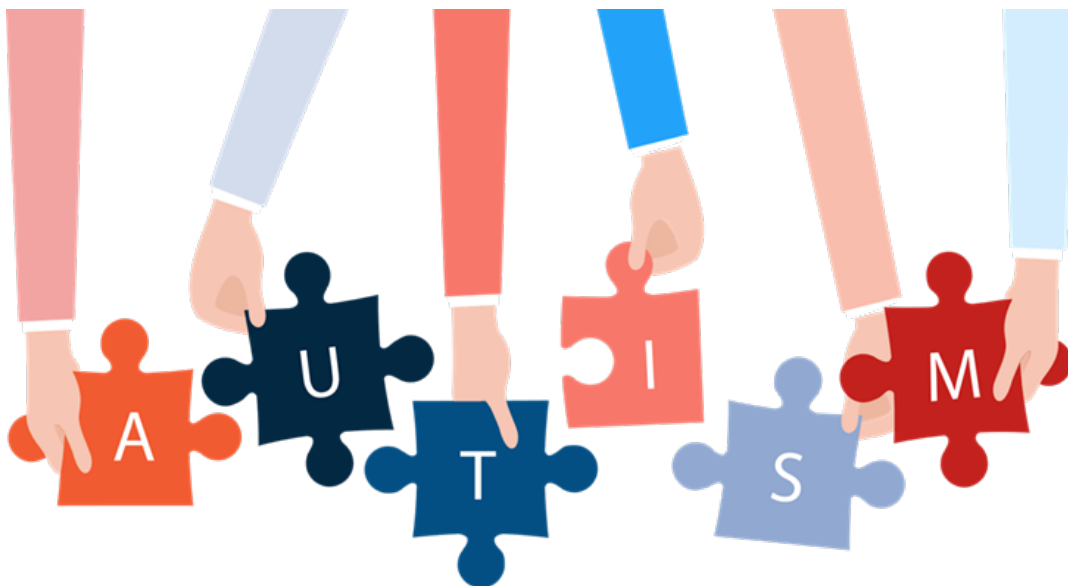
“**Epilepsy.com** is a dynamic online resource providing in-depth information and community (blogs, forums, groups, discussions) for people living with **Epilepsy.**”

LESSON  
Autism / Autism Spectrum  
Disorder

4

Arizona Statutory Definition

“A condition characterized by severe disorders in communication and behavior resulting in limited ability to communicate, understand, learn and participate in social relationships.”



Centers for Disease Control Definition

“Autism Spectrum Disorder (ASD) is a developmental disability that can cause significant social, communication and behavioral challenges.”

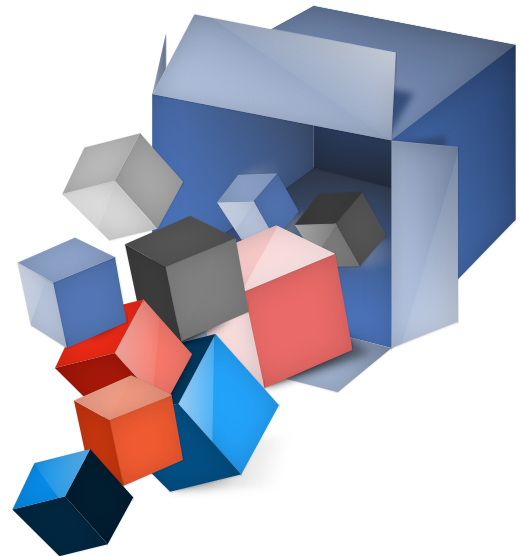
# SIGNS AND SYMPTOMS OF ASD

Autism / Autism Spectrum Disorder (ASD) is the name for a group of developmental disorders caused by differences in the brain. ASD includes a wide range of symptoms, skills, and levels of disability. Some people are mildly impaired by their symptoms while others are severely disabled.

The symptoms of ASD vary greatly from person to person, so it is important to understand that each individual's symptoms will be different.

## A person with ASD might:

- Not respond to their name by 12 months
- Not point at objects to show interest (point at an airplane flying over) by 14 months
- Not play "pretend" games (pretend to "feed" a doll) by 18 months
- Avoid eye contact and want to be alone
- Have trouble understanding other people's feelings or talking about their own feelings
- Have delayed speech and language skills
- Repeat words or phrases over and over (echolalia)
- Give unrelated answers to questions
- Get upset by minor changes
- Have obsessive interests
- Flap their hands, rock their body, or spin in circles
- Have unusual reactions to the way things sound, smell, taste, look, or feel



It is important to note that some people without ASD might also have some of these symptoms. But for people with ASD, the impairments make life very challenging.



## S o c i a l   S k i l l s

Social issues are one of the most common symptoms in all of the types of ASD. People with an ASD do not just have social "difficulties" like shyness, the social issues they have cause serious problems in everyday life.

### Examples of social issues related to ASD:

- 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

Typical infants are very interested in the world and people around them. By the first birthday, a typical toddler interacts with others by looking people in the eye, copying words and actions, using simple gestures such as clapping and waving "bye-bye", and also show interests in social games like peek-a-boo. But a young child with an ASD might have a very hard time learning to interact with other people.

Some people with an ASD might not be interested in other people at all. Others might want friends, but not understand how to develop friendships. Many children with an ASD have a very hard time learning to take turns and share – much more so than other children.

People with an ASD might have problems with showing or talking about their feelings. They might also have trouble understanding other people's feelings. Many people with an ASD are very sensitive to being touched and might not want to be held or hugged.

*Source: <http://www.cdc.gov/NCBDDD/autism/data.html>*

## C o m m u n i c a t i o n

Each person with ASD has different communication skills. Some people can speak well. Others can't speak at all or only very little. About 25%–30% of children with ASD have some words at 12 to 18 months of age and then lose them. Others might speak, but not until later in childhood.

### Examples of communication issues related to ASD:

- Delayed speech and language skills
- Repeats words or phrases over and over (echolalia)
- Reverses pronouns (e.g., says "you" 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 sing-song voice
- Does not pretend in play (e.g., does not pretend to "feed" a doll)
- Does not understand jokes, sarcasm, or teasing

People with ASD might use language in unusual ways. They might not be able to put words into real sentences. Some people with ASD say only one word at a time while others may repeat the same words or phrases over and over.

People with ASD might have difficulty using and understanding gestures, body language, or tone of voice. For example, people with ASD might not understand what it means to wave goodbye. Facial expressions, movements, and gestures may not match what they are saying. For instance, people with an ASD might smile while saying something sad.

People with ASD might say "I" when they mean "you," or vice-versa. Their voices might sound flat, robot-like, or high-pitched. People with an ASD might stand too close to the person they are talking to, or might stick with one topic of conversation for too long. They might talk a lot about something they really like, rather than have a back-and-forth conversation with someone. Some children with fairly good language skills speak like little adults, failing to pick up on the "kid-speak" that is common with other children.



Source: <http://www.cdc.gov/NCBDDD/autism/data.html>

## U n u s u a l I n t e r e s t s a n d B e h a v i o r s

Many people with ASD have unusual interest or behaviors.

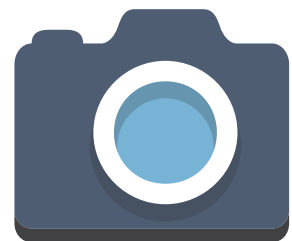
Examples of unusual interests and behaviors related to ASD:

- 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

Repetitive motions are actions repeated over and over again. They can involve one part of the body or the entire body or even an object or toy. For instance, people with an ASD might spend a lot of time repeatedly flapping their arms or rocking from side to side. They might repeatedly turn a light on and off or spin the wheels of a toy car. These types of activities are known as self-stimulation or "stimming."

People with ASD often thrive on routine. A change in the normal pattern of the day – like a stop on the way home from school – can be very upsetting to people with ASD. They might "lose control" and have a "melt down" or tantrum, especially if in a strange place.

Some people with ASD also may develop routines that might seem unusual or unnecessary. For example, a person might try to look in every window he or she walks by a building or might always want to watch a video from beginning to end, including the previews and the credits. Not being allowed to do these types of routines might cause severe frustration and tantrums. Source:



Source: <http://www.cdc.gov/NCBDDD/autism/data.html>

## Development

Children with ASD develop at different rates in different areas. They may have delays in language, social, and learning skills, while their ability to walk and move around are about the same as other children their age. They might be very good at putting puzzles together or solving computer problems, but they might have trouble with social activities like talking or making friends. Children with an ASD might also learn a hard skill before they learn an easy one. For example, a child might be able to read long words but not be able to tell you what sound a "B" makes.



Children develop at their own pace, so it can be difficult to tell exactly when a child will learn a particular skill. But, there are age-specific developmental milestones used to measure a child's social and emotional progress in the first few years of life. To learn more about developmental milestones, visit "Learn the Signs. Act Early." – a campaign designed by CDC and a coalition of partners to teach parents, health care professionals, and child care providers about early childhood development, including possible "red flags" for Autism / Autism Spectrum Disorder.

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Source: <http://www.cdc.gov/NCBDDD/autism/data.html>

## Other Symptoms

Some people with ASD have other symptoms. These might include:

- Hyperactivity (very active)
- Impulsivity (acting without thinking)
- Short attention span
- Aggression
- Self-injury
- Temper tantrums
- Unusual eating and sleeping habits
- Unusual mood or emotional reactions
- Lack of fear or more fear than expected

People with ASD might have unusual responses to touch, smell, sounds, sights, taste, and feel. For example, they might over- or under-react to pain or to a loud noise. They might have unusual eating habits. For instance, they may limit their diet to only a few foods. Others might eat nonfood items like dirt or rocks (this is called pica). They might also have issues like chronic constipation or diarrhea.

People with ASD might have odd sleeping habits. They also might have unusual moods or emotional reactions. For instance, they might laugh or cry at unusual times or show no emotional response at times you would expect one. In addition, they might not be afraid of dangerous things, and they could be fearful of harmless objects or events.

# VIDEO

Autism “Awareness” Ten Things You Should Know

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## AUTISM SPECTRUM DISORDER DIAGNOSIS

In the past, Asperger’s syndrome and autistic disorder were separate disorders. They were listed as subcategories within the diagnosis of “pervasive developmental disorders.” In recent years, the American Psychiatric Association has shifted to include a range of characteristics and severity within one category. People whose symptoms were previously diagnosed as Asperger’s syndrome or autistic disorder are now included as part of the category called Autism Spectrum Disorder (ASD).

To be considered an accepted diagnosis for DDD, a person must have a diagnosis of Autism / ASD and experience 3 of the 7 functional limitations.

DDD supports approximately \_\_\_\_\_ people with a diagnosis of Autism / Autism Spectrum Disorder.

# PREVALENCE OF AUTISM \*

In March 2012, new information about the prevalence of Autism and Autism Spectrum Disorders was released by the Centers for Disease Control:

- About 1 in 88 children has been identified with an Autism Spectrum Disorder (ASD) according to estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network.
- ASDs are reported to occur in all racial, ethnic, and socioeconomic groups.
- ASDs are almost 5 times more common among boys (1 in 54) than among girls (1 in 252).

## **Identified Prevalence of Autism Spectrum Disorder**

### **ADDM Network 2000 - 2012**

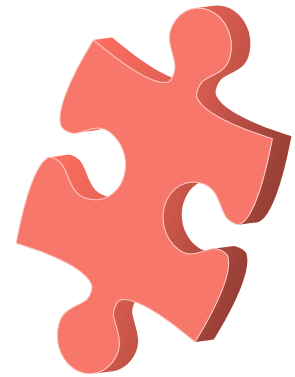
Combining Data from All Sites

Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Prevalence per 1,000 Children (range)	This is about 1 in X children...
2000	1992	6	6.7 (4.5 - 9.9)	1 in 150
2002	1994	14	6.6 (3.3 - 10.6)	1 in 150
2004	1996	8	8.0 (4.6 - 9.8)	1 in 125
2006	1998	11	9.0 (4.2 - 12.1)	1 in 110
2008	2000	14	11.3 (4.8 - 21.2)	1 in 88
2010	2002	11	14.4 (5.7- 21.9)	1 in 68
2012	2004	11	14.6 (8.2 - 24.6)	1 in 68

*\*<http://www.cdc.gov/NCBDDD/autism/data.html>*

# TREATMENTS AND INTERVENTIONS

## Behavior and Communications Approaches



According to reports by the American Academy of Pediatrics and the National Research Council, behavior and communication approaches that help children with ASD are those that provide structure, direction, and organization for the child in addition to family participation. Some of these approaches are as follows:

- Applied Behavior Analysis (ABA). ABA has become widely accepted among healthcare professionals and used in many schools and treatment clinics. ABA encourages positive behaviors and discourages negative behaviors in an effort to improve a variety of skills. The various types of ABA include:
  - Discrete Trial Training (DTT) is a style of teaching that breaks lessons down into the simplest parts and use positive reinforcement to reward correct answers.
  - Early Intensive Behavioral Intervention (EIBI) is a type of ABA best used for very young children with an ASD.
  - Pivotal Response Training (PRT) aims to increase a child’s motivation to learn, monitor his own behavior, and initiate communication with others.
  - Verbal Behavior Intervention (VBI) focuses on teaching verbal skills.
- Occupational Therapy teaches skills that help a person live as independently as possible. Possible skills might include dressing, bathing, eating, etc.
- Sensory Integration Therapy helps the person deal with sensory information such as sights, sounds, and smells. This could be used for a child that does not like to be touched.
- Speech Therapy helps to improve a person’s communication skills. Where some people with ASD are able to learn verbal communication skills, others rely on gestures or picture boards to communicate.



## DIETARY APPROACHES

Some dietary treatments have been developed by reliable therapists. But many of these treatments do not have the scientific support needed for widespread recommendation. An unproven treatment might help one child, but may not help another.

Many biomedical interventions call for changes in diet. Such changes include removing certain types of foods from a child's diet and using vitamin or mineral supplements. Dietary treatments are based on the idea that food allergies or lack of vitamins and minerals cause symptoms of ASD. Some parents feel that dietary changes make a difference in how their child acts or feels.

## MEDICATION

Although there are no medications that can cure ASD or any of the main symptoms, certain medication can be used to help manage related symptoms such as:

- High Energy Levels
- Inability to Focus
- Sleep Disturbances
- Depression
- Seizures

## COMPLEMENTARY AND ALTERNATIVE TREATMENTS

To relieve the symptoms of ASD, some parents and health care professionals use treatments that are outside of what is typically recommended by the pediatrician. These types of treatments are known as complementary and alternative treatments (CAM). They might include special diets, chelation (a treatment to remove heavy metals like lead from the body), biologicals (e.g., secretin), or body-based systems (like deep pressure).

These types of treatments are very controversial. Current research shows that as many as one third of parents of children with an ASD may have tried complementary or alternative medicine treatments, and up to 10% may be using potentially dangerous treatments.

## A d d i t i o n a l   R e s o u r c e s

### **Autism Speaks**

[www.autismspeaks.org](http://www.autismspeaks.org)

Autism network for research, professionals, and families. Includes access to large video library.

### **Autism Society**

[www.autism-society.org](http://www.autism-society.org)

The Autism Society, the nation's leading grassroots autism organization, exists to improve the lives of all affected by autism. We do this by increasing public awareness about the day-to-day issues faced by people on the spectrum, advocating for appropriate services for individuals across the lifespan, and providing the latest information regarding treatment, education, research and advocacy.

### **HELPGUIDE.org**

Trusted guide to mental, emotional & social health

<https://www.helpguide.org/articles/autism/autism-spectrum-disorders.htm>

[www.parentcenterhub.org](http://www.parentcenterhub.org)

### **Autism & Me Series: Just a skinny Boy**

<http://bit.ly/29rNaEL>

Autism "Awareness" – Ten Things You Should Know

<https://www.youtube.com/watch?v=x5m5vqrFZpc>

# LESSON Cerebral Palsy

# 5

## DEFINITION OF CEREBRAL PALSY

### Arizona Statutory Definition



“A permanently disabling condition resulting from damage to the developing brain which may occur before, after, or during birth which results in loss or impairment of control over voluntary muscles.”

### CerebralPalsy.org Definition

“Cerebral Palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitations, attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of Cerebral Palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behavior, epilepsy, and by secondary musculoskeletal problems.”



## Statistics about Cerebral Palsy

- About 10,000 babies per year in the U.S will develop Cerebral Palsy (Centers for Disease Control and Prevention)
- About 2-3 children per 1,000 have Cerebral Palsy (March of Dimes)
- About 800,000 people have Cerebral Palsy in the U.S. (United Cerebral Palsy)
- Cerebral Palsy is the most common motor disability in childhood (Centers for Disease Control)

# CAUSES OF CEREBRAL PALSY

## C o n g e n i t a l C e r e b r a l P a l s y

According to United Cerebral Palsy, in most cases, the cause of congenital cerebral Palsy is unknown.

**Results from brain injury during intra-uterine life and present at birth.**

Accounts for about 70% of children diagnosed with Cerebral Palsy

**Results from Brain injury in the birthing process.**

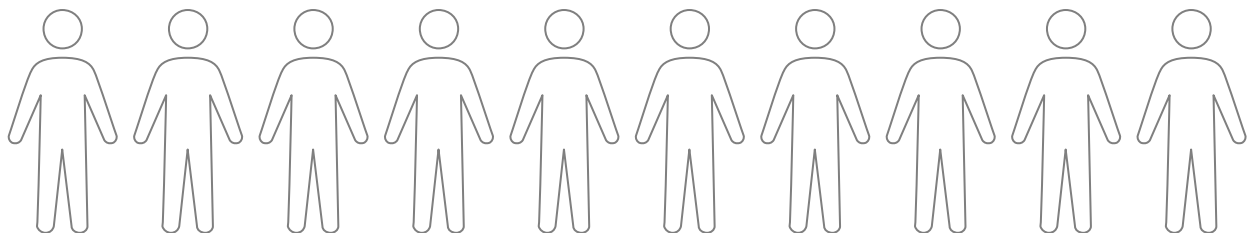
Accounts for about 20% of children diagnosed with Cerebral Palsy

## A c q u i r e d C e r e b r a l P a l s y

**Results from brain damage in the first few months or years of life and can follow brain infections, such as bacterial meningitis or viral encephalitis, or the results of head injury.**

Accounts for about 10% of children diagnosed with Cerebral Palsy

\*All statistics provided by United Cerebral Palsy



# SIGNS OF CEREBRAL PALSY

## 0-6 months

- Head lags when picked up from lying on back
- Feels stiff
- Feels “floppy”
- Legs get stiff and cross when picked up



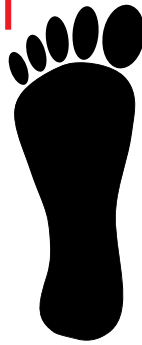
## 6-10 months

- Doesn’t roll in either direction
- Cannot bring hands together
- Difficulty bringing hands to mouth
- Legs get stiff and cross when picked up



## 10+ months

- Crawling in a lopsided manner, pushing off with one hand and leg while dragging the opposite hand and leg
- Scoots around on buttocks or hops on knees, but does not crawl on all fours



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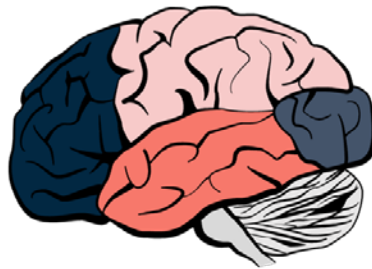
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# TYPES OF CEREBRAL PALSY

Increased muscle tone  
– stiff limbs

Hypertonic /  
Pyramidal

Most common type



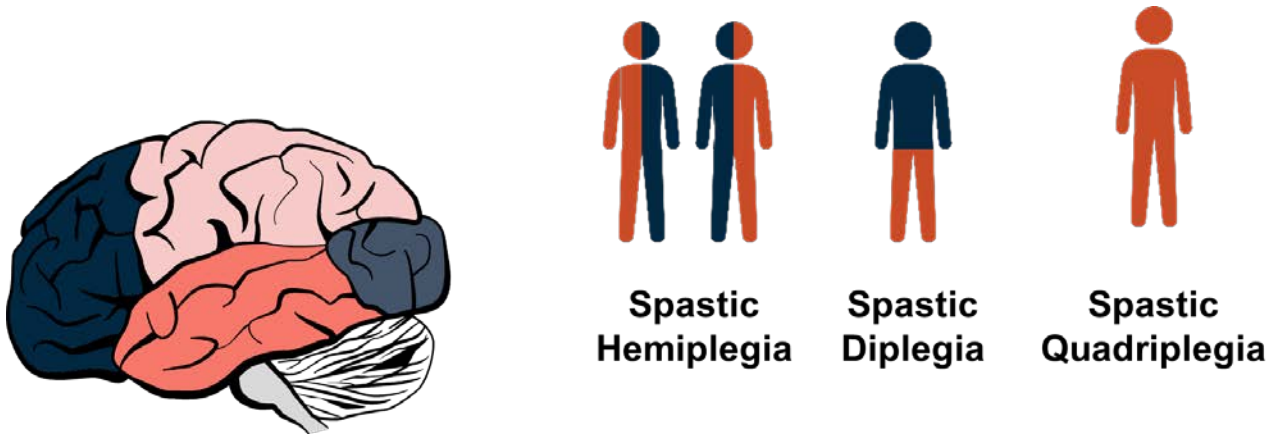
## **Non - Spastic**

Decreased muscle tone  
– floppy limbs

Hypotonic /  
Extrapyramidal

Fluctuating muscle  
tone – involuntary  
movements

# Spastic Cerebral Palsy



Spastic CP is the most common type (80% of people with CP). People will experience increased muscle tone and their movements may appear stiff or awkward.

Spastic CP usually is described by what parts of the body are affected.

## **Spastic diplegia/diparesis**

In this type of CP, muscle stiffness is mainly in the legs, with the arms less affected or not affected at all. People with spastic diplegia might have difficulty walking because tight hip and leg muscles cause their legs to pull together, turn inward, and cross at the knees (also known as scissoring).

## **Spastic hemiplegia/hemiparesis**

This type of CP affects only one side of a person's body; usually the arm is more affected than the leg.

## **Spastic quadriplegia/quadriparesis**

Spastic quadriplegia is the most severe form of spastic CP and affects all four limbs, the trunk, and the face. People with spastic quadriparesis usually cannot walk and often have other developmental disabilities such as intellectual disability; seizures; or problems with vision, hearing, or speech.

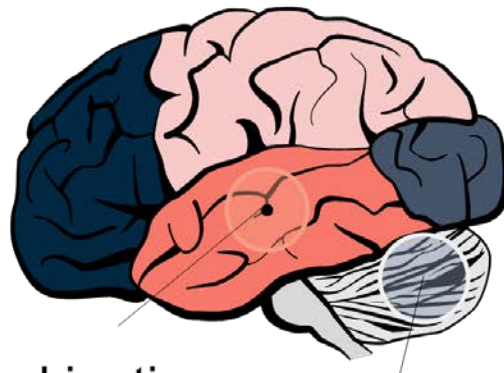
# Non-Spastic Cerebral Palsy

## Dyskinetic

Slow and uncontrollable movements of extremities

Muscle hyperactivity in face/ tongue

Intelligence rarely affected



Dyskinetic

Ataxic

## Ataxic / Ataxia

Impaired balance and coordination

Wide and irregular gait

Impaired eye movements/vision

Affects fine motor skills

**Dyskinetic Cerebral Palsy** (also includes athetoid, choreoathetoid, and dystonic cerebral palsies)

People with dyskinetic CP have problems controlling the movement of their hands, arms, feet, and legs, making it difficult to sit and walk. The movements are uncontrollable and can be slow and writhing or rapid and jerky. Sometimes the face and tongue are affected and the person has a hard time sucking, swallowing, and talking. A person with dyskinetic CP has muscle tone that can change (varying from too tight to too loose) not only from day to day, but even during a single day.

## Ataxic Cerebral Palsy

People with ataxic CP have problems with balance and coordination. They might be unsteady when they walk. They might have a hard time with quick movements or movements that need a lot of control, like writing. They might have a hard time controlling their hands or arms when they reach for something.



## ACCOMPANYING ISSUES

### **Delayed Growth and Development**

Children with moderate to severe CP, often lag behind in growth and development. The muscles and limbs affected by CP tend to be smaller than normal, especially in children with spastic hemiplegia, whose limbs on the affected side of the body may not grow as quickly or as long as those on the normal side.

### **Learning Disability**

Approximately 30 – 50 percent of individuals with CP will be intellectually impaired. Mental impairment is more common among those with spastic quadriplegia than in those with other types of cerebral Palsy.

### **Spinal Deformities and Osteoarthritis**

Deformities of the spine – curvature (scoliosis), humpback (kyphosis), and saddle back (lordosis) – are associated with CP. Spinal deformities can make sitting, standing, and walking difficult and cause chronic back pain. Pressure on and misalignment of the joints may result in osteoarthritis (a breakdown of cartilage in the joints and bone enlargement).

### **Hearing Loss**

Impaired hearing is also more frequent among those with CP than in the general population. Some children have partial or complete hearing loss, particularly as the result of jaundice or lack of oxygen to the developing brain.

### **Impaired Vision**

Many people with CP have strabismus, commonly called “cross eyes,” which left untreated can lead to poor vision in one eye and can interfere with the ability to judge distance. Some people with CP have difficulty understanding and organizing visual information.

**1 in 10 people with CP have severe vision impairment**

## **Speech and Language Disorders**

Speech and language disorders, such as difficulty forming words and speaking clearly, are present in more than a third of those with CP. Poor speech impairs communication and is often interpreted as a sign of cognitive impairment, which can be very frustrating to people with CP, especially the majority who have average to above average intelligence.

**1 in 5 people with CP cannot talk**

## **Epilepsy**

Many people with Intellectual Disability and CP also have epilepsy. In general, drugs are prescribed based on the type of seizures an individual experiences, since no one drug controls all types. Some individuals may need a combination of two or more drugs to achieve good seizure control.

**1 in 4 children with CP have epilepsy**

## **Pain**

Pain can be a problem for people with CP due to spastic muscles and the stress/strain on parts of the body that are compensating for muscle abnormalities. Some individuals may also have frequent and irregular muscle spasms that can't be predicted or medicated in advance. Medications such as diazepam can reduce the pain associated with muscle spasms and gabapentin has been used successfully to decrease the severity and frequency of painful spasms. Botulinum toxin injections have also been shown to decrease spasticity and pain. Intrathecal baclofen has shown good results in reducing pain. Some children and adults have been able to decrease pain by using noninvasive and drug-free interventions such as distraction, relaxation training, biofeedback, and therapeutic massage.

**1 in 2 people with CP live in chronic pain**

# TREATMENTS AND INTERVENTIONS

Cerebral Palsy cannot be cured, but treatment will often improve a child's capabilities and quality of life. The earlier treatment begins, the better chance children have of overcoming developmental disabilities and learning new ways to accomplish the tasks that challenge them.

Although there are many treatments for Cerebral Palsy, there is no standard treatment that works for every individual with CP. Depending on the type of CP and the severity, a team of medical professionals will determine the correct treatment for each individual's needs and concerns.

The four main types of Treatments are:



Therapeutic



Surgery



Drug Treatment



Complementary  
and  
Alternative  
Treatments

\*All information provided by the National Institute of Neurological Disorders and Stroke

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## Therapeutic Treatments

The main types of therapeutic treatments for individuals with CP are:

### Physical Therapy

- Specific sets of exercises and activities can maintain or improve muscle strength, balance, motor skills, and prevent contractures.

### Occupational Therapy

- Focuses on upper body function such as improving posture and making the most of a child's mobility. Occupational therapy also helps individuals learn new ways to overcome everyday activities that might be made harder by CP or any of the associated conditions.

### Recreation Therapy

- Encourages participation in art and cultural programs, sports, and other events that aid in expanding an individual's physical and cognitive skills and abilities. This helps with a child's speech, self-esteem, and emotional well-being.

### Speech and Language Therapy

- Can improve a child's ability to speak more clearly, aid in any swallowing disorders, and potentially teach new ways to communicate such as using sign language or special communication devices.

## Drug Treatments

Oral medications can be used as a first line defense to treat muscle stiffness, contracted or overactive muscles. These medications are most appropriate for children who only need mild reduction in muscle tone or who have widespread spasticity.

### Botulinum Toxin (BT-A)

- Injected locally has become a standard treatment for overactive muscles in children with spastic movement disorders such as CP.

### Intrathecal Baclofen Therapy

- Utilizes an implanted pump to deliver a muscle relaxant into the fluid surrounding the spinal cord. This is most appropriate for individuals with chronic, severe stiffness or uncontrolled muscle movement throughout the body.

# Surgery

## Orthopedic Surgery

- Used when spasticity and stiffness are severe enough to limit the ability for an individual to move, or enough to make pain too severe for an individual to walk. Surgeons can lengthen muscles and tendons that are proportionately too short, which can improve mobility and lessen pain. Surgery can also greatly improve spinal deformities in people with CP.

## Surgery to Cut Nerves

- This is recommended for cases of severe spasticity when all or most of the therapeutic and drug treatments are unable to reduce spasticity or chronic pain. A surgeon selectively severs over activated nerves at the base of the spinal column. This treatment is most commonly used to relax muscles and decrease chronic pain in one or both of the lower or upper limbs. It is also sometimes used to correct an overactive bladder. Potential side effects include sensory loss, numbness, or uncomfortable sensations in limb areas once supplied by the severed nerve.

# Complementary and Alternative Therapies

Many children and adolescents with CP use some form of complementary or alternative medicine. Controlled clinical trials involving some of the therapies have been inconclusive or showed no benefit, and the therapies have not been accepted in mainstream clinical practice. Such therapies include hyperbaric oxygen therapy, special clothing worn during resistance exercise training, certain forms of electrical stimulation, assisting children in completing certain motions several times a day, and specialized learning strategies.

## Stem cell therapy

- This therapy is currently being investigated as a treatment for CP but research is still in the early stages. Stem cells are capable of becoming other cell types in the body. Scientists are hopeful that stem cells may be able to repair damaged nerves and brain tissues. Studies in the U.S. are examining the safety and tolerability of umbilical cord blood stem cell infusion in children with CP.

## A d d i t i o n a l   R e s o u r c e s

### **United Cerebral Palsy**

<http://www.ucp.org/>

“United Cerebral Palsy (UCP) educates, advocates and provides support services to ensure a life without limits for people with a spectrum of disabilities.”

### **National Institute of Neurological Disorders and Stroke**

[http://www.ninds.nih.gov/disorders/cerebral\\_Palsy/cerebral\\_Palsy.htm](http://www.ninds.nih.gov/disorders/cerebral_Palsy/cerebral_Palsy.htm)

Clearinghouse of information related to cerebral Palsy.

### **MyChild Cerebral Palsy**

<http://cerebralPalsy.org>

“Our mission at MyChild™ is to provide you with the most comprehensive resource and compassionate voice for all things related to caring for a child with cerebral Palsy, and other neurological conditions. We provide an ever expanding number of topics and a community blog at this website, in combination with unlimited access to our caring and compassionate MyChild™ call center representatives. We’re striving, every day, to be your ULTIMATE Resource for EVERYTHING cerebral Palsy. Read and share, be inspired and call us to find the answers you need, and to receive the help you and your child deserve.”

### **Zach Anner Video**

<https://youtube.com/ZachAnner>

## A d d i t i o n a l   R e s o u r c e s

### **Kids as Self Advocates**

[www.fvkasa.org](http://www.fvkasa.org)

“We model leadership and the power of self-advocacy. We are active in our schools, communities, families and places of employment. We share our message with other youth who have disabilities or chronic health conditions, as well as with our friends and peers.”

### **National Centers for Independent Living**

[www.ncil.org/](http://www.ncil.org/)

As a membership organization, NCIL advances independent living and the rights of people with disabilities through consumer-driven advocacy. NCIL envisions a world in which people with disabilities are valued equally and participate fully.

### **Sibling Support Project**

[www.siblingsupport.org](http://www.siblingsupport.org)

The Sibling Support Project is a national effort dedicated to the life-long concerns of brothers and sisters of people who have special health, developmental, or mental health concerns.