

Autism in the Healthcare Setting Mud Symposium March 25th 2011

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Autism Spectrum Disorder
(ASD)

**1 out of every
110 children Dx
with Autism
1 out of 70
1 out of 60...**

- Diagnoses are increasing at an alarming rate across the country and our world
- We as healthcare providers see an increased rate of contact with individuals with autism as patients', victims of crime, students, witnesses, and/or offenders.

Like a Snowflake

- Communications, behaviors, intent, and ability levels of people with autism vary greatly and present challenges for even the most experienced professionals.
- Put **100** people who have Autism and look at all their individual differences..
- You cannot have **One** set way to interact with them...
- EACH IS an INDIVIDUAL/ Different needs
- **EACH SEPARATE Experience** with the same person could be DIFFERENT, depending on their mood, sensory issues, environment, sights and sounds around them

Sound Hard??? .. YES!!!!
BUT not Impossible... **PATIENCE**.....

Definitions and Diagnosis

- **Autism** is defined as a neuro-developmental disability, involves the brain starts very early in life ; still plastic, and still changeable.
- **PDD** is not a specific Dx but an umbrella term under which the specific diagnoses are defined.
- **Aspergers**: differences from ASD
- is the severity of the symptoms
- absence of language delays..
- frequently persons have good language and cognitive skills

Definition Cont..

- Autism involves differences and difficulties in several areas:
 - Social Interaction
 - Communication
 - Repetitive behaviors
 - Difficulty adjusting to change
 - Sensory Integration Issues

Common Characteristics of Autism

- Unique personality and combination of characteristics.
- Mildly affected : slight delays in language
- Greater challenges with social interactions.
- Difficulty initiating and/or maintaining a conversation.
- Communication is described as talking "at" others instead of "to" them.
- Process and/or response to information in unique ways

Characteristics cont..

Aggressive and/or self-injurious behavior may be present.

Traits:

- Insistence on sameness: resistance to change
- Difficulty expressing needs,
- Using gestures or pointing instead of words
- Repeating words or phrases ..
- Preference to being alone: aloof manner
- Tantrums, laughing for no reason,
- Shows distress for reasons not apparent to others
- Non responsive to verbal cues..
- Acts deaf, but hearing is normal

Characteristic cont

- Not wanting to cuddle or be cuddled
- Little or no eye contact
- Unresponsive to normal teaching methods
- Sustained odd play: spinning objects
- Obsessive attachment to objects
- Apparent over sensitivity or under sensitivity to pain
- Noticeable physical over activity or extreme under activity
- Uneven gross/fine motor skills

Occurrence

- ASD occurs four times more in boys than girls.
- ASD Persons are seven times more likely to encounter the police than the average person..

Occurrences and examples

Unaware of trouble

Threatening

Statements

Inappropriate advances

Get into trouble without realizing they have committed an offense

Personal, telephone, or internet stalking

Downloading child pornography;

Accomplice in a crime with false friends

Making physical outbursts certainly strike most people as offenses which should demand punishment.

This assumption, though valid does not allow for issues that challenge the individuals

Occurrences cont

- Wide range of intellectual ability
- IQ's range from below 25 to above 150
- Co-Morbidities
 - 25% Mental Retardation
 - 40% Seizure Disorder
 - Psych disorders
 - Poly pharmacy

What Causes Autism?

Wish I knew.....

- No known single cause for autism,
- Accepted theories: abnormalities in brain structure or function.
- Links with : *heredity, genetics, and medical problems*
- Some children born with a susceptibility to autism, but researchers have not yet identified a single "trigger"

Other Factors

- “Research indicates that other factors besides the genetic component are contributing to the rise in ASD
- Environmental toxins (e.g., heavy metals such as mercury)
- Metabolic impairment that reduces their ability to rid their bodies of heavy metals and other toxins.
- Build-up of these toxins can lead to brain & nervous system damage & developmental delays.”

ASA Environmental Health Project ,2006

Medical Components of ASD.. Did you know?

Gastrointestinal Tract

- May cause alterations in the beneficial bacteria
- Leads to digestive disorders such as diarrhea & constipation.
- Some symptoms are increased by milk or wheat products

Immune System:

- Problems with the immune system may be one of the causes Psychological stressors,
- Exposure to chemical triggers and infectious agents adversely influenced
- Children at risk of ASD may be susceptible to chemical/environmental triggers
- Improper immune responses that impact the developing nervous system

Elevated Toxins:

- Metabolic impairment that reduces the ability to rid the bodies of heavy metals and toxins.
- Build-up of toxins in the body can lead to brain and nervous system damage and developmental delays.
- Methyl mercury, arsenic, lead, and cadmium, enter through air, food and water,
- Can cause a range of illnesses and organ damage, including cancer
- Damage kidneys, GI tract and nervous system
- And even DEATH.
- These toxins are particularly dangerous to infants, fetuses and children.. (ASA Medical Components of ASD.. Jan 08)

Things to remember in a split second...

PLEASE always have PATIENCE.. YOU NEVER KNOW...
Your patient, student, friend or loved one....may ...??

- Non verbal or limited speech
- Avoids eye contact
- Prefers not too be touched
- Lacks fear -May go back to dangerous situation
- High tolerance to PAIN
- Noise of sirens, fire drills & lights-Put them in sensory overdrive
- May seek sensory stimulation.. heavy pressure, hand flapping, bizarre/repetitive behaviors

Even more things to remember in a milli second..

- Inappropriate laughing or giggling
- Avoidance too touch
- Spin or twirl object and exhibit finger, arm or wrist flicking, rock back & forth
- If verbal: may have trouble with speech volume (loud, whisper, monotone, computer like vocal intonation)
- Cover their ears and look away
- Display clumsiness, toe-walk or have difficulty running
- Talk to themselves or no one in particular, echo words and/or phrase
- Display fascination with water, lights, reflections and shiny objects...

Tips for Interactions

- Attempts to stop the behaviors may increase anxiety ,cause the individual to act out aggressively
- Display calming body language: give person extra personal space, slow breathing
- Use simple language..speak slowly..repeat & rephrase questions as necessary
- Allow extra time for response
- Give praise and encouragement

More Tips

- Consider use of pictures, written phrases and commands, sign language
 - Use low gestures for attention: avoid rapid pointing or waving, keeping hands low
 - Examine for medical alert jewelry or tags, ask for an autism handout card
 - Exercise caution if restraint is indicated. The person may have a seizure disorder & low muscle tone.
- AVOID POSITIONAL ASPHYXIA.. KEEP AIRWAY CLEAR..
TURN PERSON ON SIDE OFTEN.. GIVEN TIME AND SPACE PERSON MAY DE-ESCALATE BEHAVIOR

PATIENCE.....

- PATIENCE...

Logic with Autism: Does not work..

Logic does not work -the ability to integrate different sources of information is limited.

Even when it may seem to you that your question is clear, misinterpretations can occur.

- Trouble conceptualizing in complex situations.
- May use preservative behaviors.
- Have trouble with context & figuring out how things get connected & what they mean.
- **Patience:.. Not so** good at this .. Please give them time!
- They look at one situation: concretely & not in the context of trying to figure out what would be the different connections in that situation.

Wandering & Autism

- Children and adults with ASD may wander away from caregivers and healthcare workers, teachers and even parents....
- The person may also wander into traffic or attempt to enter nearby patient rooms...other offices, classrooms
- Search nearby water sources... parking lot.. Car tires...(tying a shoe & the river bank, Dads car)
- Encourage families to provide key information to the 911 Database. # in NH.. 603.271.6911

RESPONSE...

- Speak in Direct, short phrases such as: "Stand up now" or "Sit on the bed"
- Avoid figurative expressions: such as "What's up your sleeve?" or "Are you pulling my leg?"
- Allow for delayed responses to your questions or commands
- Repeat and/or rephrase
- Consider use of pictures, written phrases & commands & sign language
- Use low gesture for attention: avoid rapid pointing or waving
- Examine for presence of medical alert jewelry or tags, or an autism handout card
- Model calming body language (such as slow breathing & keeping hands low)
- Model the behavior you want the person to display

De-escalation of Behavior

- You may be called to a scene where the person with autism is displaying escalated behavior and they have hurt themselves or others in the process...
- A call like this will challenge the training & instincts of even the most experienced veteran healthcare worker..
- Please consider...
 - Well in a split second...many things need to go through your mind as you are approaching the scene...

Patience.... Patience...

- If the person's behavior escalates.. maintain a **safe distance** until any inappropriate behaviors lessen, but making sure the patient is in a safe place..
- Remain **alert** to the possibility of outbursts or impulsive acts
- Use your discretion. If possible..**allow the person to de-escalate themselves** without your intervention.. (unless its life threatening)
- **Stimming..noise..actually is good**.. It vibrates the inner ear creating balanced autonomic reflexes in the brain to coordinate balance & **self regulation**... let it go...

Simple questions.. For you maybe...

- The person with autism will have difficulty processing your questions..
- They may be unable to give name, address, phone #, or be unable to present ID when asked
- PATIENCE...
- It will take more time too evaluate a person on the Spectrum.. Please take the time.. Pause and give them 5-10 second for response time back to you..
- Its common for people with autism to repeat your words & phrases back to you... called Echolalia
- Be aware that the person may also model your body language & emotional state

Whats going through your mind and theirs.. How will you react...???

- A person may **not react well to changes** in routine or presence of uniformed strangers
- Person may display "**fight or flight**" reaction when approached
- You should not interpret the **person's failure to respond** to questions as a lack of cooperation or a reason to ignore the person.. Equally.. lack of care for this person
- **Seek information & assistance** from a **parent** or others..ask about how to communicate with & de-escalate the persons behavior

Last Resort Restraint

- Despite your best efforts, you may have to restrain for their own health
- Hypotonia of trunk muscles
- May not be able to support their own airway
- Avoid positional asphyxia. Turn the person on their side to
- Monitor the person's condition frequently to prevent further trauma
- Asthma & heart conditions are also common.
- May not recognize the futility of resistance & continue to struggle .. Even though you are just trying to help
- Continue to use communication, de-escalation, & calming response techniques
- Avoid standing too near or behind. The person may suddenly lurch backward or forward ..(been there... done that...ouch!!!)

Victims...

- People with autism are often times victims of crime, such as sexual, verbal or physical assault..
- Ask parents, caregivers, & people who know the victim for tips about how the person gives & receives information
- If not verbal, how do they communicate?
 - Sign Language
 - Via Pictures
 - Symbols
 - Computers...

Transport to the Hospital...hmm

- Alert the hospital staff Re: Autism Dx
- Private room: best practice
- Things you have learned at the scene.. Relay to the staff at the hospital.. Communication, touch, pain issues-Every little bit counts...
- Remember.. Many have a HIGH tolerance to Pain..
 - (Can even throw a baseball with a Fx clavicle..)
- Yes my Jacob...

Social Stories..

- www.helpautismnow.com:
 - they have read along stories for getting a shot, going to the doctor, lab draws
- www.childrenshospital.org:
 - Uses Arthur and his friends as a guide for MD visits, pre-op, hospital stays, people they are going to meet, and even games to play (lab staff are *detectives*..looking for clues to find out what makes you sick)

**Books: Sesame Street with Grover & Franklin..

Options...

- Use of photo albums.. Real pics or computer, stick figures
- EEG: suggest to wear a hat at home for several days
- Use dolls to demonstrate a procedure.. Then let the patient perform the procedure on the doll
- A little extra time taken & a little planning will go a long way
- Clear all distractions..if possible turn off pagers, phones..and bring as few people into the room as possible

Ask the Parents/Caregivers..

- Aggressive when not sick....very quiet when sick
- Normally well behaved..Now ill .. Start biting & kicking
- Be prepared for a “moving exam”
- Be prepared..respond with calmness...provide simple explanations prior to each step of tx

More Tips

- Perform exams distal to proximal
- Presume the person's competence. Just b/c they can't speak doesn't mean they don't understand you - JAMA 2009 & Sound
- Resources: www.autismsource.org “Safe & Sound”
- Integrative Therapies: massage, guided imagery, Reiki, acupuncture, expressive arts, yoga, & therapeutic touch
- **PATIENCE...**

Attitude... Attitude... Attitude..

- Plays a big role in any situation..
- If the Parent and Healthcare personal are supportive and calm.. most times, the patient will feel confident and not as frightened.
- Options for younger kids: call a shot “a booster” or a “power booster”

All about Choices..

- Kids tend to like choices.. Right??
- Ask them would you like a “shot” or a “booster”??
- Would you like a big needle or a little tiny one we use for babies.. (they don’t need to know it’s the same)
- If there is an option of the site... ask them arm or leg...??

Distraction... Distraction...

- Hold the patient tight if tolerated..
 - Wrap in a blanket
 - Use several blankets for deep pressure
 - Let them listen to music
 - Use of a pacifier, chewy toy...
As tolerated: gum, life saver, ice cube, popsicle
- Distraction tools..
Posters.. Needing to count or find objects

Buzzy...

- Used for IV starts, finger sticks, shots.. Etc
- The vibration upstream of the procedure with the use of “Buzzy” confuses the nerves & blocks the pain..
- www.buzzy4shots.com
- Also could use cold & vibration above the procedure site (5-10cm proximal) and between the brain... can this work with adults..Yes.. Relieves pain...
- Compared with no intervention this combo reduced pain significantly 95%..interventions were also more helpful for those with greater pre-procedural fear...(Bantier, Leong, Mathew. Clinical Journal of Pain; Oct 2009-Vol 25 Issue 8 pp705-710)

Look Beyond the Diagnosis

- Dr. Tim Buie, a pediatric gastroenterologist from Harvard/Mass General.. Performed over 500 GI endoscopies... his findings show more than “½ of these children had treatable gastrointestinal problems that ranged from moderate to severe; including esophagitis, gastritis & enterocolitis along with the presence of lymphoid nodular hyperplasia.”

Dr Buie’s Opinion

- Children are ill, in distress and pain; not just mentally, neurologically dysfunctional.
- Many of the symptoms of autism and self abusive behavior (self mutilation, head-banging, unexplained outbursts, atypical sleep patterns, disrupted sleep or night awakenings) are actually symptoms of pain that the child is not able to communicate. (Harvard Research Team: Northwest Autism Foundation; Portland Oregon 2001)

911 Information

- 911 data base registry and alert programs available
- Offer times for ASD families too come to the hospital and check out the rooms, equipment etc..
- This can enhance education for all .. in areas of recognition & response to the vulnerable person
- You can learn from each other during these controlled, safe, and non-stressful interactions

Autism Awareness Ribbon

- The puzzle pattern represents the mystery & complexity of the autism spectrum.
- The different colors & shapes represent diversity of the people & families living with the condition.
- The brightness of the ribbon signals hope
- Hope that through increased awareness of autism, & through early intervention & appropriate treatments, people with autism will lead fuller & more complete lives. (Autism Society of America)

How are we all alike? Universal Needs

1. To be respected, not disrespected
2. To be asked, not told what to do
3. To be told why
4. To be given options, not threats
5. To be given a second chance

Patience.....

- Patience... Patience ...
- Thank you for your time..
 - If you ever have questions please don't hesitate to contact me.. ****sws13@roadrunner.com**** or ****www.jbtautism.org****
 - If you know of families in need please send them my way...
 - PS... Patience...

Questions

- PS..
- Patience...