Welcome to

Introduction to

Developmental Disabilities

ECHOING HOPE RANCH

Values and Philosophy

PEOPLE WITH DISABILITIES ARE PEOPLE

FIRST

FOREMOST

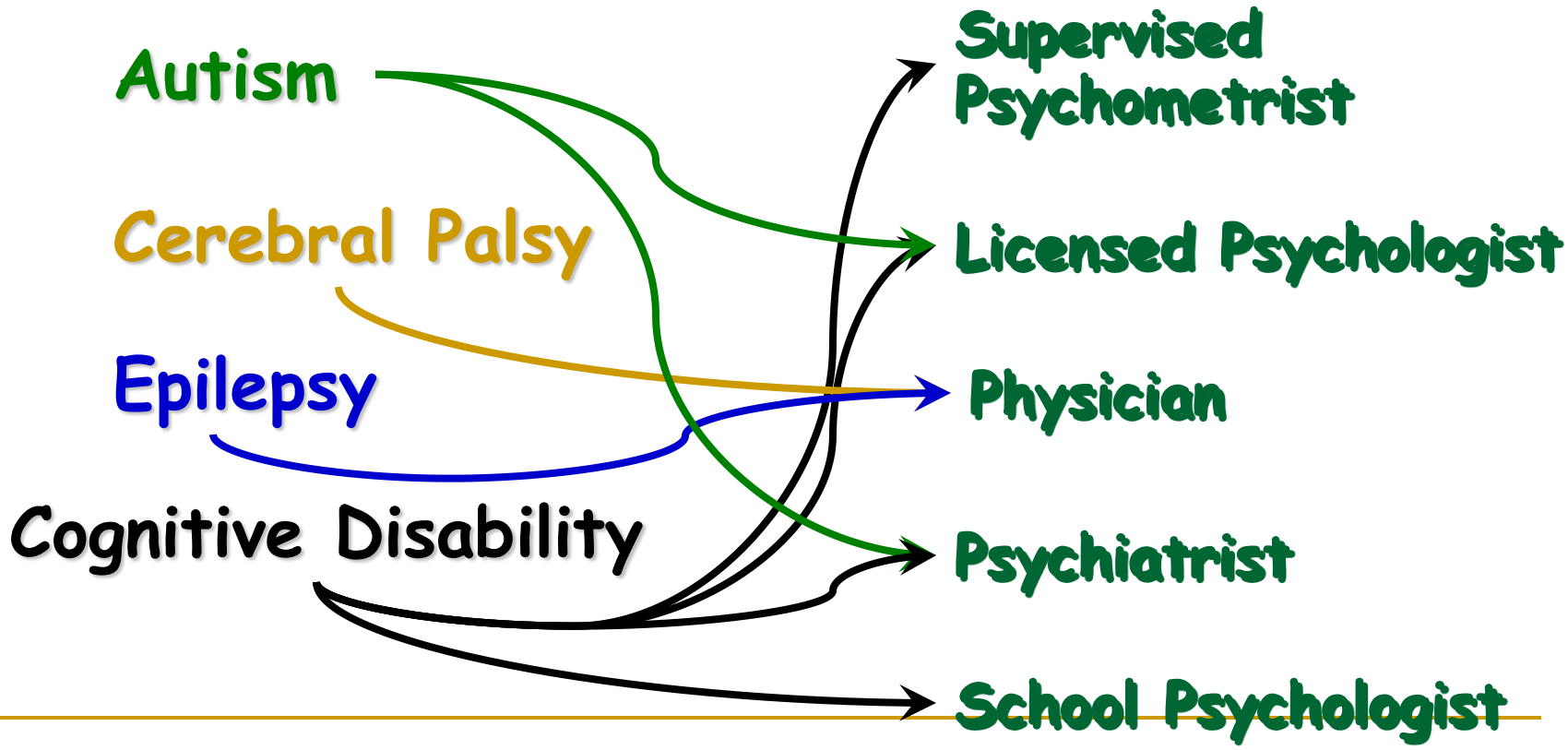
ALWAYS

What are the four Developmental Disabilities

- **Cognitive Disability**
- **Epilepsy**
- **Cerebral Palsy**
- **Autism**

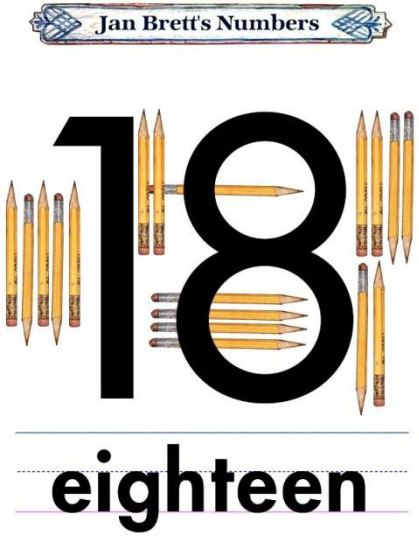
Diagnostic Criteria

Who can diagnose:



Diagnostic & Functional Criteria

- **Manifested before age 18**



- **The condition is chronic (likely to continue indefinitely)**

Diagnostic & Functional Criteria

- *Substantial Functional Limitations* in at least 3 of the following life skills domains:
  - **Self-care**
  - **Receptive and Expressive Language**
  - **Learning**
  - **Mobility**
  - **Self-Direction**
  - **Capacity for Independent Living**
  - **Economic Self-sufficiency**

Substantial Functional Limitation in 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 extraordinary as to impair the ability to retain employment or conduct other activities of daily living."

Substantial Functional Limitation in Receptive and Expressive Language

"When a person is unable to communicate with others, or is unable to communicate effectively without the aid of a third person, a person with special skills, or without a mechanical device."

Substantial Functional Limitation in Learning

"When cognitive factors, or other factors related to the acquisition and processing of new information are impaired to the extent that the person is unable to participate in age appropriate learning activities without utilization of additional resources"

Substantial Functional Limitation in Mobility

"When fine or gross 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 extraordinary as to impair ability to retain employment and conduct other activities of daily living."

Substantial Functional Limitation in Self-Direction

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

Substantial Functional Limitation in Capacity for Independent Living

"When, for a person's own safety or well-being, supervision or assistance is needed at least on a daily basis, in the performance of health maintenance and housekeeping."

Substantial Functional Limitation in Economic Self-Sufficiency

"When a person is unable to perform the tasks necessary for regular employment or is limited in productive capacity to the extent that earned annual income, after extraordinary expenses occasioned by the disability, is below the poverty level. "

Common Causes of Developmental Disabilities

- Toxins: Alcohol, Drugs, Lead
- Disease or infection
- Trauma or injury
- Genetic Factors
- Environmental factors

Treatment of Developmental Disabilities

- Early Intervention ------- It's No. 1
- Therapeutic treatments : OT, PT, Speech
- Nutrition
- Adaptive/ Augmentative technologies
- Specialized teaching
- Medication
- Counseling
- Alternative therapies
- Surgery

Cognitive Disability

(Previously known as Mental Retardation)

Cognitive Disability

Arizona Statutory Definition of Cognitive Disability

"Cognitive Disability, as defined in A.R.S., means a condition involving sub-average general intellectual functioning and existing concurrently with deficits in adaptive behavior manifested before age 18."

Arizona Statutory Definition of Cognitive Disability

- "Adaptive Behavior" means effectiveness or degree too which the individual meets standards of personal independence and social responsibility expected of the persons age and cultural group
- "Sub-average general intellectual functioning, as defined in A.R.S. means measured intelligence on standard psychometric instruments of two or more standard deviations below the mean for the tests used."

Cognitive Disability

People with Cognitive Disability feel, think, and hope just like everyone else

Despite their limitations, they have more similarities with others than they have differences

Cognitive Disability

As many as 1 American out of 35 may have Cognitive Disability

A child is born with Cognitive Disability every 5 minutes, more than 10,000 per year.

Cognitive Disability should not be confused with Mental Illness

Degrees of Severity of Cognitive Disability

- Mild Cognitive Disability: IQ level of 50-55 to approximately 70
- Moderate Cognitive Disability: IQ level of 35-40 to 50-55
- Severe Cognitive Disability: IQ level of 20-25 to 35-40
- Profound Cognitive Disability: IQ level below 20-25

Cognitive Disability Facts

- Prevalence- 1 in 100 persons
- Gender- more common in males
- Persons with Cognitive Disability
- Mild range. 85%
- Moderate range 10%
- Severe range 3-4%
- Profound range 1-2%

Levels of Support

- Mild Range Intermittent
- Moderate range Limited
- Severe range Extensive
- Profound range Pervasive

Common Causes of Cognitive 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

Common Causes of Cognitive Disability

- Genetic causes, such as inborn errors of metabolism or chromosomal aberrations
- Examples: Down Syndrome,

  Fragile X Syndrome

  Phenylketonuria (PKU)

  Tuberous Sclerosis

Common Causes of Cognitive Disability

- Perinatal (one week prior to birth to about 4 weeks after) causes include infections and birth trauma
- Medical Conditions of infancy or childhood, such as central nervous system trauma or infection, or lead poisoning

Common Causes of Cognitive Disability

Physical malformations such as hydrocephalus (fluid accumulation in the brain) and craniostosis (premature ossification of the sutures of the skull), sometimes result in Cognitive Disability.

Epilepsy & Seizures

What Is the Difference Between Epilepsy & Seizures?

- **Epilepsy** is a disorder characterized by recurring seizures (also known as "seizure disorder")
- **A seizure** is a brief, temporary disturbance in the electrical activity of the brain

A seizure is a *symptom* of epilepsy

Who Has Epilepsy?

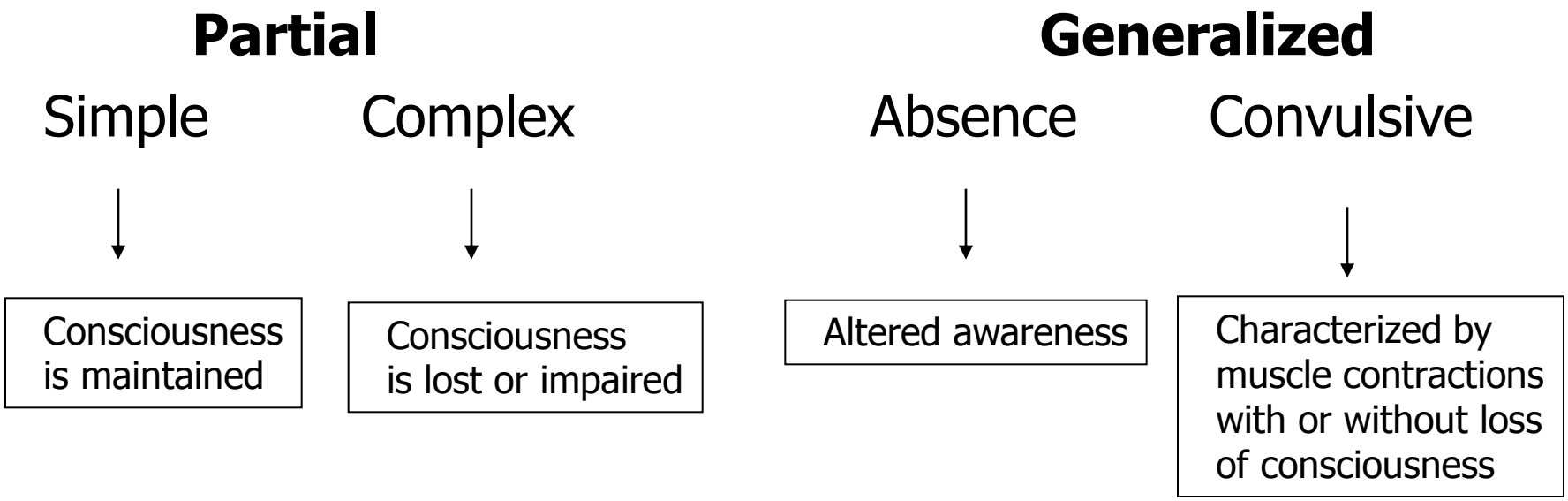
- About 2.3 million Americans have epilepsy
- Roughly 181,000 new cases of seizures and epilepsy occur each year
- 50% of people with epilepsy develop seizures by the age of 25; however, anyone can get epilepsy at any time
- Now there are as many people with epilepsy who are 60 or older as children aged 10 or younger

What Causes Epilepsy?

- In about 70% of people with epilepsy, the cause is not known
- In the remaining 30%, the most common causes are:
  - Head trauma
  - Brain tumor and stroke
  - Lead poisoning
  - Infection of brain tissue
  - Heredity
  - Prenatal disturbance of brain development

Classifying Epilepsy and Seizures

- Classifying epilepsy involves more than just seizure type
- Seizure types:



Symptoms That May Indicate a Seizure Disorder

- Periods of blackout or confused memory
- Occasional “fainting spells”
- Episodes of blank staring
- 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

Seizure Triggers

- Missed medication (#1 reason)
- Stress/anxiety
- Hormonal changes
- Dehydration
- Lack of sleep/extreme fatigue
- Photosensitivity
- Drug/alcohol use; drug interactions

First Aid for Seizures

- Stay calm and track time
- Do not restrain person, but help them avoid hazards
  - Protect head, remove glasses, loosen tight neckwear
  - Move 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 following verbal instructions may not be possible
- 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 unless stated otherwise in the Individual's ISP.

Potentially Dangerous Responses to Seizure

DO NOT

- Put anything in the person's mouth
- Try to hold down or restrain the person
- Attempt to give oral anti-seizure medication
- Keep the person on their back face up throughout convulsion

When to Call 911 or Emergency Medical Services

- A convulsive seizure occurs in a person not known to have seizures or lasts more than 5 minutes unless stated otherwise in their ISP.
- 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

Types of Treatment

- Medication
- Surgery
- Nonpharmacologic treatment
  - Ketogenic diet
  - Vagus nerve stimulation
  - Lifestyle modifications

Epilepsy in Women

- Hormonal effects
  - Hormonal changes during puberty, menopause, and the monthly cycle may affect seizure frequency
  - Polycystic ovary syndrome
- Sexuality & contraception
  - Sexual dysfunction
  - Birth control pills may be less effective
- Pregnancy & motherhood
  - Need to continue medication
  - Slight increased risk for birth defects

Epilepsy in Infants & Young Children

- Balancing normal development and the special concerns of epilepsy
- Good parenting skills
- Childcare
- Effects on brothers and sisters
- Early childhood intervention services

Epilepsy in Children Aged 6-12

- Handling feelings
- Family relationships
- Safety
- School and childcare
- Developmental stages

Epilepsy in Teens & Young Adults

- Assuming responsibility
- Dealing with feelings
- Friends and social pressures
- School
- Driving
- Drinking
- Dating
- Employment

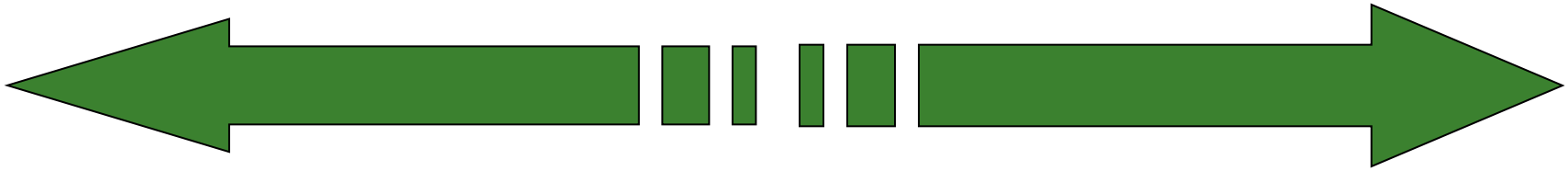
Epilepsy in Older Adults

- Epilepsy is common in the elderly, and is often unrecognized or misdiagnosed
- Older people face increased treatment risks
- Maintaining independence is a challenge after the diagnosis of epilepsy

A Spectrum of Severity

Uncomplicated epilepsy, Seizures controlled with medication

Seizures refractory to treatment; Epilepsy is disabling due to frequent seizures and other problems



Seizures not completely controlled by treatment; Epilepsy lowers standard of living due to social, emotional, and educational problems

Social Issues in Epilepsy

- Fear and other emotions
- Relationships
- Financial costs
- School
- Employment
- Driving
- Recreational activities

Safety Concerns

- Personal safety
  - Sports
  - Activities such as riding bikes, swimming
  - Showering/bathing
- MedicAlert * bracelets
- Helmets and seat belts

*MedicAlert® is a registered trademark of the MedicAlert® Foundation.

Developing a Relationship With School

- Try to meet all of the child's teachers
- Inform teachers and staff about:
  - Child's seizure disorder
  - Possible effects of medication
  - What to do in case a seizure occurs at school
- Encourage Foundation to provide epilepsy education for staff and students

Employment

- Finding a job can be a challenge
- Americans with Disabilities Act (ADA)
  - Prohibits discrimination on the basis of disability if applicant is qualified
  - Employer must provide reasonable accommodations

Driving

- Every state has some restrictions
  - Usually seizure-free for 6 months - 1 year
  - May need doctor's statement
  - Will probably need to report any seizures
  - Not eligible for commercial driver's licenses
- For information, contact DMV or EF
- Alternatives
  - Public transportation
  - Friends, family

National and Community Resources

- The Epilepsy Foundation
  - Local affiliates
  - Website: www.epilepsyfoundation.org
- MedicAlert Foundation
- Social Security Administration
- Accreditation Council on Services for People with Disabilities
- US Dept. of Education
- State Offices
  - Vocational Rehabilitation
  - Protection and Advocacy
  - Division of Developmental Disabilities

Cerebral Palsy

http://www.youtube.com/watch?feature=player_embedded&v=2jSwCnuWcQ0#!

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."

Cerebral Palsy: from www.about-cerebral-palsy.org

- Cerebral palsy is characterized by an inability to fully control motor function, particularly muscle control and coordination.

- Depending on which areas of the brain have been damaged, one or more of the following may occur:

  Muscle tightness or spasm

  Involuntary movement

  Disturbance in gait and mobility

  Abnormal sensation and perception

  Impairment of sight, hearing or speech

  Seizures

- About 1 in 500 children born in the U.S. have some type of cerebral palsy

Common Causes of Cerebral Palsy

- Failure of the brain to develop normally
- Neurological damage to the developing brain (for example, intraventricular hemorrhage as seen in very premature infants, lack of oxygen to the brain or infections)

Common Causes of Cerebral Palsy

- lack of oxygen before, during, or after birth.
- bleeding in the brain.
- toxic injuries, or poisoning, form alcohol or drugs used by the mother.
- head trauma resulting from a birth injury, fall, car accident, or other cause.
- severe jaundice, very low glucose levels, or other metabolic disorders.
- infections of the nervous system such as encephalitis or meningitis

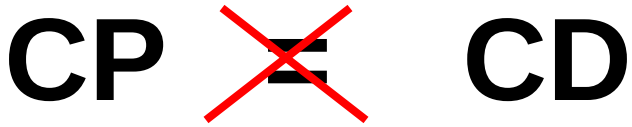
Types of Cerebral Palsy

- Spastic – most common type; tense contracted muscles
- Athetoid – constant uncontrolled movement of the head, limbs and eyes
- Rigid – tight muscles that resist movement
- Ataxic – impaired gait and sense of balance
- Tremor – uncontrollable shaking that interferes with coordination

Cerebral Palsy can be

- Mild- affects fine precision movement
- Moderate- affects gross and fine motor movements and speech clarity impaired
- Severe- affects all activities of daily living, will need supports though out life

People who observe a person with Cerebral Palsy may assume he or she has Cognitive Disability



Cerebral Palsy

- All though a Cognitive Disability can exist with CP, CP alone does not interfere with a persons ability to think, reason, or understand.
- CP is a muscle control issue.

Treatment of Cerebral Palsy

- Speech and Language therapy
- Physical and Occupational therapy
- Medical intervention
- Counseling
- Vocational training
- Assistance with personal care

Autism

http://www.youtube.com/watch?v=34xoYwLNpvw

Autism - Definition

- Autism is one of the most challenging of disabilities to understand and relate to and, therefore, one of the most challenging disabilities for direct-support professionals to work with.
- Autism is a complex neurological developmental disability that typically lasts throughout a person's lifetime. It occurs in all racial, ethnic, and social groups and is four times more likely to strike boys than girls.

Autism - Definition

- Autism typically appears during the first three years of life and is the result of a neurological disorder which affects the normal functioning of the brain, impacting development in the areas of social interaction and communication skills. Both children and adults with autism typically show difficulties in verbal and non-verbal communication, social interactions, and leisure or play activities.

Autism -Definition

- It is also associated with rigid routines and repetitive behaviors, such as obsessively arranging objects or following very specific routines. Symptoms can range from very mild to quite severe.

Autism -Definition

- Autism is one of five disorders that fall under the umbrella of Pervasive Developmental Disorders (PDD), a category of neurological disorders characterized by “severe and pervasive impairment in several areas of development.” It is a spectrum disorder and it affects each individual differently at varying degrees

Autism -Prevelance

- Autism is the most common of the Pervasive Developmental Disorders, affecting an estimated 1 in 88 births (Centers for Disease Control Prevention, 2012). Roughly translated, this means as many as 1.5 million Americans today are believed to have some form of autism. It is estimated that by the year 2023, there will be 380,000 adults with autism in need of extensive services.

Autism -Prevalance

- Based on statistics from the U.S. Department of Education and other governmental agencies, autism is growing at a startling rate of 10-17 percent per year. At this rate, the ASA estimates that the prevalence of autism could reach 4 million Americans in the next decade.
- Autism knows no racial, ethnic, or social boundaries; family income levels; lifestyle choices; or educational levels, and can affect any family and any child.

Autism -Causes

- There is no known single cause for autism, but it is generally accepted that it is caused by abnormalities in brain structure or function. Brain scans show differences in the shape and structure of the brain in children with autism versus neuro-typical children.

Autism -Causes

- Researchers are investigating a number of theories, including the link between heredity, genetics and medical problems. In many families, there appears to be a pattern of autism or related disabilities, further supporting a genetic basis to the disorder.

Autism -Causes

- While no one gene has been identified as causing autism, researchers are searching for irregular segments of genetic code that children with autism may have inherited. It also appears that some children are born with a susceptibility to autism, but researchers have not yet identified a single “trigger” that causes autism to develop.

Autism -Causes

- Other researchers are investigating the possibility that under certain conditions, a cluster of unstable genes may interfere with brain development, resulting in autism. Still other researchers are investigating problems during pregnancy or delivery as well as environmental factors, such as viral infections, metabolic imbalances, and exposure to environmental chemicals.

Autism - Common Characteristics

- Many family members report that they “just knew something was wrong.” In many cases they asked their physician who described the problem as a “phase” the child was going through. It is important that parents follow their instincts.

Autism - Common Characteristics

- Families should seek the advice of a trained expert and if autism is suspected, it is critical that the professional be familiar with recognizing and supporting a person with autism.
- In the case of autism, there are no medical tests to establish a diagnosis and often the unusual behaviors that a person with autism displays may not be present until the age of 18 months to 3 years.

Autism - Common Characteristics

- Every person with autism is an individual, and like all individuals, has a unique personality and combination of characteristics. Some individuals mildly affected may exhibit only slight delays in language and greater challenges with social interactions. They may have difficulty initiating and/or maintaining a conversation.

Autism - Common Characteristics

- Their communication is often described as talking at others instead of to them. (For example, a monologue on a favorite subject that continues despite attempts by others to interject comments).
- People with autism also process and respond to information in unique ways. In some cases, aggressive and/or self-injurious behavior may be present.

Autism - Common Characteristics

Persons with autism may also exhibit some of the following traits:

- Insistence on sameness; resistance to change
- Difficulty in expressing needs, using gestures or pointing instead of words
- Repeating words or phrases in place of normal, responsive language (echolalia)
- Laughing (and/or crying) for no apparent reason; showing distress for reasons not apparent to others
- Preference to being alone; aloof manner
- Tantrums

Autism - Common Characteristics

- Difficulty in mixing with others
- Not wanting to cuddle or be cuddled
- Unresponsive to normal teaching methods
- Little or no eye contact
- Sustained odd play
- Spinning objects
- Obsessive attachment to objects
- Apparent over-sensitivity or under-sensitivity to pain
- No real fears of danger

Autism - Common Characteristics

- Noticeable physical over-activity or extreme under-activity
- Uneven gross/fine motor skills
- Non-responsive to verbal cues; acts as if deaf, although hearing tests in normal range
- Difficulty understanding and/or processing sensory stimuli (aroma, sound, sight, touch, taste, movement)
- Difficulty regulating levels of emotional arousal, attention, action, inhibition and mood.

Autism - Neurological Disorder

- Autism is considered neurological disorder which means that the make-up of the brain of a person with autism is different than the make-up of a “typical” person. Certain areas of the brain are affected by autism including the Amygdala, Cerebellum, Purkinje Cells, Frontal Lobe and Hippocampus.

Autism - Neurological Disorder

These are important because research has shown that they serve the following purposes:

- Amygdala – Processing and regulating emotions;
- Cerebellum – Integrating/filtering sensory perception, motor timing and coordination;
- Purkinje Cells – Filtering and inhibiting input;
- Frontal Lobe – Executive Function;
- Hippocampus – Storing, processing and finding memory, and navigation.

Autism - Neurological Disorder

Because of these differences in the structure of the brain, it can be physically difficult for a person with autism to:

- Plan or mentally work toward a desired goal;
- Organize or sequence activities effectively;
- Display socially appropriate inhibitions of inappropriate responses and actions;
- Be flexible in their thinking and actions;

Autism - Neurological Disorder

- Self monitor and self manage progress by keeping plans and goals in mind and acting accordingly;
- Filtering sensory input to be able to focus on what is important instead of all input available, i.e. filter out the sound of the TV in the background to have a conversation with the person in front of them.

Autism - Sensory Systems

- Sensory processing is the way the nervous system receives, organizes and uses information from the sense throughout activities and throughout the day. Many people with autism have challenges with their sensory process systems. These challenges may affect any of the senses including sight, hearing, taste, touch, smell, vestibular and/or proprioceptive.

Autism - Sensory Systems

- The vestibular system, which contributes to our balance and our sense of spatial orientation, is the sensory system that provides the dominant input about movement and balance.

- The proprioceptive sense informs us about the position of our own limbs in relation to one another and to the space around us.

Autism - Sensory Systems

- Some considerations direct-support staff should have in working with people with autism may have significant sensory issues such as perceptual distortion, auditory involvement such as hypersensitivity or auditory process delays, oral motor problems, olfactory sensitivity, limited filters and allergies.

Autism - Sensory Systems

These issues can cause:

- attention problems:
- difficulty being relaxed and still alert;
- avoidance of touch, movement or groups;
- clumsy actions;
- self-stimulation, self-injury;
- persistent irritability
- intolerance of change, rigidity
- unpredictable explosions of emotion
- poor social relationships
- fixations

Autism - Sensory Systems

- Temple Grandin, a world renowned designer of cattle industry systems, has autism and has written many books and speaks about her autism.

Autism - Sensory Systems

She has said:

- I always wanted to be hugged. I wanted to experience the good feeling of being hugged, but it was just too overwhelming. It was like a great, all-engulfing tidal wave of stimulation, and I reacted like a wild animal. Being touched triggered flight; it flipped my circuit breaker. I was overloaded and would have to escape, often by jerking away suddenly or hitting someone.

Autism - Sensory Systems

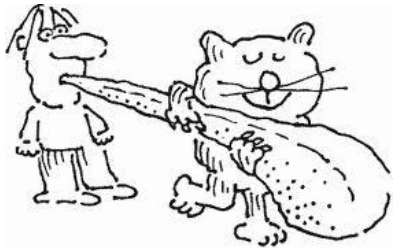
- Her sensory systems were craving the deep sensory input that could be provided though a hug but she her senses overwhelmed her so much being that close to a person that she had a constant unmet need which ended in behavioral challenges.

Autism - Communication

Communication is a challenge for all people with autism in some manner. It is made of both receptive and expressive functions. Receptive communication is the process of sensory stimulation being perceived by our systems, the flow of that information to our brains, our brains processing that input and our bodies reacting to the information. Expressive communication is the response system to stimulation and process of expressing a person needs and desires – i.e. talking or taking an action.

Autism - Communication

People with autism may experience challenges with any or all parts of the communication process. They have little understanding of idioms and will generally take all language literally.



The more concrete a direct-support professional can be in their manner of speaking, the easier it will be for a person with autism to understand.

Autism - Communication

Every action may be a form of communication. It is important for direct-support professionals to be good listeners/observers. Listen and observe the verbal and non-verbal messages contained in every form of communication.

Wait and watch for the answer!

Autism - Communication

Know the person – what they like/dislike, what is motivating, etc. Know the signs – when I do this, it means that. Use every part of the brain. Memory and information retrieval can be enhanced by smelling something, visual signs, physical activity, humor/positive association and other auditory activities like rhymes and repetition.

Autism - Strategies that Work

Overtime, some basic strategies have been found to work well for most individuals with autism. They include but are not limited to:

- **Structure and Consistency** – Individual with autism do best when there is a clear structure and routine to their day. Schedules can calm an overloaded system plus develop awareness of expectations, give direction and sequence of events, ease transitions, help with predicting what's going to happen, motivate toward a goal, enhance communication and choice making and give a sense of completion.

Autism - Strategies that Work

- **Visual Systems** – Individuals with autism can process visual stimulation much better than auditory so providing information in visuals systems will help eliminate confusion and enhance independence or interdependence.

- **Design Work/Home Space** – Make the environment as quiet as it needs to be to maintain a calming yet productive workplace.

Autism - Strategies that Work

- **Use Strengths and Abilities** – Some people with autism may have great skills in a specific area, like music, number and fine motor skills. Utilize their strengths to overcome areas of weakness. If you can incorporate creativity, you are also challenging them and encouraging success.
- **Know the person** you are working with so that you can support his individual needs.

Autism - Strategies that Work

- **Breaks are Part of Work** – Many people with autism have lowered thresholds for frustration, so encourage breaks to avoid sensory overload. Breaks should be timed and planned! Engage the person mentally or physically for refreshment . . . just sitting doing NOTHING is not necessarily relaxing for everyone! If the breaks are more frequent than the work, more focus should be put on the work than on the breaks.

Autism - Strategies that Work

- **Efficiency is Not Necessary**
  By crafting certain activities to be more labor intensive, the opportunities for exercise and interaction increase. Turning the compost with a shovel or pitchfork provides opportunity to both get exercise and a sense of accomplishment when the bin is empty. The same task could be done with a composting barrel but the process is lost. Heavy work and exercise release endorphins which help us to feel good!

Autism - Strategies that Work

- **Appreciate Uniqueness** – People can sense whether other people like them or not – even people with autism. Try to find ways to appreciate the uniqueness of each individual. If he like music, try to find ways of incorporating music into parts of his day. If she likes to swing, make time for swinging. If he enjoys running, find a safe place to run and allow him to run. The more we appreciate the strengths offered, the less challenges we will see.

REMEMBER!

- IQ Scores alone do not dictate a persons ability

- Supports depend on a variety of issues: Behavioral, Medical, Mental Health, Social

http://www.youtube.com/watch?v=wunHDfZFxXw