

Noah's Ark Institute
Making the world a better place for everyone with autism

ALERT
Autism Lifesaving Emergency
Response Training
No One Left Behind




Autism

Practically Speaking:
A Talk About Autism

Autism is:

- ▶ a neurodevelopmental disability that typically appears during the first three years of life
- ▶ caused by a complex interaction between genetic and environmental factors.
- ▶ It affects a person's ability to communicate and interact socially with others
 - associated with repetitive behaviors and interests.



Definition

- ▶ Autism is called a spectrum disorder because the behaviors by which it is identified appear in different combinations and with varying severity
 - A constellation of symptoms
- ▶ The terms 'autism' and 'autism spectrum disorders' (ASD) are often used interchangeably and refer to a broad continuum of brain disorders
 - Autism, Autistic Disorder, Asperger's Disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)

What is Neurodevelopment

- ▶ Neurology
 - More than brain development
 - a medical specialty dealing with disorders of the nervous system. Specifically, it deals with the diagnosis and treatment of all categories of disease involving the
 - **CNS central nervous system** (brain and spinal cord),
 - **PNS peripheral nervous system** extends outside the central nervous system. The main function of the PNS is to connect the CNS to the limbs and organs, (Information highway of the body)
 - **ANS autonomic nervous system**, control system functioning largely below the level of consciousness, and controls visceral functions.
 - The ANS affects heart rate, digestion, respiration rate, salivation, perspiration, dilation of pupils, micturition (urination), and sexual arousal. Whereas most of its actions are involuntary, some, such as breathing, work in tandem with the conscious mind.

Neurodevelopmental Disability

- ▶ Neurodevelopment
 - Simply, how the neurological systems are developing or have developed
 - When there are problems with these systems there may be a neurodevelopmental disability identified by the neurologist.
- ▶ When you think about neurodevelopment think simply
 - **C.P.A.**
 - Central
 - Peripheral
 - Autonomic

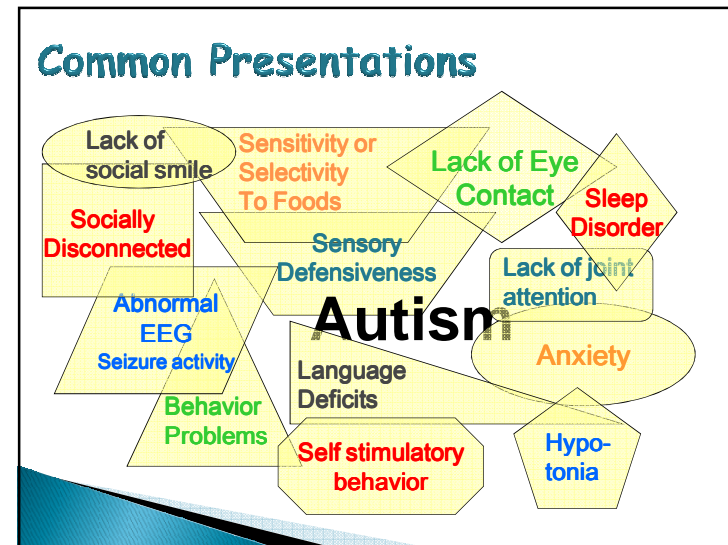
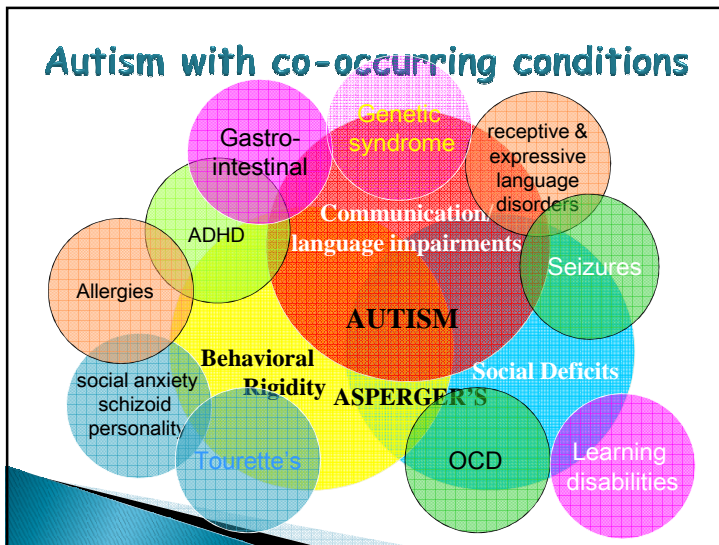
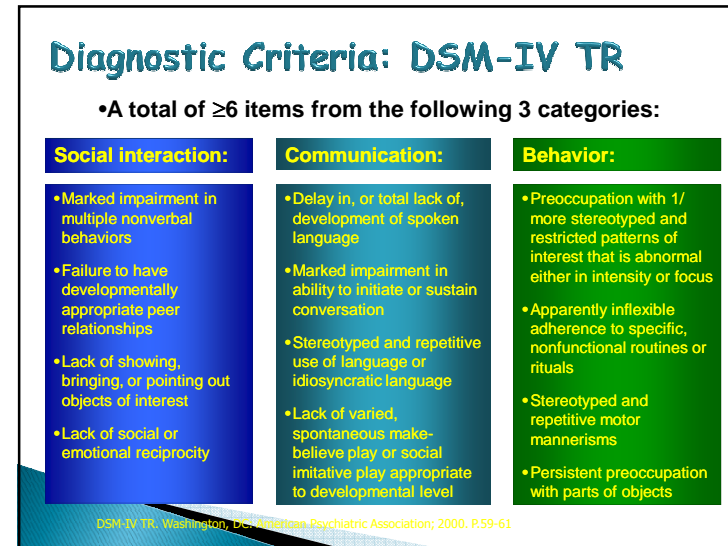
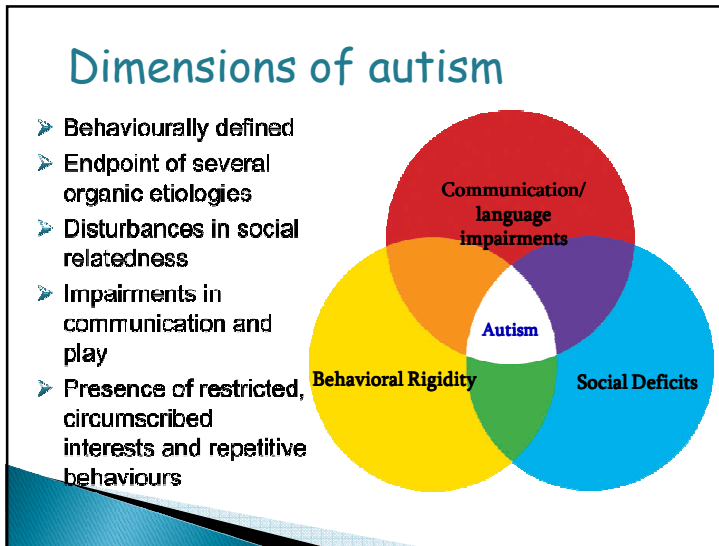
Autism is a spectrum

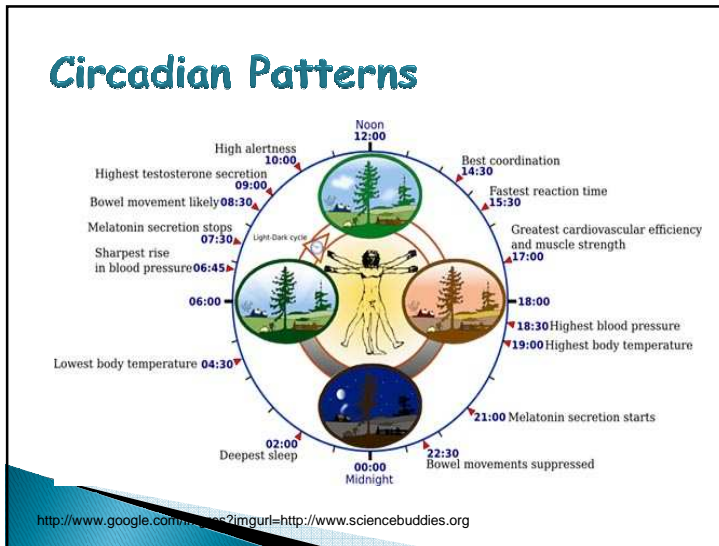
▶ The big problem:

We use one term (Autism) to refer to and plan for a **vastly heterogeneous population** of individuals in our community.

It has been said that if you know one person with autism you know one person with autism.

One size fits all solutions will not work.





Epilepsy & Autism: The Co-Condition

- As many as one-third of individuals with Autism also have Epilepsy.
- Two peaks of onset: infancy and adolescence.
 - The risk of Epilepsy is low, about 2% by 5 years and 10% by 10 years, for those with Autism who do not have Mental Retardation or Cerebral Palsy.
- Individuals with both Autism and Epilepsy have a more challenged developmental trajectory than those with either Autism or Epilepsy alone.
- Individuals with Autism and severe Mental Retardation have a risk of acquiring Epilepsy of 5% at 1 year, 15% at 5 years, and 25% at 10 years.
- Individuals with Autism and both Mental Retardation and Cerebral Palsy have a risk of acquiring Epilepsy of 20% at 1 year, 35% at 5 years, and 65% at 10 years.

<http://www.djfdllefoundation.org/news/attach/DJF-EpilepsyBrochure.pdf>

Epilepsy

- Epilepsy persists in the majority of patients into adult life with remission in only 15% of adults with Autism and Epilepsy.
- Epilepsy and Autism may reflect the same underlying brain abnormality
 - there are many disorders such as Fragile X, Tuberous Sclerosis and Down Syndrome where Autism and Epilepsy may co-occur on this basis.

<http://www.djfdllefoundation.org/news/attach/DJF-EpilepsyBrochure.pdf>

Epilepsy Seizure Incident Suggestions

- ▶ No Need to Call An Ambulance
 - If medical I.D., jewelry or card says "Epilepsy," and
 - If the seizure ends in under five minutes, and
 - If consciousness returns without further incident, and
 - If there are no signs of injury, physical distress, or pregnancy.
- ▶ An Ambulance Should Be Called
 - If the seizure has happened in water.
 - If there's no medical I.D., & no way of knowing if the seizure is caused by Epilepsy.
 - If the person is pregnant, injured, or diabetic.
 - If the seizure continues for more than five minutes.
 - If a second seizure starts shortly after the first has ended.
 - If consciousness does not start to return after the shaking has stopped.

The preceding are suggestions to help people with Epilepsy avoid unnecessary trips to the emergency room and help one decide whether or not to call an ambulance. One should not rely on this general information as individual cases may vary, therefore a physician should always be consulted in all emergencies.

Watch for the Red Flags of Autism

(The following red flags may indicate a child is at risk for atypical development, and is in need of an immediate evaluation.)

In clinical terms, there are a few "absolute indicators," often referred to as "red flags," that indicate that a child should be evaluated. For a parent, these are the "red flags" that your child should be screened to ensure that he/she is on the right developmental path. ***If your baby shows any of these signs, please ask your pediatrician or family practitioner for an immediate evaluation.***

- ▶ No big smiles or other warm, joyful expressions by six months or thereafter
- ▶ No back-and-forth sharing of sounds, smiles, or other facial expressions by nine months or thereafter
- ▶ No babbling by 12 months
- ▶ No back-and-forth gestures, such as pointing, showing, reaching, or waving by 12 months
- ▶ No words by 16 months
- ▶ No two-word meaningful phrases (without imitating or repeating) by 24 months
- ▶ Any loss of speech or babbling or social skills at any age

*This information has been provided by First Signs, Inc. ©2001-2005. For more information about recognizing the early signs of developmental and behavioral disorders, please visit <http://www.firstsigns.org> or the Centers for Disease Control at www.cdc.gov/actearly.

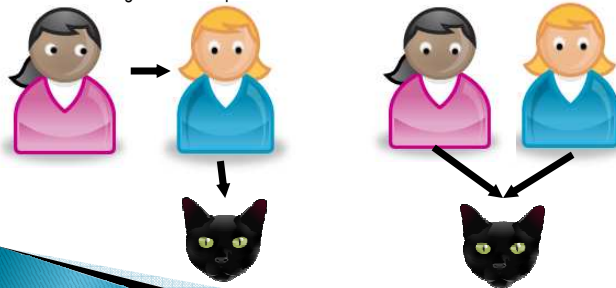
Communication

- ▶ In autism one of the core characteristics is an impairment in communication
 - Verbal communication
 - Delayed speech/ no speech
 - Echolalic speech patterns
 - Voice modulation/porosity difficulties
 - Non verbal communication
 - Emotion blindness
 - Lack of joint attention

Non verbal communication

▶ Joint Attention

- The process of sharing one's experience of observing an object or event, by following gaze or pointing gestures.
- It is critical for social development, language acquisition, and cognitive development.



Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS)

- Implies the presence of fewer and at times less severe signs of autism
- Outcomes tend to be better as a group than their autism counterparts
- Less cognitive impairment
- The distinction has little to do with how the child should be treated
- The line of distinction varies widely from doctor to doctor or clinic to clinic
- Should be treated with the same intensity and aggressive therapy as a diagnosis of autism

Asperger's Syndrome

► Milder variant of Autistic Disorder

- Both Asperger's Disorder and Autistic Disorder are in fact subgroups of Autism Spectrum Disorders

► Affected individuals are characterized by

- impairments in two-sided social interaction and non-verbal communication
- social isolation
- eccentric behavior in childhood
- abnormalities of inflection and repetitive patterns of speech
- awkwardness in their articulation
- clumsiness in gross motor

What I like to do:

- circumscribed areas of interest which leave little or no time for more age appropriate, common interests
 - Ex. cars, trains, French Literature, door knobs, hinges, cappuccino, meteorology, astronomy or history



Growing up with autism

► Children with autism spectrum disorders grow up to be adults with autism spectrum disorders

- Autism is a developmental disorder and does not affect a persons lifespan
- Therefore all of the concerns of an aging population will be multiplied by the overlay of autism.
- Autism knows no bounds by race or socio-economic status



Media

- Does the intense interest in autism in the media translate to a true rise in prevalence?



Prevalence

- ▶ New study 1 in 88 nationally (CDC 2009)
 - First large-scale prevalence study in the US
 - Autism and its associated behaviors have been estimated to occur in as many as 1 in 150 in individuals (Centers for Disease Control and Prevention 2007)
- ▶ Autism is four times more prevalent in boys than girls and knows no racial, ethnic, or social boundaries
- ▶ Autism is the fastest growing developmental disability
 - Increase of 10-17 percent per year
- ▶ Family income, lifestyle, and educational levels do not affect the chance of autism's occurrence

Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008. Department of Health and Human Services, Centers for Disease Control and Prevention. *Morbidity and Mortality Weekly Report*, 30 March 2012.

Tools for the Toolkit



Toolkit

- ▶ First and foremost
 - In all you do first responder safety in paramount
- ▶ The following are suggestions for your use
 - Autism is complex and unpredictable
 - You must always use your judgment in any and all situation
 - As keen observers of behavior take autism into account as you respond to a call for service

Proactive vs. Reactive

First Responders

- ▶ Must take a proactive approach in learning how to recognize and work with individuals on the autism spectrum, to better provide for their welfare and safety



Proactive vs. Reactive

- ▶ From early diagnosis and intervention programs specifically designed to meet the needs of the autism population, the opportunity for many individuals to fully participate in community life has increased exponentially
 - Your likelihood of direct interaction is increased accordingly
 - Your familiarity with the varied often counterintuitive presentation of these individuals is increasingly vital

Proactive Response

- ▶ When first responders arrive on the scene, a caretaker may not be available to inform them of the individual's condition
 - Your ability to establish communication by relating and receiving information is **critical**



Contact Situations

- ▶ A first responder may come into contact with an individual with ASD
 - emergency call
 - missing child
 - missing adult
 - Driving accident or incident
 - Outbursts or behaviors mistaken as alcohol or drug induced and/or dangerous
 - Crime scene



Autism/ Alzheimer's

- ▶ Like Alzheimer's patients, individuals with ASD will sometimes run away from caretakers
 - **Elopement or running**, is one of the greatest threats to individuals with ASD
 - Due diligence on the part of first responders not to attribute the event to abuse or neglect on the part of the caretaker is needed
 - **Children with ASD who run away are often attracted to water**
 - This is a particularly dangerous combination as many individuals on the autism spectrum show *no concept of fear* and do not know how to act in emergency situations



Out Of Harms Way

Individuals with autism may act in a counter-intuitive way



To ensure for their safety, once moved out of harms way, be certain to assign an individual on your team to be in charge of that person or persons

Out Of Harms Way



Though you may have removed them from the home or building if unattended **they may wander back inside** in search of their perceived safe spot within the dwelling.

Make sure that the person is away from potential hazards or dangers (busy streets, etc.) since they may not acknowledge or have any fear of danger or potentially dangerous situations.

Outreach Outreach Outreach

- ▶ Do you know where everyone in your community resides?
- ▶ Knowing the special needs and accommodations of those individuals residing in your community ahead of time will lead to a safer resolution in a call for service.
- ▶ How many group homes, supported apartments or other living arrangements are in your service area?
- ▶ Having a presence at town events with paperwork available for families to self identify their needs is very useful

Outreach

- ▶ Is the fire marshal available to advise families on how to secure their dwellings safely when they have an eloper?
- ▶ If a child or adult is a frequent wanderer the family may have gone to herculean steps to secure the dwelling
 - Bedroom doors locked from outside
 - Windows nailed shut
 - Glass panes replaced with plexi or lexan

Outreach

- ▶ Community based drills and exercises
 - It is never appropriate to use “actors” pretending to have a disability
 - You cannot know what it is like to have disability unless you have a disability
- ▶ Pre planning to include individuals in the context of the exercise is vital
 - Extra time in the planning is essential and accommodating individuals day of is also extremely important

Understanding Autism

- ▶ *This individual may not understand the law*
- ▶ *This individual may not know right from wrong*
- ▶ *This individual also may not understand the consequences of his or her actions*

What are Miranda rights?

Your Miranda Rights

- ▶ *"You have the right to remain silent. Anything you say will be used against you in a court of law. You have the right to an attorney, and if you cannot afford one, one will be appointed for you."*

Miranda

- ▶ A number of autistic persons were read their rights, and asked if they waived them, and all of them slowly raised their right hands, exhibiting the autistic mindset of understanding language quite literally. Still other autistic persons could easily fall victim to common interrogation techniques, and give a false confession to either escape the situation, or to appease the authority figure (the interrogator), presenting problems especially if the person is innocent.

<http://fugitiveseekingtruth.blogspot.com/2010/07/your-miranda-rights.html>

Case Example

Jonny is a 21 year old young man with autism who lives at home with his aging parents. He loves to wander around by himself, especially in the evening when everyone in his family is asleep. Usually he wanders in his home, however, he awoke and got out of his house and walked five blocks from his home and entered a neighbor's home. The residents awoke startled and called the police. Jonny was arrested for trespassing and immediately said yes to the question of waving his Miranda rights. He was asked numerous questions by detectives including if he intended to burglarize the home. Jonny answered yes to all questions followed by a plea, "Go home now", after each answer. He spent an anxious night in jail repeating "go home now" and banging his head on the cell bars until he needed medical attention and was transfer to a guarded hospital room. Jonny was released to his parents' and is awaiting trial on charges of breaking and entering, trespassing and attempted robbery.

First Responder Helpful Information

Expect the unexpected: Individuals with autism cannot be identified by appearance, they look the same as anyone else

- ▶ They are identified by their behavior
 - Autism is a spectrum disorder, it presents differently in each individual
 - What works for one individual with autism may not work for another
- ▶ 30 - 40% of individuals with autism will develop epilepsy or some other seizure disorder during adolescence



http://www.cdc.gov/vaccinesafety/00_images/Group%20of%20kids.jpg

Wong Rating Scale

Individuals with autism have a difficult time reading facial expressions

Wong-Baker FACES Pain Rating Scale



Explain to the person that each face is for a person who feels happy because he has no pain (hurt) or sad because he has some or a lot of pain. Face 0 is very happy because he doesn't hurt at all. Face 1 hurts just a little bit. Face 2 hurts a little more. Face 3 hurts even more. Face 4 hurts a whole lot. Face 5 hurts as much as you can imagine, although you don't have to be crying to feel this bad. Ask the person to choose the face that best describes how he is feeling.

Rating scale is recommended for persons age 3 years and older.

Brief word instructions: Point to each face using the words to describe the pain intensity. Ask the child to choose face that best describes own pain and record the appropriate number.

From Wong DE, Henderson-Eaton M, Wilson D, Winkelman M, Schwartz P. Wong's Essentials of Pediatric Nursing, 6th, St. Louis, 2001, P. 1301. Copyrighted by Mosby, Inc. Reprinted by permission.

Pain Rating Scale

0		No Hurt
1		Hurts Little Bit
2		Hurts Little More
3		Hurts Even More
4		Hurts Whole Lot
5		Hurts Worst

First Responder Helpful Information

Autism at its core is a processing problem

- ▶ Receptive vs. Expressive
 - **Receptive skills are generally better than expressive skills**
 - An individual with autism may not respond as anticipated
 - They may not understand what is being demanded of them
 - they may be scared
 - If they are scared, that may be the only thing they can focus on and respond to
 - An individual with autism may not be able to process language
 - unable to understand a directive or simple command exacerbated by stress and fear
 - They may fixate on or stare at an object in the room (or on your body -- a badge, earrings, buttons...)
 - They may not recognize your uniform or your authority

First Responder Helpful Information

Self stimulatory behavior

Self stimulatory behavior may be defined as behaviors which are adaptive attempts at regulating the environment when the environment becomes chaotic

examples include:

- hand flapping
- finger flicking
- eye blinking
- string twirling
- rocking
- pacing
- spinning
- making repetitive noises
- saying repetitive phrases that have no bearing on the topic of conversation

This type of behavior may be calming to the individual, even if it does not appear so.

Proactive Response

- ▶ When you are called to service, the individual you encounter may be under considerable stress and/or trauma
 - this may affect the individual's behavior and response to you
 - trauma and stress may increase characteristics associated with autism
 - some behaviors which may seem odd or aggressive to you are, in fact, behaviors intended to communicate or simply demonstrate information to the first responder
 - behaviors may include rocking, hand wringing, pacing, loud verbal outbursts, and self-hitting, among others
 - these are not behaviors to be managed or stopped by the responder, but understood as part of the individual's normal behavior or exaggerated due to the stress of the event or moment

First Responder Helpful Information

- ▶ If behaviors are not presenting as a danger to themselves or others it is best not to interfere with them
- ▶ Allow behaviors to continue as long as the individual is safe and is safe to be around
- ▶ Trying to stop behaviors may increase anxiety and may cause the individual to act out aggressively

First Responder Helpful Information

- ▶ Behavior tip
 - Behaviors do not exist in isolation
 - Therefore they will not be extinguished in isolation
 - Example: stop that
 - Try redirecting the behavior with a preferred action
- ▶ Model the behavior you wish the person to copy

Case Example

First responders are called to a busy mall parking lot where they find an eight year old male wandering through parked cars and into mall traffic. The boy presents as non verbal and does not acknowledge the first responders. One officer repeatedly calls to the young boy to move out of the traffic and into the squad car so he can be transported to the station for processing. After repeated attempts the boy flaps his arms and spins in place mumbling to himself in an incoherent babble. Another first responder joins the team and recognizes this boy's autistic behavior. He slowly commands the boy to "Stop" and then commands, "In car". He then leads the boy by the hand and enters the car with him without further incident. The officers find his mother's cell phone number in the boys pocket on an ID card and she is called and picks up her son.

First Responder Helpful Information

- ▶ Echolalia (fm Greek: echo=repeat Lalia=babble)
Is the automatic repetition of vocalizations made by another person
 - An individual with autism may repeat something you said or something they heard over and over and over again.
 - Though individuals with autism may memorize lengthy dialogue by rote they may not understand the meaning of what they are saying

First Responders Helpful Information

Sensory systems which are hyper /hypo sensitive

- ▶ Whenever possible, avoid touching these individuals
 - Some, but not all, individuals with autism will become more agitated and possibly aggressive when touched
 - If necessary gesture where you wish the person to go or slowly guide the person
- ▶ Tell them what you are going to do

First Responders Helpful Information

Tactile Sensitivity

- Hand-cuffs or other restraining systems may negatively increase anxiety and possible aggression



- Crowded quarters may cause sensory overload
- Alert personnel prior to returning to station
- Sound and light sensitivity is common in autism
- When possible avoid use of sirens and flashing lights

First Responder Helpful Information

Sensory systems which are hyper/hypo sensitive

- Some individuals with autism do not have a normal range of sensations and may not feel:
 - cold
 - heat
 - pain in a typical manner
 - Individuals with ASD may fail to acknowledge pain in spite of significant pathology being present
- They may show an unusual pain response that may be counter intuitive
 - laughter, humming, singing and removing of clothing

First Responder Helpful Information

- Expect the sensory stimulation of the station such as equipment, lighting, noises, aromas and commotion to cause a negative escalation of behavior
- Avoid sensory overload
 - Request a quiet isolated area or room for the individual with autism

Physical Restraint

- If you must go hands on
 - Individuals with ASD may be terrified by restraint systems
 - Be aware that many individuals with ASD have a poorly developed upper trunk area
 - Positional asphyxiation could occur if steps are not taken to prevent it:
 - frequent change of position
 - not keeping them face down
 - Individuals with ASD may continue to resist restraint

First Responder Helpful Information

- ▶ If caregiver is available
 - allow the caretaker to ask the questions
 - may increase the likelihood of getting information from the person
 - Allow a caretaker to ride with the individual if possible
 - This will reduce anxiety and make your job less difficult

Modifications

- ▶ Stay calm
- ▶ Be patient
 - Approach in a calm manner
 - Speak simply
 - Slow down language
 - Speak clearly
 - Use as few words as possible to get point across
 - Speak in a calm even tone
 - Speak to the individuals face directly
 - Approach from the side
 - Avoid possible "head butt"
- ▶ Give one-step directions or commands
 - Allow extra time to process information
 - A 3 – 4 second delay is not uncommon
 - Repeat your question and wait again
 - Be aware that some individual's use of "yes" and "no" to answer questions may be random and misleading
 - Try rewording your questions to validate the individual's response

Communication Strategies

- Idiomatic Speech
 - Idiom from Greek *idiōma*, special feature, special phrasing, one's own
 - an expression, word, or phrase whose sense means something different from what the words literally imply
 - Avoid using phrases that have more than one meaning such as
 - Spread eagle
 - Knock it off
 - Cut it out
 - Barking up the wrong tree
 - Bite your tongue
 - Sick as a dog
 - Take a seat
 - Kick the bucket
 - A piece of cake
 - Between a rock in a hard place
 - Hold your horses
- ▶ Many individuals with autism have a very literal understanding of language and will be confused by the use of this type of phrasing

First Responder Helpful Information

- ▶ Identification can often be found on individuals with autism by a Medic Alert Bracelet or necklace used in a different or unusual way
 - Some families may thread the ID into a shoelace, into a belt, or as a zipper pull
 - A business card with personal information may be in a pocket or wallet
 - Look for a washable tattoo, usually in the arm or shoulder area



First Responder Helpful Information

Receptive vs. Expressive

- ▶ 50% of individuals with autism are nonverbal throughout their life span
 - Those with communication skills even relatively good skills may present as non verbal in highly stressed situations
 - Do not presume a nonverbal child or adult who seems not to be listening, can't understand
 - Individuals who present as nonverbal may be able to write or type responses
 - Provide paper and pen/pencil/crayon or laptop for the best chance of getting the information that is needed
 - Utilize non-verbal communication systems, such as the picture exchange communication system known commonly as PECS

People who have autism

- ▶ The person with autism may or may not be able to communicate with words. The individual should be approached gently and spoken to softly as high levels of sensory input may cause agitation.
- ▶ Understand that a person with autism may become stressed when their regular routine is disrupted.
- ▶ Unless absolutely necessary, don't touch someone with autism without the person's permission. Many people with autism are very sensitive to touch and simple touch can be painful.
- ▶ Understand that rocking, repetitive motion, and repeating words or phrases can be comforting to a person with autism during an emergency.
- ▶ Avoid loud noises, bright lights, and high levels of activity whenever possible.
- ▶ Don't assume that a person does not understand if they are not using words.


Autism Perspectives

- ▶ Individuals with an autism spectrum disorder often don't see things from other's perspectives, so the effect of how other people view them may escape them completely.
- ▶ Often they are not motivated by the same things as others.
- ▶ Verbal praise often is not motivating.
- ▶ Many tasks are more effortful due to the skill deficits associated with their disability.
- ▶ Effortful tasks require strong motivators which may or may not be readily available in an emergency situation.


Communication Tools

- ▶ Picture Exchange Communication System (PECS)
- ▶ Visual Schedules
- ▶ Clear signage
- ▶ Provide quiet areas
- ▶ Repeat directions in calm voice
- ▶ Allow extra time for response


Communication




IPad & iPhone




Visual Schedule



Daily Planner



Picture Board Example















PECS


- ▶ PECS/ Picture Exchange Communication System
 - Use of visual supports for enhanced communication
 - synonymous with picture cards of any type



















Picture Board example

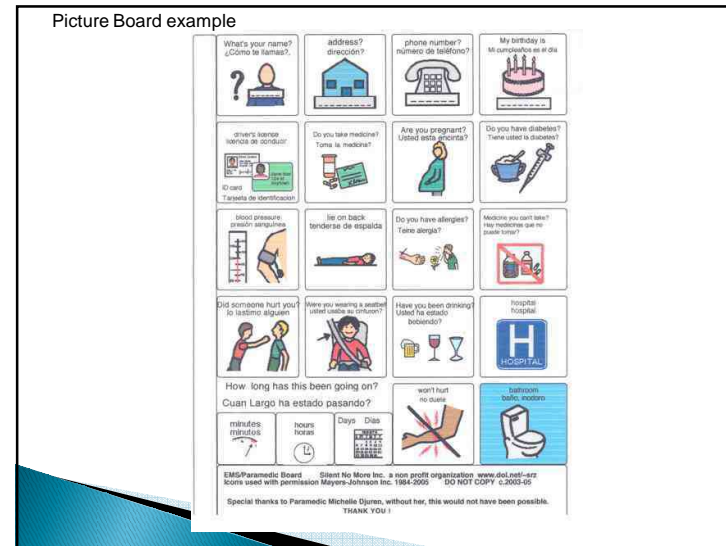
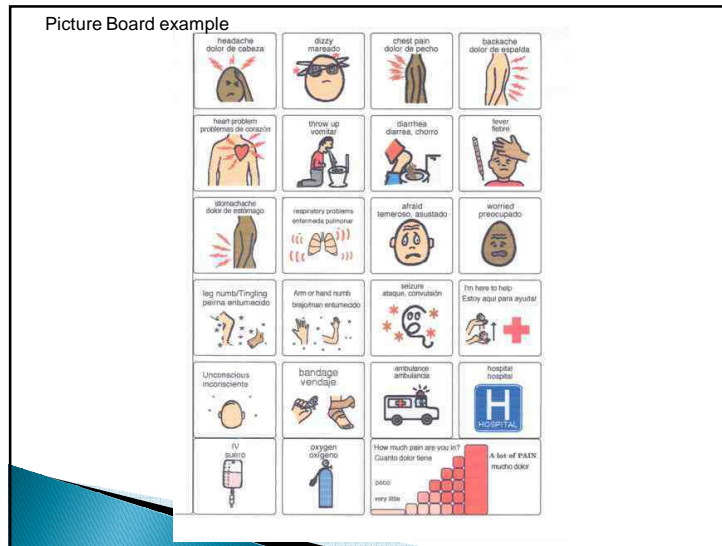
What's your name? ¿Cómo te llamas? 	phone number número de teléfono 	address dirección 	parents padres, papás 
driver's license licencia de conducir 	police car patrulla 	police station estación de policía 	wait here esperar aquí 
I need help necesito ayuda 	lost perdido 	I'll take you home yo le tomare hogar 	tow truck coche grúa 



Picture Board example

ambulance ambulancia 	hospital hospital 	I'm sick enfermo/hauseas 	I am hurt me duele 
Did someone hurt you? lo lastimo alguien 	Do you take medicine? Toma la medicina? 	Have you been drinking? ¿Usted ha estado bebiendo? 	sit down sentarse 
bathroom baño, inodoro 	drink tomar, beber 	eat comer 	stay with me quédate conrriego 





Project Lifesaver

- Through Project Lifesaver, lost or wandering people with autism, Down syndrome or Alzheimer's disease can be tracked through a personalized wristband that emits a tracking signal. Those who wear the wristband can be quickly located and returned to their families and caregivers
- Project Lifesaver relies on radio technology and a specially trained search and rescue team.
 - Caregivers notify the local Project Lifesaver agency that a person is missing, a search and rescue team is dispatched to the wanderer's area and starts searching with the mobile locator tracking system.

Search times have been reduced from hours and days to minutes

Project Lifesaver

- What is the cost for my agency to establish Project Lifesaver?**
 - Implementation cost is \$5,600.00, which includes all the equipment you need to get started and the training tuition and paperwork, guides and supporting structure to get your program implemented
- What is the cost to maintain the Program?**
 - Monthly cost for the agency per transmitter in the field is about \$8.75
- This covers the cost of the replacement battery and band. These charges may be accessed in the way of a "fee" to clients enrolled
- How can we join?**
 - Call 757-546-5502, Col. Tommy Carter (Chief of Training) or join@projectlifesaver.org
- Do you charge membership fees?**
 - We charge a new agency a one time membership fee. We strive to keep our costs as low as possible to allow every agency the opportunity to participate
- Where can we obtain funding?**
 - Most agencies joining Project Lifesaver have enjoyed much success by appealing to the community, i.e., civic, fraternal and service clubs
 - Also, many businesses and hospitals have assisted agencies in starting
 - From time to time, there are grant opportunities available from Project Lifesaver
- Project Lifesaver will not sell the equipment without the necessary training and support that goes with the program**

In 2013, the Autism Society of America states:

Autism is estimated to cost \$3.2 million per child over a lifetime. In ten years the United States this epidemic will cost society close to \$2 and \$4 trillion.

<http://www.autism-society.org/about-autism/facts-and-statistics.html>

Silent Disabilities

- ▶ Examples include:
 - PDD/Autism
 - Autism on the rise: Prevalence 1 in 110
 - Learning Disabilities
 - Communication Disabilities
 - Cognitive/ Intellectual Impairment
 - Senior Citizens
 - Psychiatric Disorders
 - Mood Disorder
 - Schizophrenia
- ▶ Sometimes referred to as “silent disabilities”

People who have a Cognitive Communication or Intellectual Disability

- ▶ Remember that receptive skills are generally better than expressive skills
- ▶ Some people may be distracted with a lot of activity and noise around them.
- ▶ Be prepared to repeat what you say, orally or in writing.
- ▶ Offer assistance and instructions and allow extra time for processing information and decision making.
- ▶ Be patient, flexible and supportive. Take time to understand the individual and make sure the individual understands you.

People who have a Cognitive Communication or Intellectual Disability

Say:

- ▶ My name is ____. I am here to help you.
- ▶ I am a ____ (name your job).
- ▶ I am here because (explain the situation).
- ▶ I look different than my picture on my badge because ____ (Ex., if you are wearing protective equipment).

Show:

- ▶ Your picture identification badge (as you say the above).
- ▶ That you are calm and competent.

Give:

- ▶ extra time for the person to process what you are saying and to respond.
- ▶ respect for the dignity of the person as an equal and as an adult (example: speak directly to the person).
- ▶ accurate, honest information
- ▶ an arm to the person to hold as they walk. If needed, offer your elbow for balance.
- ▶ quiet time to rest (if possible, to lower stress/fatigue).

Use:

- ▶ Short sentences. Simple, concrete words.
- ▶ Pictures and objects to illustrate your words.

Setting up for Success

- Develop & Apply concepts around Expectations/Routines
 - Have everyone explicitly practice appropriate behaviors & routines
 - Create consistent & effective routines
- Respond consistently
 - to reward appropriate behavior
 - to inappropriate behavior w/ corrective feedback



Setting up for Success

Be prepared! Be proactive!

- ▶ Anticipate behaviors you will see and know how you will respond
- ▶ List potential behaviors
 - Identify what behaviors and expectations you can teach in advance to prevent anticipated problem behaviors and link with a reinforcement program
 - List out how you will respond to problem behavior
 - Identify who has capacity and capability to manage behaviors



Strategies That Work

- ▶ **Have a consistent structure** (to the day)
- ▶ **Use visual strategies** (schedules, written instructions, visible progress towards goal)
- ▶ **Be clear** (communicate to the individual on his/her level)
- ▶ **Be consistent** (don't change rules in anyone's favor)
- ▶ **Warn about transitions and changes**
- ▶ **Find out what motivates and use it as part of a well thought out, consistent, positive, proactive plan.**



Setting up for Success

▶ Skill Deficit v. Motivation Problem

- For skill deficits we can:
 - Provide more instruction or support to alleviate specific skill deficit or
 - Provide easier tasks to increase participation
- For motivation problems we can:
 - Find incentives which motivate the person to engage in the task



People who use a Service Dog

- ▶ Traditionally, the term service dog is referred to dogs that assist people who are blind; however there are many types of service dogs trained to assist people with a disability. (2010: New Guidance for Service Animals)
- ▶ More recently, service dogs have been trained to assist returning soldiers with Post Traumatic Stress Disorder (PTSD) and children with autism. (www.ada.gov/regs2010/factsheets/title2_factsheet.html)
- ▶ A service dog is not a pet. Service dogs are allowed to go anywhere a person could go, including food preparation and medical areas.
- ▶ Do not touch, give the dog food or treats without permission of the owner.
- ▶ When a dog is wearing its harness, it is considered working and **on duty**. In the event you are asked to take the dog while assisting the individual, hold the leash and not the harness.
- ▶ Plan to evacuate the dog with the owner. **Do not separate them!**


People who use a Service Dog

- ▶ Service Dogs are not required to be registered and there is no proof that the dog is a service dog. If the person tells you it is a service dog, treat it as such. However, if the dog presents a direct threat to the individual or others, you do have the leeway to remove it from the site.
- ▶ *Remember though, that in disasters, animals are also nervous and anxious; take all considerations into your decision before removing a service animal from its owner. (For example, if a person steps on a dog's tail while on a crowded bus with lots of people in panic, and the dog reacts to it, that may be considered a normal reaction)*
- ▶ A person is not required to give you proof of a disability that requires a service dog. If you have doubts, wait until you arrive at your destination and address the issue with the supervisors in charge.
- ▶ A service dog must be in a harness or on a leash, but need not be muzzled.

In addition to the economic costs of treatment, autism is a tremendous burden to family members who must provide lifelong care to loved ones affected by the disorder.

Activity


- ▶ Create a scenario where you are required to evacuate an individual who presents as non verbal. How will you explain the evacuation situation and prepare this person for transport to a shelter.



www.noahsarkinstitute.org

Pre/ Post Test


Test what you know about autism

1. Name two of the three core domains considered in a diagnosis of autism?
Communication / Language impairments/ Social deficits
2. Name two observable "presentations" for autism.
Anxiety, and self stimulatory behavior, repetitive speech, non verbal, lack of eye contact, avoidance of directions
3. Name one possible co-occurring diagnosis that may be present with autism.
ADHD, Epilepsy, Genetic Syndrome, MR
4. What is the prevalence of autism in the USA?
1 in 88
5. Name one reason why elopement is such a serious threat to individuals with autism.
Attracted to water, no fear response


www.noahsarkinstitute.org


www.noahsarkinstitute.org

6. In ASD, receptive skills are generally better than expressive skills. State two modifications you may use to increase the likelihood of being understood.
Slow down language and allow extra time to process information
7. Define self stimulatory behavior or give two examples.
Behaviors which are adaptive attempts at regulating the environment when the environment becomes chaotic. Ex. Spinning, Rocking
8. Why is positional asphyxiation a danger in handling individuals with ASD?
Many individuals with ASD have poorly developed upper trunk areas, (Hypotonia)
9. Name one unusual way a medic alert bracelet, or ID may be used to identify a person with ASD?
Threaded through a shoe lace, belt buckle, tattoo
10. What does the acronym PDD-NOS stand for?
Pervasive Developmental Disorder Not Otherwise Specified



www.noahsarkinstitute.org

Community Resilience

Do not underestimate the resilience in the community


Against difficult circumstances individuals with disabilities not only accommodate environments which are complicated and unforgiving... they thrive though the process.

Use their expertise as you design your programs and strategies.


www.noahsarkinstitute.org

“Although the world is full of suffering, it is also full of the overcoming of it.”

Helen Keller


www.noahsarkinstitute.org

We can make it happen!



Individually we are one drop
Together we are an ocean

Kyunoksuke Satoro



Through all of the programs and initiatives of the Noah's Ark Institute we continually strive to provide the most comprehensive and highest quality programs available, while nurturing the respect of the families and clients it is our privilege to serve.

Noah's Ark Institute



Making the world a better place for everyone with autism

Presented By:
B. Madeleine Goldfarb, MA
www.noahsarkinstitute.org
bmadeleine@noahsarkinstitute.org
(973) 619-0963