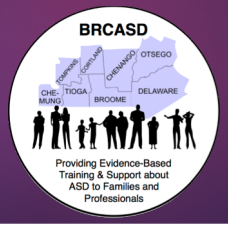
Autism Spectrum Disorder: Health Services & Emergency Responding

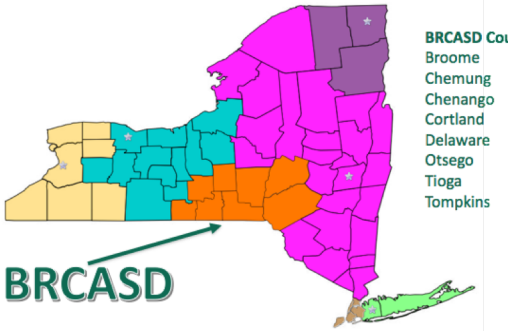
THE BINGHAMTON REGIONAL CENTER FOR AUTISM SPECTRUM DISORDERS



Regional Centers for Autism Spectrum Disorders
NYSRCASD

BINGHAMTON UNIVERSITY
STATE UNIVERSITY OF NEW YORK

NYS REGIONAL CENTERS FOR ASD



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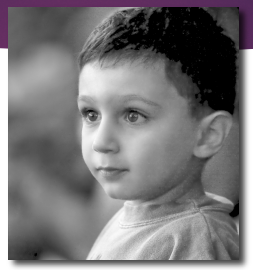
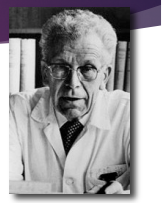
BROOME

OVERVIEW

- What is Autism Spectrum Disorder?
- Challenges in routine & specialty healthcare
- What does someone with ASD do in distress?
- ASD and emergency medical support
- Evidence-based recommendations
- Final thoughts

HISTORY OF ASD





DR. LEO KANNER
1943

DR. HANS ASPERGER
1944

AUTISTIC DISTURBANCES OF AFFECTIVE CONTACT

AUTISTIC PSYCHOPATHY

AUTISTIC DISORDER

ASPERGER'S SYNDROME

DSM-5 (2013) – ASD CRITERIA

- Social Communication Deficits (3 of 3 criteria)
  - Deficits in socio-emotional reciprocity
  - Deficits in nonverbal communicative behaviors used for social interaction
  - Deficits in developing and maintaining relationships appropriate to developmental level
- Restricted, Repetitive Patterns of Behaviors, Interests, and Activities (2 of 4 criteria)
  - Stereotyped or repetitive speech, motor movements, or use of objects
  - Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change
  - Highly restricted, fixated interests that are abnormal in intensity and focus
  - Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment

Severity Level	Social Communication	Restricted, Repetitive Behavior
Level 1 "Requiring support"	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions and clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions.	Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence.
Level 2 "Requiring substantial support"	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions and reduced or abnormal response to social overtures from others.	Inflexibility of behavior, difficulty coping with change, or other RRB appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.
Level 3 "Requiring very substantial support"	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning; very limited initiation of social interactions and minimal response to social overtures from others.	Inflexibility of behavior, extreme difficulty coping with change, or other RRB markedly interfere with functioning in all areas. Great distress/difficulty changing focus or action.

**ALSO – SPECIFY PRESENCE OF LANGUAGE IMPAIRMENT AND INTELLECTUAL IMPAIRMENT, AS WELL AS ANY GENETIC OR MEDICAL CONDITION OR OTHER NEURODEVELOPMENTAL DISORDER

WHAT IS ASD?

- A disability across the lifespan
  - *Autism does NOT only affect children.*
- There is no "cure" for ASD - We all have shared responsibility for understanding individuals with ASD.
- Diagnosed as early as 2 years old but often not until after 5 years old; some individuals don't get diagnosed until much later in life.
- Invisible disability/disorder – no physical marker

BASIC STATISTICS

- Prevalence rates = 1:59 children or ~2% (CDC, 2018)
  - Context - US Population in 2018 = ~326.8 million ~6.5 million individuals with ASD
- Male to female ratio is about 4:1
- Approximately 50% of individuals with ASD are nonverbal; 44% had average-above average intelligence (i.e., 56% intellectual impairment)
- 1/3 of those with ASD are also affected by epilepsy
  - Sub-clinical epilepsy thought to play a role in clinical regression (Acosta & Pearl, 2004)

COMMONLY ASSOCIATED CONCERNS

- Anxiety
- Phobias
- OCD
- ADHD
- Aggression, including self-injury or self-harm
- Sleep
- Appear insensitive to pain OR overly sensitive to certain types of stimulation

INJURY & ASD

- 2-3 times more likely to experience medically attended injuries
- Significantly reduced life expectancy
- Engagement in more risk-taking behaviors than peers

LEE, ET AL, 2008; MCDERMOTT, ET AL., 2008; SHAVELLE, ET AL., 2001; STRAUB & ROMANCZYK, 2009

CAUSES OF UNINTENTIONAL INJURY

(CDC, 2004; McDermott, et al., 2008; WHO, 2008)

Rank	ASD	Typical
1	Falls	Falls
2	Struck By / Against	Struck By / Against
3	Natural Environment	Cut / Pierce
4	Cut / Pierce	Car Accident
5	Poisoning	Natural Environment
6	Car Accident	Bicycle
7	Burn	Burn
8	Bicycle	Poisoning

PREDICTORS OF UNINTENTIONAL INJURY

EFFECT OF HAVING ASD IS CURRENTLY UNCLEAR...

- Male
- Over the age of 5 years old
- High impulsivity
- Presence of physical or mental disability
- Impairments in attention, communication, & social interaction
- Low SES
- Exposure to hazardous environments

FEAR AND INJURY

- Cognitive and emotional determinants
  - Awareness of impending threat for bodily or emotional harm with expectation of undesirable outcome
  - Fear and accurate appraisals of injury risk
  - Lack of fear associated with elevated injury risk

MORRONGIELLO & MATHEIS, 2007; SCHWEBEL, 2004

ASD, FEAR, AND EMOTION

- Individuals with ASD do not process facial expressions of emotions of fear, anger, or sadness as well as individuals without ASD (Farran, Branson & King, 2011).
- Body movements/postures of emotions – mixed results in research.
- Individual differences largely account for differences in fear acquisition and its impact on social interaction (South et al., 2011).

PARENT VIEWS: A PILOT STUDY

- Children with ASD were perceived by caregivers as having no fear to many items
- Being afraid to hurt oneself might be a protective factor against injury in children with ASD
- Caregivers might be intervening when children show no fear to dangerous situations
  - *Injury risk could be underestimated due to caregiver intervention for children with no fear*
  - *No one to intervene when not present*

CAVALARI & ROMANCZYK, 2014

CHALLENGES IN ROUTINE AND SPECIALTY CARE

IMAGE VIA OHIO STATE UNIVERSITY

IMAGE VIA CHILDREN'S HOSPITAL OF PHILADELPHIA

IMAGE VIA NOVA SOUTHEASTERN UNIVERSITY

LET ME ASK YOU…

- What are things you normally do or should do when providing care in your respective fields? Yes, take a minute and write a few items down.
- NOW – given what I have told you so far about ASD, which of those items might not be feasible?

FAMILY PERSPECTIVES

- Davignon, et al. (2014)
  - 20 children (ages 3-17) and their parents interviewed
  - First major theme
    - Productive Provider-Family Interactions
      - Providers need to learn how to communicate with individuals with ASD, use more picture cues and and other visual aids, and obtain training in behavioral strategies
      - Parents need preparatory guidance well before the procedure, including detailed accounts of what to expect during an encounter and tools parents could use to instruct their child about the visit

FAMILY PERSPECTIVES

- Davignon, et al. (2014) continued
  - Second major theme
    - Organization of Healthcare Delivery
      - Timely care (minimal waiting), but slower pace of procedures during appointments
      - Individualizing the treatment environment as much as possible, with fewer providers entering and leaving the room and caring for child than might be typical

FAMILY PERSPECTIVES

- Muskat, et al. (2015)
  - Interviews of 42 participants (youth with ASD, parents, and health-care providers)
    - Supportive health-care providers defined as those who:
      - Acknowledged parents as experts
      - Inquired about the requirements of patients with ASD
      - Accommodated unique clinical needs of the individual patient

PATIENT HISTORY AND PREPARATION

- Assessment (Souders, et al., 2002)
  - Person's communication, social, sensory, and behavioral skills and needs
  - Successful strategies for compliance
- Plan additional time as well as possibly additional visits to the treatment setting
- Meet the individual and have discussions with him or her (when possible) as well as caregivers involved.

SOUDERS ET AL. (2002)

- Key Components in Nursing Care Plan

  (for care of individuals with ASD undergoing complex medical procedures)

  1. Contact prior to visit.
  2. Instruct parents to bring communication mode, token system, or rewards.
  3. Prepare for behaviors – extra staff, bodily fluids.
  4. Prepare environment.
  5. Train staff,
  6. Offer pain management.
  7. Allow adequate time.

THOMPSON & TIELSCH-GODDARD (2014)

BOX 4. Presurgical checklist: individualizing care for the patient with autism

- Confirmation of autism spectrum disorder diagnosis
- Parent description of patient's abilities, response to verbal commands, behavior in new environments
- Techniques, toys, electronic devices, or other strategies that help calm the child
- Behaviors or cues when the patient is stressed
- Cues before a significant emotional meltdown
- Common behaviors the patient displays when working to cope with a stressful situation
- Behaviors the child portrays when having difficulty coping
- Sensitivity to touch, noise, bright lights, hospital linens/clothing
- Special interests of the patient
- Will the patient be able to wait in the registration area or surgical waiting area prior to his or her appointment? (If not, make special accommodations based on response)
- Encourage parents to bring a special toy, game, music, stuffed animal, blanket (regular or weighted) or other calming devices
- Confirm if the patient uses a special communication device, and if so have the parent bring it for the visit

ADDITIONAL SUPPORTS

Figure 5 The first picture is a nurse showing the patient what is going to happen next. The second picture is of the provider performing the task and the third picture is of the child placing the picture in the "done" box.

EXPERIENCE OF PAIN

- Arguments of hyporeactivity and hyperreactivity, but inconsistent findings
- Review by David Moore (2015)
  - Results of wide literature search that yielded 17 articles that fit inclusion criteria
  - While self/parent report and clinical observation studies indicated hyposensitivity to pain, observations of actual medical procedures indicated normal to hypersensitive responses
- Importance of understanding the danger of assumptions – a person with ASD with tactile undersensitivity might have a normal or hyperreactive response to painful stimulation

PRACTICE MAKES…THINGS EASIER

- Individuals with ASD might require additional visits and practice completing mock treatment scenarios to be able to comply with requests and participate during scheduled procedures
  - Such activities can be planned with parents and other caregivers, behavioral health providers, or others involved in case management

AN EXAMPLE

Clinical Practice in Pediatric Psychology
2013, Vol. 1, No. 2, 121–128

2169-4826/13/$12.00 DOI: 10.1037/cpp0000013

Teaching an Adolescent With Autism and Intellectual Disability to Tolerate Routine Medical Examination: Effects of a Behavioral Compliance Training Package

Rachel N. S. Cavalari
May Institute, Randolph, Massachusetts and Binghamton University

Melanie DuBard, James K. Luiselli, and Kirstin Birtwell
May Institute, Randolph, Massachusetts

The present study evaluated graduated exposure and positive reinforcement in a compliance training intervention package with an adolescent female who had autistic disorder, intellectual disability, and long-standing avoidance of routine medical examination. Intervention consisted of slowly introducing her to a 12-step examination hierarchy and reinforcing compliant responding within a changing criterion experimental design. Reinforcement for appropriate alternative behavior and modeling were also components of intervention. A behavioral clinician first implemented procedures that were subsequently generalized to nurses. The participant learned to comfortably tolerate a medical examination that she had resisted for nearly 2 years. We discuss clinical and research implications of the case.

Table 1
Desensitization Hierarchy for Medical Exam

Targeted hierarchy	
Mastery component	Example verbal discriminative stimulus
Leave car/classroom	"It's time to go for a walk."
Enter building/hall and walk to medical suite/doctor's office	"Let's go inside/to the hall this way."
Stand in front of doorway to medical suite/doctor's office	"Stand/wait here, please."
Enter waiting room	"Let's go in this room. Go ahead."
1. Sit in waiting room chair	"Sit over here" while pointing to chair. (Staff may sit with her)
2. Comply with height measurements	"I'm going to see how tall you are. Stand here, please."
Tolerates standing in front of measuring tape 10 s	
Walk to exam room door upon staff request	"It's time to go to the next room. Walk this way, please."
Enter exam room	"Let's go inside. Go ahead."
3. Comply with weight measurements	"I'm going to see how much you weigh. Stand here, please."
Stands on scale at least 5 s (max 10x)	
4. Sit in chair in exam room 1 min	"Sit over here" while pointing to chair. (Staff may sit with her)
5. Comply with blood pressure measurement	"I'm going to touch your arm to listen to your pulse."
Allow cuff to be placed around hand	
Allow cuff to be slid up to bicep while open	Count as appropriate for seconds (5 s) or pumps (1–5+)
Allow cuff to be tightened around arm with Velcro	
Tolerate stethoscope 5 s	
Tolerate 1 pump	
Tolerate 3 pumps	
Tolerate 5 or more pumps	
6. Comply with lung exam	"I'm going to listen to your lungs/touch your back."
Tolerate stethoscope 3 s in 2 locations	
Tolerate stethoscope 5 s in 2 locations	
Takes one breath	
Takes 3 breaths	
Takes 4–6 breaths	
7. Comply with heart exam	"I'm going to listen to your heart/chest."
Tolerate stethoscope 1 s	
Tolerate stethoscope 3 s	
Tolerate stethoscope 5 s	
Tolerate stethoscope 10s	
Tolerate stethoscope in 2 locations	
8. Lay on exam table 30 s to 1 minute	"Lie down on the table."
9. Comply with abdominal exam	"I'm going to listen to/touch your stomach."
Tolerates hand to abdomen contact in a single location 1 s	
Tolerates hand to abdomen contact in a single location 3 s	
Tolerates hand to abdomen contact in a single location 5 s	
Tolerates hand to abdomen contact in a single location 10 s	
Tolerates 1 palpation	
Tolerates 2 palpations	
Tolerates 3 palpations	
Tolerates 4 palpations	
10. Comply with mouth/throat exam	"I'm going to look in your mouth."
Tolerates otoscope near open mouth 5 s	
11. Comply with eye exam	"I'm going to look in your eyes."
Tolerates use of otoscope to view 1 eye for to 3 s	
12. Comply with ear exam	"I'm going to look in your ears."
Tolerates otoscope near ear 1 to 3 s	
Tolerates otoscope touching ear for 1 to 3 s	
Tolerates use of otoscope to view ear for 1 s each	
Tolerates use of otoscope to view ear for 3 s each	
Tolerates use of otoscope to view ear for 5 s each	

THE HIERARCHY AND STEPS/SUB-STEPS REQUIRED FOR LEARNING TO TOLERATE A ROUTINE MEDICAL EXAM (CAVALARI, ET AL., 2013)

TIME NEEDED FOR SUCCESS FOR AN INDIVIDUAL W/ SIGNIFICANT REFUSAL HISTORY

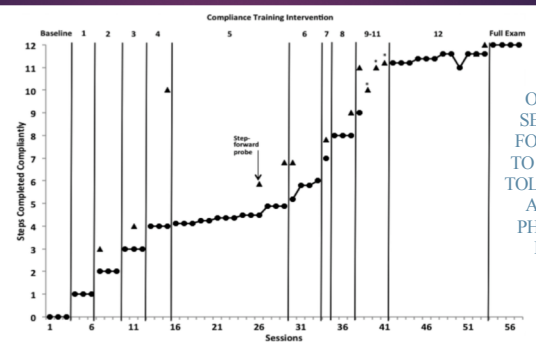


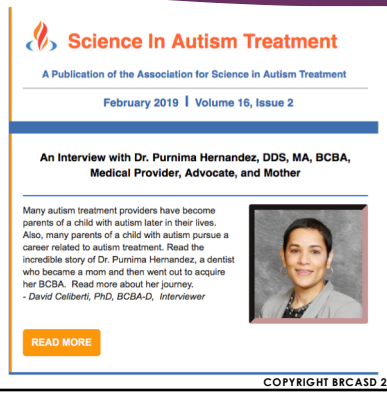
Figure 1. Number of steps in the hierarchy that Alice completed compliantly. Phase labels indicate targeted criterion step. Steps 5 and onward have sub-steps for gradual increase in mastery to complete the full step (ascending line to reach criterion step requirements). Asterisks indicate the transition to nursing staff during generalization programming.

OVER 50 SESSIONS FOR ALICE TO MASTER TOLERATING A BASIC PHYSICAL EXAM

SUMMARY POINTS

- Very important to understand that an individual with ASD receiving treatment in your facility might have weaknesses in specific areas; HOWEVER,
  - Previous experience with an individual with ASD does not provide sufficient understanding of a new patient with ASD. Each person's strengths, weaknesses, and needs are different.
- Engaging in patient-centered planning requires many of the strategies that you would need for individuals with ASD, but perhaps with more acclimation and procedure completion time added to the clinical plan.

RESOURCE – PROVIDER AND PARENT PERSPECTIVE



Science In Autism Treatment

A Publication of the Association for Science in Autism Treatment

February 2019 | Volume 16, Issue 2

An Interview with Dr. Purnima Hernandez, DDS, MA, BCBA, Medical Provider, Advocate, and Mother

Many autism treatment providers have become parents of a child with autism later in their lives. Also, many parents of a child with autism pursue a career related to autism treatment. Read the incredible story of Dr. Purnima Hernandez, a dentist who became a mom and then went out to acquire her BCBA. Read more about her journey.
- David Celiberti, PhD, BCBA-D, Interviewer

READ MORE

- https://asatonline.org/research-treatment/interviews/interview-with-purnima-hernandez/

OUR OWN PERCEPTIONS

- Imagine that you're in the supermarket and you see a parent struggling to control their young child who is screaming and kicking violently. What would be your first thought?
- Imagine that you're waiting at a bus stop and a young man you've never seen before comes up to you. He gets quite close and speaks to you very loudly in a monotone voice. He keeps asking when the bus is coming and shifting from one foot to another. What would be your first thought about this man?

PASSAGES FROM: *THINK DIFFERENTLY ABOUT AUTISM*. THE NATIONAL AUTISTIC SOCIETY

WHAT DOES SOMEONE WITH ASD DO IN DISTRESS?

- Sometimes distress is not detected
- Freeze
- Upset, aggression
  - Seems out of control
  - Be empathic
- Confusion
  - Go back into a burning building; seemingly irrational action for danger
- Hiding
- Bolting/fleeing

YOU NEED TO BE AWARE THAT…

- Not responsive to sound or requests/questions but can hear
  - Appears deaf
  - Difficulty speaking (or cannot)
- Might not understand consequences of their actions (aggression)
- Difficulty with abstract or ambiguous language, words, phrases.
- Sometimes disruptive behavior is due to perceived threat or difficulty communicating to you

WANDERING AND ELOPEMENT

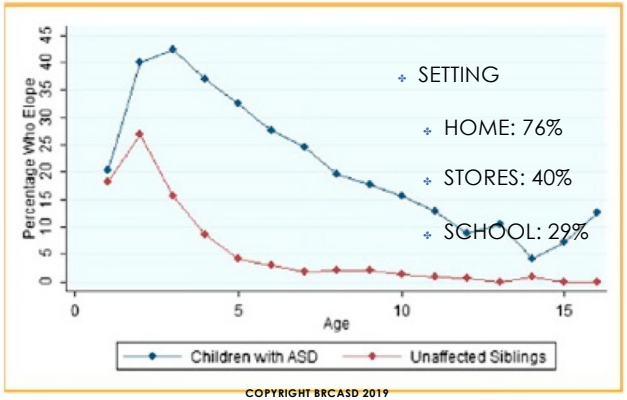
- **Wandering:** Moving/walking about from place to place.
  - Goal-oriented: to get to or away from something
  - Non-goal-oriented: no purpose, random movement
  - Due to something else: nighttime, disorientation, confusion
- **Elopement:** The act of running away, wandering away, walking away, escaping, or otherwise leaving a safe setting unsupervised or unnoticed.
  - Bolting/Fleeing: Suddenly running away, typically from something negative/stressful

LETHAL OUTCOMES IN AUTISM SPECTRUM DISORDERS (ASD) WANDERING/ELOPEMENT
LORI MCILWAIN, WENDY FOURNIER - NATIONAL AUTISM ASSOCIATION, JANUARY 20, 2012

FACTS ABOUT ELOPEMENT/WANDERING

- 92% of parents reported children with ASD had a tendency to wander (2007)
  - One of the most "stressful events" for parents (56%)
- Poor parenting not at root of wandering/elopement
- About 49% of children with ASD will wander/elope (2011)
  - 53% gone for long enough to be concerned (41 min avg)
- 2009-2011: 91% of deaths for children with autism ages 14 and younger were due to accidental drowning following wandering/elopement
  - 68% of these were in a nearby pond, lake, creek or river
  - 23% at a family outing
  - Death occurs within 15 min to 20 hours of disappearance

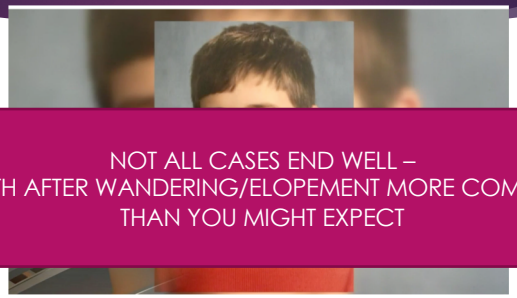
ELOPEMENT: RISK FACTORS



CONSIDER SPECIAL INTERESTS

- Streets/highways
- Trains
- Heavy equipment
- Fire trucks
- Roadway signs
- Bright lights
- Traffic signals
- Animals (only found at the zoo)
- Clock towers
- Mascots (Rumble Ponies)

RECENT & LOCAL – APRIL 2019



NOT ALL CASES END WELL –
DEATH AFTER WANDERING/ELOPEMENT MORE COMMON THAN YOU MIGHT EXPECT

SWEATSHIRT, SWEATPANTS, ONE SNEAKER – DISAPPEARED AT NIGHT
11 HOURS MISSING BEFORE BEING FOUND

FOR SEARCH & RESCUE

- Make sure you understand the degree of Autism you are dealing with. It will make a difference in dealing with the person when located.
- Find out if there has been anything that has attracted the attention of the person within the past 24 hrs. Have they been obsessed with a location or object, at a location, within that time.
- Do not expect the person to reply if you are calling their name. You'll most likely have to make visual contact to locate them.
- On many of the searches, the person has hidden from first responders.
- Check any location that has water, such as, pools, ponds, lakes, rivers, et al. immediately. These are points of attraction for those with Autism.
- Remember that someone with ASD will, most likely, not experience fear as we do. Don't discount searching any location because you feel a reasonable person would not go there.

QUOTED SOURCE: HTTPS://WWW.AUTISMSPEAKS.ORG/FAMILY-SERVICES/AUTISM-SAFETY-PROJECT/FIRST-RESPONDERS/SEARCH-RESCUE

ASK PARENTS IMMEDIATELY

- What do they like? Something familiar to them?
- Can they swim?
- Can they respond to their name being called by a stranger? By police?
- Can they cross the street independently?
- Are they afraid of dogs? What do they do around dogs?
- Experience with police? Color of uniform?
- Loud noise – sirens – what do they typically do? (cover their ears?)
- When they are upset, how to calm down?
- What do they do when scared? Where do they go?

MORE QUESTIONS FOR PARENTS

- Where did the child last request to go? (and was denied)
- Favorite places, objects, things, people, etc.
- History of wandering/elopement
- Stranger perception
- Was the child recently upset? Engaging in high level of self-stimulatory or repetitive behavior, perseveration?
- Use of pictures/signs to communicate?

SUMMARY OF HELPFUL TIPS FOR INTERACTING WITH SOMEONE WITH ASD DURING CARE

- Speak slowly and use simple language
- Use concrete terms
  - "Get in." "Sit Down." "Wait here."
- Repeat simple questions
- Allow time for responses
- Do not attempt to physically block self-stimulating behavior
- Do not make assumptions about individual preferences or capacity to communicate
- Remember that each individual with autism is unique and may act differently than others
- Watch for bolting/fleeing
- When restraint is necessary, be aware that many individuals with ASD have a poorly developed upper trunk area.

INITIATIVES

- Safe and Sound by the Autism Society
- Take Me Home – Pensacola Police Department
  - Free
- Free courses: http://www.missingkids.com/NCMECUniversity
- Think Differently – Dutchess County

Thank you!

PLEASE REFER TO THE PROVIDED READING LIST FOR REFERENCES!

- Visit our website: **brcasd.binghamton.edu**
- Email us: **brcasd@binghamton.edu**
- Call us at: **855-423-3212** (Toll Free)
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