

It's All About Them:

Autism Preparedness for EMS Professionals

Presentation Handout and Lecture Notes

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Notes:

Section One: Introduction to Autism Spectrum Disorders

What is an Autism Spectrum Disorder?

Autism spectrum disorders (ASD) are three closely-related developmental disorders of neurobiological origin, characterized by impaired social interaction, impaired communication and restrictive, repetitive behaviors, interests and activities (Jones et al, 2006). By definition, ASDs manifest by age 3, although the actual diagnosis may not be made until years later – in some cases, the person with an ASD may never be diagnosed. Diagnosis is made by the patient meeting specific behavioral criteria (DSM-IV-TR criteria), not by a blood test, a scan or any other type of study.

General behavioral criteria are:

Impaired Social Interaction

- Poor Eye Contact
- Poor use of facial expressions/gestures
- Selfishness/not sharing
- Lack of interest in socializing with peers
- Isolation / Resisting inclusion in group activities
- Inability to recognize effect of their behavior on others

Impaired Communication

- Delay or absence of speech
- Inability to perceive humor, sarcasm, idiom (takes everything seriously)
- Inability to begin/sustain conversation
- Inability to interpret other's non-verbal communications (gesturing/facial expressions)
- Lack of non-verbal communication (pointing, etc)

Restrictive, Repetitive, Stereotypical Behaviors, Interests and Activities

- Stereotyped motor mannerisms (hand-flapping/rocking)
- Rigid, inflexible adherence to nonfunctional routines and rituals
- Excessive preoccupation towards specific topics/interests

Autism spectrum disorders include the diagnoses of autistic disorder (AD), also known as “classic autism,” Asperger’s syndrome (AS) and pervasive developmental disorders – not otherwise specified (PDD-NOS) (Johnson et al, 2007). While each of these three diagnoses has defined diagnostic criteria, ASD is a “spectrum” disorder, meaning that these specific diagnoses will “blend” together. The generic term “autism” is commonly used to describe any and all points on the spectrum and will be used interchangeably throughout this handout with ASD and autism spectrum disorders.

It is not important for emergency responders to be caught up in differentiating between autistic disorder, Asperger's syndrome and PDD-NOS. It is important for you to recognize the terms that may indicate a person has an autism spectrum disorder:

- Autistic Disorder, "Classic Autism", AD
- Autism, Autistic, "Autie"
- Asperger's Syndrome, Asperger's, "Aspie", AS
- Pervasive Developmental Disorder (Not Otherwise Specified), PDD, PDD-NOS
- Autism Spectrum Disorder/Autism Spectrum Condition, ASD, ASC
- High-Functioning Autism, HFA *(and other similar...)*

Your general approach and management of the person will be basically the same: you will need to modify the normal method of "doing business" to accommodate the person. Keep in mind that each person with an ASD will show different traits and mannerisms, and as each person with autism is an individual, how you adapt to them must be individualized as well.

Who it Effects:

Autism spectrum disorders affect people of all ages, genders, races, nationalities, income levels, social statuses, lifestyles, cultures and ethnic backgrounds and have been identified in most countries.

Current Statistics indicate that:

- 1:110 American children (age 8) have an ASD,* based on Autism and Developmental Disability Monitoring Network surveillance (CDC, 2009)
- A large parent-report study found 1:91 American children (age 3-17) are diagnosed with an ASD (Kogan et al, 2009).
- The Autism Society estimates that 1.5 MILLION Americans (all ages) have been diagnosed with an ASD. (Autism Society of America, 2008)
- Increasing at rate of 10-17% per year (Autism Society of America, 2008)

Demographics:

- Affects more males than females, at a ratio of about 4:5 (CDC, 2009). Ratio increases with HFA&AS (even a greater percentage of those affected are males)
- Caucasians are more likely to have an ASD than African-Americans (CDC,2009)
- Non-Hispanics are more likely than Hispanics to have an ASD (CDC, 2009)
- There is no difference in occurrences based on income/social class of the family, nationality or cultural heritage.

*Not all persons with an ASD are not diagnosed by the age of 8, and therefore would not be included. This is particularly true if they are affected by high-functioning autism (HFA) and Asperger's syndrome. Cederlund & Gillberg (2004) found the mean age at time of diagnoses of Asperger's syndrome was 11.3 years of age, while another study placed the mean age of diagnosis for Asperger's at 28 years and HFA at 13.5 years of age (Engstrom et al, 2003).

Causes:

The causes of autistic spectrum disorders are complex and only recently have begun to be researched in earnest.

- A genetic component has been demonstrated, specific genes have yet to be identified (Newschaffer, et al, 2007).
- The heredity model is complex and not understood.

The only known risk factors are an inheritance connection and chromosomal anomaly.

- Siblings of persons diagnosed with an autism spectrum disorder are more likely to be diagnosed with an ASD than the general population (about 1:35). Even though the chance of being affected by an ASD is higher, most siblings are not affected.
- Persons with certain genetic conditions are more likely to be affected by an ASD than the general population. These conditions include fragile X, tuberous sclerosis, Angelman syndrome, duplication of 15q11-q13, Down syndrome, San Filippo syndrome, MECP2 related disorders, phenylketonuria, Smith–Magenis syndrome, 22q13 deletion, adenylosuccinate lyase deficiency, Cohen syndrome, and Smith–Lemli–Opitz syndrome (Cohen et al, 2005).

The Environmental Factor and Vaccination Connection:

- Environmental factors were once thought to be highly responsible for autism. Data does not support this link, although there is much interest as to if a combination of a genetic factor combined with an environmental trigger may cause the onset (Lawler, et al, 2004).
- Vaccinations have also historically been associated with ASD. Multiple studies, including Fombonne, et al (2001), the Institute of Medicine (2004) and others **have concluded quite clearly that vaccinations do not cause autism.**
 - This association was first suggested and popularized by Wakefield et al (1998). The article has since been **fully retracted** by *Lancet* (2010).

There is much misleading, outdated or incorrect information circulating about ASDs, and particularly the causes of ASDs. In Leo Kanner's original description of autism, he infers that parents of children with autism appeared to lack of ability to have affection for another (Kanner, 1943). In the 1960's, psychoanalyst Boris Bettelheim described autism as a reaction to unaffectionate maternal relationships and "cold parenting" styles. Popularity of the "refrigerator mother" theory grew following the release of his 1967 book, *The Empty Fortress: Infantile Autism and the Birth of the Self*. This theory has been disproven and we now know that parents play an essential role in effective treatment and support of the persons affected by autism (Myers et al, 2003) [Much of Bettelheim's work, and his credentials, later was found to be questionable]. The theories that parenting styles caused autism prevailed through the 1960s, and became discredited following the discovery that autism was neurological in etiology, first suggest by Dr. Bernard Rimland in his text, *Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior*, which included a forward by Dr. Leo Kanner (Rimland, 1964). The Autism Society of America (2008) also lists other myths, such as stress, "early life" trauma or traumatic exposures. Autism is not a new name for mental retardation. Mental retardation is a common co-existing condition of persons on the spectrum, but many on the spectrum are NOT mentally retarded.

Co-Existing and Co-Morbid Conditions

Persons diagnosed with an ASD are often affected by one or more co-existing or co-morbid diagnoses. Children with an autism diagnosis have higher reports of concurrent conditions than their non-autistic counterparts, and are more likely to use the services of the health care system (Gurney et al, 2006).

Common Co-Existing Conditions include (partial list):

- Mental retardation is commonly associated with ASDs
 - Remember: 1) Not all with ASD are MR. 2) MR ≠ ASD; ASD ≠ MR. (see pg. 5)
- Epilepsy: Approx. 1/3rd of AD patients have seizures (Danielsson et al, 2005).
- Tic disorders, including Tourette Syndrome
- Attention-deficit-hyperactivity-disorder (ADHD)
- Depression
- Obsessive/compulsive disorder (OCD)
- Aggression
- Self-injurious behaviors
- Mood disorders
- Obesity (42%) Probably due to decreased physical activity (Eaves & Ho, 2008)
- Various other medical, such as sleep disorders and gastrointestinal problems are also reported.

Cures and Management

Currently, there is no cure for autism spectrum disorders, nor can it be prevented.

- The idea of “curing” or “preventing” ASDs can be quite controversial, especially to those who have the condition.
 - Don’t assume that the person with the ASD and their family and/or caregiver shares the same view on curing/preventing autism.
 - EMS events: Best to avoid discussions/debate about cure/prevention, even if your personal opinion is “shared” by the family/caregivers.
- Management aimed at treating the individual’s areas of impairments or deficiencies, increasing the ability to function as independently as possible and improving their overall quality of life.
- Methods - Educational intervention, Family support, Behavioral therapies
- Therapy Focus - Communication, daily living, occupational, recreational and social skills, academic and occupational development and maladaptive behaviors
- Therapies to address any co-existing or co-morbid condition
- Psychiatric care as needed.
- Psychopharmacology
 - Tx features of ASD, not ASD itself. (Examples: aggression, self-injurious behaviors, perseveration, obsession, compulsive behaviors, sleep disturbances, mood stabilization, anxiety, hyperactivity, irritability, inattention and destructive or disruptive behaviors)
 - Depends on several factors; not always indicated.
 - Approximately 45% of children and adolescents and up to 75% of adults

Common medications include:

- Alpha-2 agonists
 - clonidine (Catapres)
 - guanfacine (Tenex)
 - atomoxetine (Strattera)
- Anticonvulsant mood stabilizers
 - levetiracetam (Keppra)
 - topiramate (Topamax)
 - valproic acid (Depakene)
- Antihistamines
 - diphenhydramine (Benadryl)
 - hydroxyzine (Atarax, Vistaril)
- Atypical antipsychotic agents
 - risperidone (Risperdal)
 - aripiprazole (Abilify)
 - olanzapine (Zyprexa)
 - quetiapine (Seroquel)
- Beta blockers
 - propranolol (Inderal)
 - nadolol (Corgard)
- metoprolol (Toprol XL, Lopressor)
- NSRI
 - venlafaxine (Effexor)
- SSRI's
 - fluoxetine (Prozac)
 - fluvoxamine (Luvox)
 - citalopram (Celexa)
 - escitalopram (Lexapro)
 - paroxetine (Paxil)
 - sertraline (Zoloft)
- Stimulants
 - methylphenidate (Ritalin)
 - dextroamphetamine (Dextrostat)
 - amphetamine salt combos (Adderall)
- Others
 - Melatonin
 - ramelteon (Rozerem)
 - mirtazapine (Remeron)
 - buspirone (Buspar)

Prognosis

Autism spectrum disorders are life-long conditions and those diagnosed will generally require chronic support, therapy and management of the condition. Cederlund, et al (2008) found that 26% of individuals diagnosed with Asperger's syndrome in childhood / young adulthood had very restricted lives in later life, with no occupation or friends. Even so, persons with Asperger's fared much better than those with autistic disorder. Eaves and Ho (2008) also reported that based on work, friendship and independence, 46% of persons diagnosed with an ASD in childhood had a poor outcome in early adulthood.

The fact that ASDs cannot be cured and the prognosis is generally viewed as dismal does not mean that an individual with autism cannot succeed in life. There is a significant population of persons who are on the spectrum that have completed college, have post-graduate degrees, live independently, have families of their own and maintain successful careers.

Community

People with autism spectrum disorders may be found anywhere in the community. The extent of their restriction in a community depends on the severity of the disability, co-existing conditions and their individual personality. As the age range for autism and an individual's preferences, needs and abilities vary greatly, so does where you will encounter a person with autism in the community. Here are some examples:

Schools and Education

- Mainstream schools and classrooms, independent or with limited accommodation
- Mainstream schools and classrooms with more extensive accommodations, including TSS or aide.
- Program/classroom in mainstream school not specifically designed for ASD (life support, emotional support programs, etc.)
- Autism program or classroom, with or without incorporation into mainstream classes (may be in mainstream school or remote location)
- Specialized schools, may or may not be specific to ASDs.
- Colleges and Universities
 - Technical, 2 year, 4 year, post graduate programs
 - Commute or live on campus
 - Accommodations and supports vary, many times may be somewhat transparent.

Workplaces

- Many people with ASD qualify as disabled and are unable to work or are unable to be self sufficient from work.
- Others are able to enter workforce:
 - Independently with no additional supervision, considerable accommodation or significant supports.
 - Independently with increased supervision. Often some accommodations/supports made.
 - With direct supervision, job coach or other employment aide.
- Employers – Vary greatly from specialized employment programs that make placements to employers to the corner grocery and community based businesses to major corporations.
- Jobs/Careers – Frequently employed in basic jobs, but some may be proficient and excel in their career field.

Transportation

- Some people with ASDs drive, many do not.
- Mass Transit – buses, commuter trains/light rails
- Community based transportation services, including “share-a-ride” programs
- Private vehicles of other individuals, or of where they live / work.
- Distance and Recreational Traveling – all typical forms of transportation (car, bus, train, air, boat)
- School Transportation:
 - Mainstream school buses
 - Limited route buses, vans or cars
 - Private vehicles, walking

Residency

- Live at home with relatives (parents, siblings, etc.) = most common
 - Various in-home and out-of-home supports may be used.
 - Family members usually primary caregivers.
 - Other caregivers include childcare, aides, case workers, mobile therapists, etc.
 - Additional supports may include partial hospitalization and similar programs
- Acute-Care Psychiatric Hospitals
- Residential treatment facilities (RTF) [School options may include on-site and off-site schools]
- Adults with ASD's (placement very limited)
 - Group homes
 - Specialized or semi-specialized assisted living/personal care facilities
 - Supervised and limited-supervision apartment programs
 - Skilled nursing facilities, particularly for geriatric population (may or may not be diagnosed).
- Adults may also live (may have limited or no supports):
 - With roommates
 - Alone
 - With a spouse or domestic partner
 - With their children

Recreation, Public Outings and Other Activities

Individuals with autism are normally not confined to specific settings by their disability. They can join the rest of the community in normal activities, such as shopping, going to the movies, eating out or enjoying a day at the park. It should not be unexpected to see a person on the spectrum at a pool or lake, an amusement park or even the community park. They may blend in to the crowd quite well unless a crisis emerges, or may seem somewhat "aloof" (which was a term used to describe autism by Dr. Kanner, who first identified the disability). Depending on the age of the person, the extent of their disability and their individual ability to be independent, the person with an ASD may be alone, accompanied by family/caregivers, with friends/relatives, on an "outing" with a therapist or case manager, in a group (such as a school group) or accompanied by peers/friends.

Section Two: Features of ASDs

Asperger's Syndrome, PDD-NOS and Autistic Disorder

Since autism spectrum disorders are a combination of three separate diagnoses, the presentation of the disorder varies across the spectrum. EMS practitioners should have a general understanding of how each specific diagnosis will present. Here is a basic description of each specific diagnosis.

Asperger's Syndrome

- Poor social skills and interaction
- Lack of insight
- Narrow range of interests
- Behavioral inflexibility
- IQ > 70 (note – not always able to obtain accurate test results)
- No speech delay
- Poor motor coordination / clumsy

Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)

- Generally less severe than A.D.; may be less or more severe than A.S.
- Components from all 3 portions of the triad
- Does not meet specific criteria for diagnosis of A.D. or A.S.

Autistic Disorder – “Classic Autism”

- Social and empathy deficits
- Language deficits
- Cognitively inflexible
- Speech delays / deficits

Note: Sometimes Rett Disorder and Childhood Disintegrative Disorder (CDD) are included as an ASD. They are more properly described in the “grouping” of pervasive developmental disabilities (PDD), which also include the three ASDs. This material does not specifically address Rett Disorder or CDD.

Features of Autism Spectrum Disorders

“Features” is used to describe an individual or set of behaviors, conditions, physical characteristics or traits of an individual which can be attributed to a disability. Below are several common features of autism. Most people with an ASD will present with some of these features. Not every feature is listed. The number of features an individual with autism has will vary greatly. It is important to note that most neurotypical people will also have some of these features from time to time.

General Features

- Ordering and Arranging - the methodical arrangement of items, usually in a line or specific pattern of arrangement (large to small, short to tall, etc.).
- Wandering - Also described as “lost,” “running” or “elopement.” The person with an ASD who is “wandering” may not consider himself or herself “lost” and most likely will not seek assistance (including a young child who has been separated from their parent or caregiver). He/she may be perfectly content doing so for no particular reason (like Forrest Gump when he began running) or might be seeking a favorite place or activity.
- Affinity for Water – People with an ASD, and in particular those with autistic disorder, tend to have a strong affinity for water regardless of their ability to swim or survive in water. Drowning is a leading cause of death among both adults and children with autism. Consider ALL water features during searches, both public and private: fountains (including coin fountains), wells (including wishing wells with water), ponds, lakes, streams, creeks, rivers (including natural, utilitarian and decorative), pools (including pools enclosed in buildings and fenced yards), spas and hot tubs. Check water sources that have been covered, are no longer in service, locked up or otherwise not commonly used or accessible.
- Running in & out of traffic – often with blatant disregard for safety. May be due to perceptual issues (unable to tell traffic is standing still or moving).
- Climbing / Acts of Balancing / Jumping – In & out of trees or windows or even on the outside of building. May not have regards for their height or safety. May “balance” on edge of walls and roofs, window ledges, bridges, utility towers and similar structures. May jump with no purpose, no motive and without regards to how far they are jumping or the likelihood of injury from jumping (may be perceptual).

Personality

- May be very flat, appearing to have no sense of humor and may have a very literal perception of what you say.
- May not be able to recognize patterns of speech, such as joking, sarcasm, humor, slang and teasing.
- Brutally honest, blunt and tactless.
- Little concern about social norms and little understanding of appropriateness
- Great difficulty respecting others opinions, interests or ideas.
- Frequently will be argumentative, stubborn and belligerent, even over very minor issues.
- Not interested in the perception or opinion of others.

Communication Features

One of the hallmarks of all Autism Spectrum Disorders is communication impairment. We most often associate spoken and written language with the word “communication.” However, there is more to communication than just words. In addition to language skills, we use tone inflection, phrasing, and speech patterns as forms of verbal communication. We also use non-verbal communication, including “body language,” gesturing, pointing, waving and eye contact. One’s behavior is also a method of non-verbal communication, often driven by the subconscious. Although communication is impaired in people with autism, it is not absent and the extent of the impairment varies significantly from person to person.

- Approximately 25-30% of those with some form of autism will stop speaking, usually between 15-24 months of age (Johnson et al 2007). Turner et al (2006) found 22% of persons with ASDs who stopped speaking remained non-verbal at age 9. In other cases, persons with ASDs may never begin speaking, their speech may develop late, their speech progress may be very slow to develop or speech progress is otherwise abnormal or irregular.

Spoken Language Features

- May answer all questions “no” or “why” incessantly (age inappropriate)
- Echolalia (“parroting”). Echolalia is when someone repeats something that they hear, exactly as they hear it; it may be immediate or delayed hours, days, weeks, even months or years. Includes parroting other people, television commercials, movie lines, songs, etc.
- Speech will often speak in a passive, monotone voice or speak with inappropriate volumes; they may have unusual inflections in their voice and mispronounce words, sounding like they are trying to talk like a computer at times.
- Patterns of speech and literal perception – May have difficulty distinguishing sarcasm, humor, joking, cynical statements, etc., even when it seems “obvious.” May not recognize the use of voice inflections to communicate emotions, such as anger or disgust. May not be able to effectively use these patterns of speech. (See Also-Personality Discussion)
- Difficulty distinguishing questions from statements. The individual may try to answer a statement or rhetorical question or may react to a question as if it were a statement or order.
- Difficulty in recognizing or repairing a breakdown in communication.
- May have difficulty in asking for clarification if something is not understood. May acknowledge understanding even if he or she is unclear of what is being asked or he/she is unable to comprehend the subject at hand.
- Difficulty clarifying their statements: If you ask the individual to clarify something that he or she says, the individual may repeat the thought exactly as it was expressed the first time. The individual may become frustrated by requests to rephrase what he says, because the thought is clear to him, and may infer that either the request or the person making the request is stupid.

It is also important to note that even when spoken communication is either absent or significantly impaired, it does not mean that the person with autism is incapable of understanding or expressing their thoughts using language skills. In fact, some people

with autism who have very restricted verbal abilities are able to use language skills very effectively, with a great deal of thought, insight and even eloquence through the written word or the use of sign language.

Non-Verbal Communication Features

Albert Mehrabian (1981) describes that, in specific situations, communication can be described by the “7-38-55” rule (7% language, 38% speech patterns, 55% facial expressions). This rule is limited to very specific situations and does not take in to account how much communication is other body language, but it is a good example of how much communication is based on other factors and not simply words.

Non-verbal communication includes:

- Body Language
- Facial Expressions
- Voice Inflections
- Pointing
- Gesturing
- Waiving
- Stances
- Eye Contact

- It is likely that the individual with autism will not be able to interpret or even be aware of non-verbal forms of communication.
- The person with autism often will not use usual non-verbal forms of communication or use non-verbal communication poorly, inappropriately or inconsistently with the message they are trying to send.

To aide communication, the person with an ASD may use certain tools to help them communicate, whether or not they have verbal language ability:

- Sign language
- Picture cards
- Electronic devices
- Computers

They may present an identification card or medical alerting jewelry to make you aware of their communication impairments and disability.

Other Considerations about Non-Verbal Communication:

- Mostly learned by experience and not formally taught.
- When cultures change, the “rules” of non-verbal communication change as well. (For example, a “thumbs up” in our culture is a signal of approval; while in the Middle Eastern culture, it is the crudest of insults).

Interaction with People and Authorities

- Difficulty judging personal space. May need more personal space than is typical. May not be able to judge your personal space - may not respect your wishes to increase your space, particularly if you are vague in your request. Unlikely to “yield” personal space to medical professionals trying to do an assessment.
- When approached, may move or run away. May not respond to commands to “stop,” even when made by police or uniformed personnel.
- May not recognize public safety personnel, understand our roles or know what public safety personnel’s expectations are.
- They may assume that anyone in a uniform is a public safety agent, even if they are a parking attendant or janitor. He or she may not know where to seek help or may avoid seeking help.
- When dealing with public safety personnel, persons with ASD may not be able to provide essential information (name, address, etc.) or answer your questions.
- May appear as if they are not paying attention or are uninterested (“being a poor listener” or “off in their own world”). Many times they are attentive to the speaker and are actively listening. (Don’t assume they are not listening)
- Many people with an ASD have good receptive language skills, even if they have poor or no expressive language skills. (Don’t assume they don’t understand!)
- Usually have great deal of difficulty eye contact. (The part of the brain that senses threat and fear is stimulated when a person with an ASD perceives facial features and eye contact and causes a sensation of fear and anxiety, regardless of the situation or facial expression and even if the person observed is a close family member or caregiver)
- Perseveration is very common. Focuses on a specific topic or subject that they select because it holds an interest for them, which may or may not be related to the “business at hand” and cannot be redirected, regardless of the importance or urgency.

Stereotypy

- Definition: frequent repetition of the same posture, movement, or form of speech.
- Most frequent in ASD: rocking back and forth, flapping their hands and arms, repeating a favorite phrase over and over, spinning or spinning objects or orderly arranging of objects including lining objects up.
- One function of stereotypy may be Self-Stimulatory Behaviors (SSB)
 - Referred to as “stimming”
 - Sensory stimulation in response to hypersensory or hyposensory issues.
- Stereotypy and SSB not exclusive to ASDs, “mild” stereotypy common even in general population and other species.

Routines

- Strong preference for the expected and predictable. Rigid routines and schedules that are adhered to with precision.
- The routines may be quite complex and well defined; often transparent to those who do not know the individual.
- May be purposeful in nature
- Disruption of routine likely will result in a great deal of stress and frustration. Even minor interruptions in their routine may be a “big deal” (Inability to adapt and overcome)

Preference for the Same

- Strong preference for the predictable and can be expected.
- Change, particularly unexpected change, can cause a level of fear, frustration, anxiety and stress that is not well understood by most neurotypical people. (Even small change)
- Much of this may be due to their perceptual difficulties.
- May deal with big change better than small change.

Section Three: Autism Spectrum Disorders and Emergency Medical Services

Why Is EMS Called for a Person with an ASD

1. EMS may be called to assist a person who is either having a medical emergency or who sustained an injury, and the patient has an autism spectrum disorder.
 - Persons with autism are subject to the same basic health care needs as everyone else. (Meyers, et. al. 2007) EMS may encounter the patient primarily due to a “common” emergency such as asthma, diabetes or vomiting.
 - Injuries occur more commonly in persons with ASDs than the general public, specifically: fractures, TBI, other head/face/neck injuries, injuries to the upper body, open wounds and burns. (McDermott, et al, 2008)
 - Persons with autism frequently have co-morbid and co-existing medical conditions, such as seizure disorders, that may be the primary reason EMS is summoned.
2. EMS may be called for a person acting “weird,” “impaired,” “drunk,” “high” or “psychotic.” This is often the result of a 3rd party call to the PSAP. It may begin as a police incident.
3. EMS may be called for an **escalated** situation. In these cases, the behavior of the person with the ASD has exceeded the family member’s or caregiver’s ability to effectively intervene. *Escalation crisis is discussed in detail later.
4. Access to Healthcare:
 - Large number of persons with ASD are children and adolescents
 - Pediatric mental health emergencies constitute a large/growing segment of pediatric emergency care (Pediatric Mental Health in EMS, 2006)
 - A substantial number of these patient make their first connection to treatment through EMS (Hoyle & White, 2003)

EMS may also be requested by law enforcement agencies. There are several reasons officers may become involved with a person with an ASD. The most common include:

- Lost Person:
 - The person with the ASD probably does not consider themselves lost, especially if they wandered from a controlled space (home, school, etc.).
 - Likely will not seek assistance.
 - May be perfectly happy wandering for no reason whatsoever.
 - May be seeking a place of comfort or happiness, even if walking is an impractical method to get to it.
 - May act on impulse – They may find a porch along the way a comfortable place to sit, may join a strange family unexpectedly for dinner because they are hungry.
 - Extra attention to natural and man-made water features of all types must be given in all searches. See “General Features”, page 11.
 - Searchers must also bear in mind that the person with ASD is likely to engage in “dangerous behaviors,” such as acts of balancing, climbing and jumping; searching roof tops, building walls, towers, trees, etc. is essential. See “At-Risk Behaviors/Dangerous Activities” below and “General Features”, page 11.
- Suspected Abuse/Abduction/Neglect (usually 3rd person call to police):
 - Parent/caregiver may be using “appropriate” methods to deal with escalation/meltdown that may be perceived as abuse by bystander.
 - In the process of removing a child or person with autism during escalation/meltdown, the behavior exhibited may appear as if the child/person is being abducted.
 - Parent/caregiver may appear as if they are not addressing behavioral concerns (neglect), although this may be an “appropriate” method for the individual.
 - Homes/rooms may be barren (mattress on floor w/o sheets/blanket, no furnishings) to prevent self-injury; bars on windows, multiple/complex locks on exterior doors & locks on outside of bedroom doors, doors barricaded to prevent elopement.
- At-Risk Behaviors/Dangerous Activities
 - Running in & out of traffic. Climbing in & out of trees or windows, on the outside of building, on utility towers and similar structures. May “balance” on edge of walls and roofs, window ledges and bridges. May jump from heights recklessly. Often done with blatant disregard for safety, height, or risk of injury. Intentions of suicide or a purposeful reason for activity may be missing.
 - Heavy pressure may be perceived as comfortable or a pleasant stimulus. May “hide” in dangerous places such as in between mattresses and in trash dumpsters seeking this sensation.
- Self Injurious behaviors: Examples include running full-speed into walls, head-banging, striking self repeatedly with heavy objects. May occur during escalation and other times. Police may be called by family/caregiver during escalation, 3rd party witnessing event or 3rd party suspecting person may be being abused.
- Inappropriate Presence or Activity
 - Ordering – such as a person with autism rearranging store shelves.
 - Suspicious Presences – an older teen/adult person with autism alone at a playground utilizing the playground equipment. May or may not approach children at the playground seeking to make friends or find a playmate.
 - Following/“Stalking” – the person with autism begins following another person without mutual interest. May or may not approach the person. May follow the person into unacceptable locations (such as their home).
 - Police may also be called when a person with autism appears to be “peeping” into other’s homes.

Recognizing Autism

When dealing with a person who has an autism spectrum disorder, you will need to change your usual approach and your assessment and treatment strategies and priorities may be quite different. Therefore, it is important for EMS practitioners to identify patients who may have an ASD.

1. Direct disclosure of information – The person, their family, a caregiver or knowledgeable bystander tells you about the ASD. Sometimes this information will be revealed to you voluntarily. Other times, it will not be provided unless you ask. However:
 - Patient/Family/Caregiver may choose to withhold dx of ASD (this is their right);
 - Patient may not have been diagnosed with an ASD;
 - Patient may not be able to communicate this information due to disability and no one else is able or available to provide diagnosis.
2. Indirect disclosure of information – This is a physical object that you see that will lead you to believe that your patient may be on the Spectrum. Does not require person to communicate or have family/caregiver present. Examples include:
 - On the Person: Med-info jewelry (necklace, bracelet, shoelace), non-permanent tattoos, identification cards (carried, worn or sewn in clothing). Social-cause bracelets/jewelry may be worn by the autistic person but also those who support autism awareness. Autism/Asperger's Pride clothing (T-Shirts, etc.)
 - Vehicles: Specific alerting stickers/decals on vehicle ("Autistic Person Inside," etc). Non-specific alerting stickers/decals on vehicle/carseats ("We Have A Little Emergency") – not specific to ASD/disabilities, but may be indicated. Check glove compartment, back of carseats, visors, map pockets for possible information about occupants, particularly when alerting stickers are present. Social cause stickers/decals/magnets/license plates – may or may not indicate presence of person with autism.
 - Residences: Stickers/decals on residence's doors/windows. May be specific to autism or may be rather generic ("Tot Finder," "Disabled Person," "Red Ball"). Patient info in "file/vial of life," posted on refrigerator.

Note that:

- Practitioners need to locate jewelry, ID cards, tattoos, file of life info, info on carseats.
- Stickers/decals do not usually identify who is affected by ASD, even if specific to autism. The person with the ASD may or may not be an occupant or the patient. The person with the ASD is not always a child in the car.
- "Pride" clothing usually very reliable, but only when worn.
- Also see the bullet points under "Direct disclosure of information" above.

3. Your Impression – The presenting situation, observation of the person involved, information from interviewing the patient/family/caregiver/bystanders, or other findings lead you to believe that autism may be a concern, but information about a diagnosis is not otherwise disclosed to you.
 - Keep an open mind – Autism may affect any patient. Increased suspicion when/if:
 - You find “clues”, such as those discussed under “indirect disclosure of information,”
 - The patient is not responding appropriately to your normal approach,
 - You note that something is “just not right” with the patient, or
 - The patient appears to have a mental illness but is not diagnosed with one.
 - Consider the presenting situation, dispatch information, history of events.
 - You see features of ASDs in your patient. Be aware and look for features of ASDs, but remember that many features are not exclusive to ASDs. Most neurotypical people exhibit some of the typical features of autism from time-to-time.

Important Points to Remember About Identifying ASDs:

1. **The person with an ASD will behave as a person with an ASD behaves, whether the person with the ASD has been diagnosed with an ASD or not.** It is possible, if not probable, that you will encounter patients who *should* have been diagnosed with an ASD or who *has* been diagnosed but you are not made aware of the diagnosis.
 2. **It is not your job to *diagnose* an autism spectrum disorder.** The goal of identification of an ASD is to form a working impression, that will lead you to use more appropriate assessment/treatment strategies.
 3. **You must also always consider that there is a medical reason for the behavior, especially if there is no disclosure of an ASD, as serious and even life-threatening conditions (such as stroke, brain injury, seizures and hypoglycemia) may result in similar behaviors. DO NOT IGNORE LIFE-THREATS just because your patient has autism or you suspect they do.**
4. In general: If you suspect a person has an ASD, consider using the assessment/treatment strategies (as they apply) outlined later.
 - a. If the person is not autistic, using the autism assessment/treatment strategies may be a bit rudimentary but will not be harmful.
 - b. If the person is autistic and you are using a “normal” approach, the patient encounter may deteriorate quickly and the patient may escalate due to stress.
 - c. If you begin using ASD strategies and determine the patient doesn’t require them, it is easier to go back to your usual approach than to change from your usual approach to an “autism approach” once things deteriorate.

Section Four: Stress, Escalation and Autism

Escalation

“Escalation” is the term that is used to describe an involuntary increase in tantrum-*like* behaviors that include screaming, swearing, stomping, throwing objects, hitting and/or kicking (people or objects), pushing and biting, usually as a response to one or more stressors (MPCTC, 2001). Escalation may include increased self-injurious behaviors, such as running into walls at full speed, head-banging and striking oneself with a heavy object. As escalation increases, it is also sometimes referred to as a “meltdown.”

Managing escalation is one of the most important aspects of dealing with a person with autism.

Key Points About Escalation:

- **“They just want circumstances to change, but do not know how to implement that change”** (Debbaudt/Rothman, 2001)
- During escalation, **they do not understand or comprehend the implications of their behavior** or how their behavior and actions affects others.
- The behavior is an automatic “reflex” response to stressors. **They do not “choose” their behavior.** During escalation, they may know they are out of control, but don’t know how to regain control.
- More Stressors (quality and quantity) = Faster Escalation
- **ALL emergencies cause stress!**

Additional notes about escalation:

- Escalation is a process that begins before you see it and ends after the tantrum behaviors end. Just because the person with an ASD is not actively aggressive does not mean they are not “building up.” Likewise, just because they are calm after the fact, doesn’t mean they won’t flair up again.
- Sometimes the meltdown will appear as “light-switch” behavior: It begins nearly instantaneously, continues for a defined duration, and ends abruptly, seemingly without reason.
- Don’t dismiss or underestimate the seriousness of an escalation crisis when you arrive and find everyone is calm.
 - The family/caregiver might have regained control and no longer needs your assistance;
 - The particular crisis was a sentinel event, and although the individual is calm now, they still may require intervention/evaluation.

Autistic Escalation and Meltdown vs. Temper Tantrum

The escalation and meltdown behavior shares some attributes of a “temper tantrum,” but they are different actions.

1. Temper Tantrums

- Age: Typically about 1 to 5 years of age.
- Root Cause: Attempt by the child to control a situation or to “get their way.” May also be due to “crankiness” (being tired, hungry, sick, etc.)
- Manipulative behavior requires an audience to be actively engaged.
 - If the audience is fully removed, the tantrum may stop. (Example: 3 year old who screams & yells about being left with the babysitter while Mom is still there and is completely calm and content 2 minutes after Mom drives out of sight).
 - Usually the child will pause the tantrum periodically to check to see if the intended audience is still engaged.
- May be resolved by:
 - The audience is removed or the child is otherwise unable to manipulate the audience.
 - Offering an alternative (the child may even suspend the tantrum while the alternative is introduced and the child “weighs their options”)
 - The goal is met (they get what they want)
 - Threats of punishment/consequences
- Actions during tantrum may appear reckless, but the child will take “precautions” to avoid injury or damaging treasured possessions. Unexpected injury or damage usually results in the child being startled.

2. Escalation/Meltdown

- Age: No restrictions (children, adolescents, adults)
- Root Cause: Being overstressed, overstimulated or overwhelmed. It may be due to a cognitive or sensory overload, excessive demands, disruption of routine or an unexpected situation.
- May begin as a temper tantrum but develops into a meltdown when individual is overstimulated from the tantrum itself.
- Is not a manipulative behavior. Therefore:
 - Behavior will continue with or without an audience.
 - The individual will not assess engagement.
 - There is no goal to achieve. (Even if event started as a tantrum, achieving the original goal will not thwart a meltdown)
- Threats of disciplinary action will not be comprehended and may “feed” the meltdown.
- Personal safety is compromised – actions are reckless and without control:
 - Injury is possible, and in some cases, likely.
 - Fatigue and compromised sensory systems increase risk of injury.
 - Even if injured, the meltdown is likely to continue, and may even escalate.
 - Favored objects may be abused even though damage is inevitable. Unlikely to realize damage they have done.
- **During a meltdown, the person is out of control and may need your help to regain control.**

Causes of Escalation Behavior

Fear, frustration, confusion, stress and anxiety are the “seeds” of escalation. Meltdown behavior is to be expected as a response these conditions. We will refer to them collectively as “stressors”.

Major Common Stressors Include:

- New or unfamiliar situations
- Changes in routine
- Interruption or impairment of stereotypy behaviors
- Changes to what is expected or “the sameness”
- The inability to “fix” what’s causing the increased stress
- Sensory or emotional overstimulation.

Coping Skills:

People with autism don’t have great coping skills, but they do have some strategies that they are able to use. These coping skills may appear awkward or inappropriate to us.

- Attempting to “correct” the problem.
- Increasing stereotypy behavior
- Avoidance/Persistence
- Distraction (this is not commonly self-directed)
- “Running” or “Fleeing”
- Escalation/Meltdown (failure of other coping devices)

Escalation Management

General Principles:

1. Safety First! Your safety → Bystander safety → Patient safety.
2. Approach quietly – No lights/siren, turn down/off phones, radios, pagers... Remember, people with ASDs may be sensory-sensitive.
3. Clear the Area! Minimize number of responders approaching scene and remove non-essential, non-beneficial bystanders.
4. Utilize knowledgeable sources (family/caregivers), but with care.
5. Never interfere with stereotypy (unless immediate danger)
6. Avoid moving the patient until they de-escalate
 - Unless immediate danger –or–
 - The current location/setting is contributing to the escalation
7. **Calm creates calm**
8. De-Escalation takes time: **BE PATIENT!**

“AUTISM” Approach (Debbaudt, Rothman, 2001)

- A - Approach in quiet, non-threatening manner
- U - Understand touching patient may cause unexpected reaction
- T - Talk in moderate, calm, relaxed voice
- I - Instructions and communications should be simple, specific and direct
- S - Seek indicators to re-evaluate situation
- M - Maintain safe distance

Intervention Strategies

1. Control the situation by using communication techniques (The *T* and *I* of “AUTISM” approach)
2. Utilize geographical containment
3. Consider redirection or use of a distracter:
 - Engaging person in favorite topic or area of interest, unrelated to root cause of escalation.
 - Using a favorite toy, object, interest or activity as a distraction.
4. Verbal restraint techniques:
 - Use short, specific, direct “DO” behaviors. (Example: “Stop”, “Sit Down”)
 - Avoid “DONT” behaviors (Example: Avoid – “Don’t Hit”)
 - Stance/posture, voice inflection, eye contact will have limited or no effectiveness when interacting persons with *ASDs*, *particularly during meltdown*.
5. Restraint (manual and mechanical) **See next section.**
 - Avoid whenever possible; use only if other methods fail, escalation persists or physical injury is likely.
 - Physical altercation will cause a loss of trust between the person with autism and you. It likely will complicate further assessment and treatment.
 - Use only minimum amount of intervention necessary to control situation.
 - When situation is controlled, release restraints (with great caution) and continue using less threatening techniques.

Restraint

Manual Restraint

1. Preferred Technique - Position 1 person on each side of patient, holding upper arms and wrist areas. Another person (or people) may hold lower extremities.
2. Physical Considerations
 - 51% of persons age 2-18 years old with ASD have hypotonia (poor muscle tone) (Ming, et al, 2007).
 - Persons with ASD may have underdeveloped trunk, abdomen and shoulder muscles.
3. Avoid Manually Restraining:
 - In prone position - Hypotonia and underdeveloped muscles may lead to hypoxia, trouble breathing.
 - By crossing arms in front or behind patient – May restrict diaphragm movement in those with hypotonia, leading to respiratory compromise.
4. **Never** use “hard” force to restrain person (such as putting your knee to their chest or using your body to hold the person down).

Mechanical Restraints

1. Principles:
 - Use least restrictive method to get job done (cloth over leather, etc.)
 - **Must** be compliant with protocols.
 - Patient must not be left unattended once restrained.
 - Frequent reassessment of neurovascular status of restrained extremities, respiratory and hemodynamic status of patient.
 - Be alert for underlying medical conditions requiring care (ie, hypoglycemia, seizure, etc.)
 - All agitated, restrained patients are at risk for sudden death from acidosis, excited delirium (agitation, excitability, paranoia, aggression, great strength, numbness to pain), fatal arrhythmias and other causes.
 - Chemical restraint should be considered in addition to mechanical restraint when agitation persists. **See Pages 25, 34**
2. Techniques:
 - Soft restraints (cloth or leather) preferred over hard restraints (steel)
 - 4 point preferred over restraining arms-only.
 - Consider snugly (not tightly) restraining hips, thighs and chest (in order). Use a sheet (not seatbelt-type strap) to tether to the litter.
 - Restraints must be able to be rapidly removed.
3. Contraindicated Techniques:
 - Hobble restraints (“hog-tied”) or restraining in prone position has been associated with sudden death from positional asphyxia during excited delirium (Reay et al, 1992; Stratton et al, 1995).
 - “Sandwich” restraint methods (between 2 backboards, etc.) also associated with resp. compromise, inability to monitor airway/breathing, sudden death.

Law Enforcement Techniques and Considerations:

1. Law Enforcement Devices:
 - Police Restraints – Handcuffs, Leg Irons
 - “Less-Than-Lethal Force” – Irritant sprays and foams (ie: pepper spray, etc.), immobilizing strobe lights, Tazer® guns.
2. Considerations:
 - Law enforcement devices will increase sensory stimulation and may cause the person with ASD to become more combative/aggressive. May not be effective at subduing the escalated ASD patient.
 - Straining against hard restraints may increase risk for sudden death.
See mechanical restraints section, Page 24
 - Deaths can and have occurred after use of less-than-lethal force. Although the device may not solely be responsible for the death, it may be a contributing factor.
3. Conclusion – The use of law enforcement devices to control a person with ASD must be reserved only when there is a clear and present threat to the life of others and other techniques have either failed or cannot be implemented.

Sedation/Chemical Restraint:

- Consider use of benzodiazepine (lorazepam, diazepam), butyrophenones (haloperidol, droperidol), atypical antipsychotics or diphenhydramine for management of severe agitation or aggression, particularly when restrained.
- Medication must be administered in accordance with established protocols, drug formularies and/or medical direction.
- See discussion in Section 5, subsection “medications,” Page 34

Section Five: Assessment and Treatment

Assessment Considerations:

1. The “emergency” may be characteristic of the ASD. (Example – escalation)
2. ASD characteristics may mask a true emergency
 - Signs/symptoms are written-off by family/caregivers as being characteristic of the ASD, although they actually due to a medical condition (hypoglycemia, head injury, stroke, etc.)
 - **Never** assume changes in patient’s behavior is due exclusively to the ASD
3. May not perceive sensory impulse typically
 - Unrecognized “alerting” pain (hyposensitivity to pain, inability to detect symptoms)
 - Heightened sensory perception may cause frequent requests for assistance for relatively minor conditions that the patient believes is severe/life-threatening. (Repetition of these experience may lull family/caregivers/medical personnel into false complacency, causing serious conditions to easily be missed [similar to “crying wolf”])
4. May not be able to clearly state a health problem or describe signs/symptoms typically expected regardless of verbal abilities (Morton-Cooper, 2004).
 - Notbohm (2005): Behavior is communication and all behavior occurs for a reason.
 - Owley (2004): Negative behavior may be an attempt to communicate a medical problem, such as an ear infection, a sore throat or other pain/discomfort.
 - Humming, singing, removing clothes may be response to pain (Rzucidlo, 2007)
5. Patient may choose “comfort” over “care” despite seriousness of condition. (Desire to avoid interruption in daily routines, attraction to favorite activity) Example – Playing video games instead of seeking help for a broken leg.
6. Things may not always be as they first appear

Assessment and Treatment – Setting the Stage (Morton-Cooper, 1994)

1. Provide safe environment

- Patient will already be stressed due to whatever the reason was that EMS was called (injury, medical, other)
- If the patient is in a familiar and/or safe/comfortable environment:
 - Moving the patient to the ambulance will likely increase stress
 - Maintaining the patient in “their” environment while assessment is completed and treatment is started gives the patient a sense of control and safety. It may not reduce stressors that are present, but it will not add more.
 - Is the patient’s condition severe enough to warrant rapidly extricating patient to ambulance and increasing the patient’s stress levels?
- If the patient is in an over-stressed environment:
 - Relocating patient to a place where the patient can be comfortable is preferred
 - If such a location is not available, the ambulance may be an alternative
- One familiar and knowledgeable caregiver/family member should remain with the patient
- Remove unneeded bystanders, **including personnel**
 - Support personnel (police, additional crews) should stage away from assessment/treatment area, but close enough to monitor the situation (especially if escalation is a concern)
 - Loud talking / shenanigans by support personnel may cause significantly increased stress to the patient and may cause the situation to deteriorate (whether or not in view of the patient).
 - Too many caregivers –or- caregivers that cannot provide support to the situation may hinder your attempts to help the patient.
- Allow patient to “explore” new surroundings
 - Moving the patient into the ambulance or into the ED.
 - Patients may experience anxiety from not knowing what is behind closed doors and cabinets.
 - With supervision, allowing the patient to explore these areas (if they want) may help alleviate some anxiety. Allow them to open cabinets and doors and examine the contents.
 - Weigh the time taken to allow exploration vs. the criticalness of the patient’s condition. (Not your attempt to get lunch or your boss’s next transport!)

2. Pay attention to all sensory inputs

- Sight
 - Avoid bright light / flashing lights / strobes, etc.
 - Certain colors and complex designs may cause unexpected reactions. Neutral/solid colors are preferred. (Check your stethoscope cozy)
 - Certain patients with an ASD may perceive threat based on physical characteristics (skin, hair color, sex, glasses, etc.).
 - DO NOT be offended by such sensitivities – it is not the same as a racist or sexist
 - Attempt to appease the patient's idiosyncrasy whenever possible
 - Use non-threatening and relaxed stance, calm/controlled appearance; avoid sudden/rapid/unexpected movements, minimize gesturing. Do not assume the patient with ASD will be able to interpret body language
- Sound
 - Avoid loud noises
 - Background noise can be very distracting. Even minimal background noise may be "heard" by the patient as clearly as foreground noise.
 - NEVER talk (or allow others to talk) "behind the patient's back" even if you are not in eyesight or the patient is non-verbal. NEVER use terms such as "retarded" or "stupid."
- Smell
 - Unfamiliar or unexpected odors may cause overstimulation, even if the odor is not strong. Odors perceived as strong by those with ASD may not be noticeable to most others.
 - Examples may include perfumes and colognes, tobacco smoke (even on clothing)
- Touch
 - Avoid invasion of the patient's personal space
 - Patient may not be able to distinguish "friendly" touch (pat on the shoulder) from "hostile" touch (being struck/hit)
 - Different pain thresholds: A pinprick may feel like their arm is being broken or the patient may be oblivious to something that would normally cause great pain, such as a broken arm. Sometimes both extremes are present simultaneously.
 - TOUCH MUST NEVER BE UNEXPECTED! Prepare the patient – and make sure the patient is ready – prior to touching him/her.
- Taste
 - Consideration for oral or SL medications
 - Oral stimulation may be a preferred method of self-stimulation, although may be perceived as "weird." Permit oral "stimming" when appropriate and safe, however be aware the patient may often not choose safe or appropriate oral vices.

3. Maintain clear, structured and organized approach
 - Maintain a calm and relaxed attitude
 - Maintain a professional demeanor, even if the patient does not acknowledge or respect it.
 - Gain knowledge of the patient prior to assessing him/her, when possible (family/caregivers)
 - Order and expectation is comforting to the ASD patient. Conduct assessments in orderly and logical sequence, explain EVERYTHING (even the small stuff) to the patient prior to doing it. Allow time for the patient to process your explanations first.
 - Questions should be simple and clear. Statements and commands should be clear and concise. Avoid slang and ambiguity.
 - Allow caregiver to assist with exam:
 - Provide comfort/support to the patient
 - Rephrasing/paraphrasing your questions/statements in a manner the patient might better understand
 - Interpreting the patient's response / signals
 - Demonstrating procedures you are going to perform (you demonstrate on caregiver and/or caregiver demonstrates on patient)

Communication During Assessment and Treatment:

- Don't acknowledge negative behavior
- Reaffirm good behavior
- Never assume the patient is not listening or doesn't understand.
- Utilize alternative communication methods – PECS (picture exchange card system), etc. (Free downloads at www.autismems.net)
- Short / simple questions
 - Open-ended questions are preferred
 - "Yes-or-No" questions may be answered randomly without reason, or may always be answered affirmatively/negatively.
 - "List" questions (multiple choice) – patient may always answer with the option in a certain position (first answer/last answer) or may choose their answer based on arbitrary factor (such as alphabetically)
 - May answer questions based on what they believe you want to hear. Confirm critical answers by rewording and asking again later.
- Consider literal perception
- If the patient does not perceive a problem, they won't tell you about it. They are generally poor liars and aren't trying to "cover up".
- Be Patient!
 - Allow patient time to answer questions and respond to commands, at least 5-10 seconds.
 - No response after waiting may indicate patient doesn't understand, although they may not be able to verbalize this to you.

Assessing the Patient:

Involve the patient in their care, to the best of their ability.

- Make sure the patient knows:
 - Who you are and why you are there
 - What you are going to do
 - What they might see when you do your assessment (or provide treatment)
 - Who and what else they might see (such as the ambulance, emergency department, doctors, nurses, etc.)
 - Why you are doing what you are doing
- Don't "write-off" patient as being "incapable" of participating in care, despite age, communication barrier or functional level.
- "Guided control" of the situation helps build positive rapport, patient cooperation.
 - Simple example: Allowing patient to let you know that they have had enough time to mentally prepare for a blood pressure check or IV stick
 - Offer choices based on patient's condition and cognitive ability. Choice must be real and you must accept and act on what the patient chooses. (Don't Trick the Patient!)

Assessment and Exam Tips:

- Interview family/caregiver and patient carefully and thoroughly. Seemingly insignificant recent changes in patient's behavior may indicate the onset of symptoms or other clues.
- Allow patient to completely de-escalate before beginning exam, when possible.
- Leaving the patient alone to interview bystanders may be perceived as suspicious and patient may react unexpectedly.
- Pain and discomfort may be felt differently by the ASD patient.
 - If patient feels pain differently than you describe, you risk loss of trust and cooperation. Therefore,
 - Avoid describing things as you perceive it. Be factual and unambiguous. For example, if you are taking a blood pressure:
 - Avoid telling patient "it will not hurt."
 - Tell the patient the cuff "will squeeze your arm tightly."
- Move slowly and deliberately in exam. Prepare for each step. Consider conducting exam distally to proximally.

Caregiver considerations

- Most family members/caregivers will have more than adequate knowledge and/or training about the patient. They likely will know what calming techniques and ways to carry out procedures work and which ones do not work. The family/caregiver may not be able to use the techniques on their own and may rely on your assistance.
- Caution: Caregivers may not be able to provide critical information and may lack training, particularly if they are new to a situation (new setting, new behavior or new patient), the patient has never been diagnosed with an ASD or the family/caregiver disagrees with the ASD diagnosis. *In these cases, it is possible that the family/caregiver will (unintentionally) provide incorrect or inappropriate information.*

Warning signs

- Increased restlessness, anxiousness or agitation may indicate patient is about to escalate. Signs may be subtle and missed by practitioners until it is too late. Family/caregivers may pick up on these “warning signs” earlier. Don’t dismiss their warnings.
- If possible and safe, take a break; allow patient to “regroup.”
- Before leaving, tell patient when you will return. (See below)
- Leave patient with family/caregiver if safe. Continue to monitor situation and patient’s condition.

Consider completing exam in segments

- Tell the patient what you are going to assess, perform the assessment.
- When done with a segment, explain you are taking a break. Tell patient what you will do when you return. Leave the patient with caregiver (if safe). Continue to monitor situation and patient’s condition.
- Do not use as an opportunity to talk about the patient with others.

Procedures

“Procedures” include most any “hands-on” intervention with the patient, including assessment of pulse & blood pressure, application of cardiac monitor, ECG acquisition, IV placement, drawing blood, oxygen administration, splinting and bandaging.

1. Consider targeted questions to the family/caregiver on what methods work best for carrying out procedures on the patient.
 - Usually best for the patient to be well-prepared for the procedure.
 - Some patients do better by “Git’R’Done” method (make preparations out-of-sight; when ready, act quickly leaving as little time as possible for the patient to react)
2. Ensure enough people are available - If the patient is uncooperative, even simple procedures (IV stick, etc.) may require large numbers of people.
3. Weigh benefit vs. risk of performing procedure: Consider deferring if not immediately necessary to treat/assess life-threats.
4. Be ready for the unexpected – Each ASD patient will respond differently. A patient may respond differently to the same procedures, even if all preparations were exactly the same.
5. Patient likely will not tolerate IV’s, dressings, splints, cardiac monitors, etc. well. Patient will likely try to D/C these items. ASD patients are “experts” at getting out of Kling, etc.

Assessment and Treatment Strategies:

These strategies can be used while doing assessment or performing procedures and are adopted from Souders, et al (2002).

Demonstration and Praise Technique

- Examples of Use: Stethoscope use, pulse oximetry, hands-on exam (particularly when done in segments), BP
- Methodology:
 - Demonstrate on toy / caregiver with simple explanation; Praise positive interaction (praise positive compliance with toy/caregiver and positive interaction with patient). Re-demonstrate as needed.
 - Caregiver demonstrates on same procedure on patient with simple explanation; Praise positive interaction. Repeat as needed. NOTE – do NOT acknowledge poor behavior.
 - When patient is comfortable, perform procedure on patient, providing explanation as performed and as caregiver provides support; Praise positive interaction. Do not acknowledge poor behaviors
- Hints:
 - Consider demonstrating with a non-threatening object first, then with the medical instrument.
 - You may need to demonstrate 4-6 times before performing procedure.
 - Allow the patient to explore the medical instrument prior to demonstrating and using it.

Distraction

- May be used for almost all assessments/procedures performed in prehospital setting.
- Methodology: Distract the patient by using...
 - A favorite toy or object
 - Conversation about a favorite interest or topic of the patient.
 - Singing, counting and reciting are calming to many ASD patients. Consider their “stiming” activities.

High-P / Low-P Momentum

- Example for use – Uncomfortable, short procedures, such as blood pressure, pulse-ox, pulse check, 12-lead, etc.
- Methodology
 - Definitions
 - High-P Request: Request the patient is LIKELY to comply with one first request, without further prompting (“point to your nose”, “stand up”, etc.).
 - Low-P Request: Request the patient is UNLIKELY to do.
 - Series 2 or 3 “high-P” requests together with a “low-P” request
 - Praise after each successful “high-P” compliance; extended praise for “low-P” compliance
 - No praise for “low-P” requests when non-compliant
 - Do not acknowledge poor behavior.
 - May combine with reward, distraction, and demonstration/praise
- Hints:
 - “Simon Sez...”
 - Increase praise as difficulty of Low-P requests increase
 - Combine with reward for successful completion of multiple tasks (for example, full procedure). (See reward)

Choices

- Methodology
 - Consider procedures that need to be done (for example, listen to lungs, take blood pressure, check pulse, etc.)
 - Allow the patient to select the procedure you will perform from a list of 3-4 procedures; then perform.
 - Re-order the remaining choices, replacing the procedure you performed with a new choice.
- Hints:
 - Consider using “less desired” choices to “lead” patient into choosing the procedure you need to do. Caution – you must be willing to do the “less desired” choice if selected!
 - Limit use – excessive use may confuse or overstimulate the patient.

Reward

- Methodology
 - Reward is promised to patient for allow a procedure or series of procedures to be performed.
 - Rewards must be chosen carefully (meaningful & purposeful to patient and cannot interfere with future assessment/treatment needs). Reward must be immediately available when the patient meets reward criteria.
 - Administration based on compliance and cooperation, “the spirit of the law” not necessarily “the letter of the law.”
 - Reward is NOT GIVEN if the patient is not cooperative and does not make an honest effort to fulfill their end of the bargain.
 - Clarify any conditions specifically – ASD patients (particularly Asperger’s) may be very opportunistic and manipulative.
 - Consider the length of time the patient can have the reward, the location they can have the reward, when the reward will be given to them and any conditions that would be required to get the reward.
 - Examples: Unless you specify “you can have your toy *while riding in the ambulance*,” the patient might expect it at the hospital. If you tell a patient “you will get (reward) if you ride to the hospital in the ambulance” but you don’t specify an expected behavior (ie, no tantrum), you will have to give the reward even if their behavior was inappropriate.
- Hints:
 - Small rewards for little things, big rewards for bigger accomplishments.
 - Combine with other techniques previously discussed, such as distraction.
 - Consider combining procedures for larger reward

Medications

WARNING: All medications must be given in compliance with established protocol or under medical command!

- Consider sedation for extreme agitation or aggression.
(Preferred route for administration is PO when possible)
 - Benzodiazepines
 - Caution: Watch for paradoxical reaction (increased activity, disinhibition, etc.) with benzodiazepine administration
 - Lorazepam, 0.5mg – 1mg IV/IM/PO
 - Diazepam, 2.5mg – 5mg IV/IM/PO
 - Butyrophenones
 - Haloperidol (Haldol), 0.5-2mg
 - Caution: Possible acute extrapyramidal and dystonic reaction. Consider administration with diphenhydramine, 25mg.
 - Haloperidol and lorazepam combined has synergism effect and is associated with fewer extrapyramidal reactions.
 - Droperidol
 - Caution: Associated with Q-T prolongation and torsades de pointes. (FDA Black Box Warning)
 - Not carried by many EMS systems b/c of this.
 - Atypical Antipsychotics
 - Not carried by most EMS systems.
 - May have longer onset of action.
 - Consideration in premedication for planned transfers.
 - Diphenhydramine (Brice, et al, 2003)
 - Frequently used in air-medical transport (motion illness)
 - Well-tolerated; sedative qualities
 - Medication class: Antihistamine
 - Labeled uses include “insomnia” but do not include “agitation” or “sedation.” May be useful as such, but off-label recommendation
 - Discuss use with medical director/medical command.
- Pain management considerations:
 - Standard dosages of medication for pain control may be ineffective for patients with ASDs.
 - Caution should be exercised in using “outcome-based” pain management, as higher dosing may result in unintentional overdose.
- Other considerations:
 - Patient may have uncommon side effects/adverse reactions or idiopathic sensitivities to routine drugs. Screen drug sensitivities closely before administration of any drug.
 - Patient may be on uncommon medications that may have interaction with drugs given in out-of-hospital setting. Screen medication lists carefully before administration of any drug.

Section Six: Caregiver Emergencies

Caregivers are subject to injury and illness and may need EMS assistance. This may be a result of the person with ASD's actions, but most often is unrelated. However, ensuring continued care and safety of the person with ASD is paramount.

In this discussion "caregiver" includes family members.

Key Point:

A caregiver experiencing an emergency:

- Interferes with the person with ASD's routines and schedules.
- Is unexpected.
- Threatens their "comfort" and "security."

Perceptual Issue

1. The person with ASD may not realize that the caregiver is experiencing an emergency and needs assistance.
2. The person with ASD may perceive rescuers as a threat to the caregiver.
3. The person with ASD may perceive that rescuers are trying to separate or isolate them from the caregiver.

Expected Responses

The person with ASD will likely react inappropriate or unpredictably. The expected response is to expect the unexpected!

They may:

- Isolate themselves
- Run off
- Cause disruption in providing care to the patient (caregiver).
 - Interfering to prevent you from providing care.
 - Clinging to patient. Not intentionally disrupting care, but making treatment difficult.
- Escalation/Meltdown.

Managing the Patient and the Person with ASD

1. You must be able to assess and treat the patient as their condition dictates.
2. Provide clear, concise instructions to the person with ASD when needed.
 - Remember, telling the person with ASD what to "DO" is better than telling them what to "do not."
3. If interested, the person with ASD should be kept in the loop:
 - Don't ignore their concerns or questions.
 - Explain what is happening and why you are doing what you are doing.
4. Additional providers (EMS, police, etc.) may be necessary to support the person with ASD while primary crew is caring for the patient.
 - Must be appropriately trained to deal with the person with ASD.
 - Consider early. Easier to return extra help than to get it when situation deteriorates.

Transporting the Patient

1. If patient's condition allows, wait for a secondary caregiver familiar with the person with autism to arrive.
2. If transport of the patient cannot be delayed:
 - a. Trained responder stays and supports the person with autism in their home until secondary caregiver arrives.
 - b. Person with autism will need to be transported to hospital with the patient.

If the person with autism must be taken to hospital with the patient:

- The person with the ASD must be supported by a trained responder at all times during transport.
- The person with ASD may be prone to unpredictable behaviors during transport. This is especially true if they *perceive* that something is going wrong with the patient.
- The person with ASD must be supported by trained staff at the hospital.
 - Early notification of this need must be communicated to the hospital.
 - Security may be inappropriate companions for the person with ASD!
 - A secondary caregiver is preferred companion.
- Consider taking distracters along for the person with autism (I-Pod, toy, game, book, etc.)
- Options:
 1. Transport the person with autism as a passenger in the ambulance carrying the patient.
 - Patient's condition must be stable, minor and predictable.
 - Adequate support must be available to support the person with autism.
 - Person with autism has established history of predictable behavior under stressful situations.
 2. Transport the person with autism in a second vehicle (supervisor, police, etc.)
 - Crew of two persons usually required – one driver, one to support the person with autism. Driver alone is not adequate to support the person with autism.
 - May react unpredictably (including escalation) if they *perceive* something as wrong (ambulance stops unexpectedly, ambulance transports or doesn't transport with lights/siren on, ambulance changes response mode, etc.)
 - Consider "staggered" transport
 - Take person with autism to hospital before ambulance departs scene. Be prepared to deal with waiting for the ambulance's arrival at the hospital.
 - Leave scene after the ambulance has departed. Leave enough time for ambulance to be out of eyesight.

The ABCs of Autism

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The concept of the “ABCs of Autism” is a mnemonic that describes the basic actions that should be taken by EMS professionals when responding to an emergency involving a patient who has an ASD, and it is applicable in almost every encounter situation, whether it is due to an autistic crisis (escalation and meltdown), a medical emergency or an injury and stand for Awareness, Basic, Calm and Safe (Kelble, 2009). While the information is not discussed in detail here, these concepts can be found throughout the handout. This appendix also serves as a course review.

Awareness:

- ✚ People with ASDs may not behave or react as most patients will. Perceptual, social interaction and communication barriers influence behavior/interaction.
- ✚ EMS providers need to change their approach and strategies to meet the needs of the patient.
- ✚ Disruption of the routines and what is expected is not well tolerated; adaptation is difficult.
- ✚ Escalation/meltdown is an involuntary response to one or more stressors.

Basic:

- ✚ Keep instructions basic: simple, clear, precise. Avoid slang, joking or inference.
- ✚ Keep questions basic: closed-ended questions may be easier to answer. Allow time to answer. May not ask for clarification if they don't understand.
- ✚ Basic=Less stuff: Keep radios, pagers, cell phones, flashlights, etc. off and out of sight. Turn off red lights/siren when approaching & don't use when transporting. Also, watch sensory stimuli from other sources.
- ✚ Keep treatment basic: Avoid performing treatment that isn't absolutely necessary.
- ✚ ***Be aware that pt. may have atypical complaints, high pain thresholds or chose a distraction over getting help. Assess your patient!***

Calm

- ✚ Calm creates calm.
- ✚ Show of force is ineffective deterrent to meltdown; may increase frustration/anxiety/poor behavior.
- ✚ Keep controlled, clear voice.
- ✚ Be empathetic, compassionate and reassuring. Allow the patient to express their concerns.
- ✚ Take the time necessary to assist the patient. That is, “It's there timeline.”

Safe

- ✚ Environment may offer familiarity and security, even if it is not apparent.
- ✚ Assess slowly. Explain each step. Allow for questions and wait until pt. is ready. Take “breaks” as needed. Prepare the patient for what happens next. Consider toe-to-head exam.
- ✚ Avoid explaining things subjectively, as how you (or most people) perceive it. Be concrete.
- ✚ Allow patient to explore new environments, choose their seat, etc.
- ✚ Avoid manual/physical restraint. Only if needed, use appropriate soft restraints.

Notes:

Diagnostic criteria for Autistic Disorder

- A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
- (1) qualitative impairment in social interaction, as manifested by at least two of the following:
 - (a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - (b) failure to develop peer relationships appropriate to developmental level
 - (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 - (d) lack of social or emotional reciprocity
 - (2) qualitative impairments in communication as manifested by at least one of the following:
 - (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
 - (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 - (c) stereotyped and repetitive use of language or idiosyncratic language
 - (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
 - (3) restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
 - (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - (b) apparently inflexible adherence to specific, nonfunctional routines or rituals
 - (c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 - (d) persistent preoccupation with parts of objects
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Diagnostic criteria for Asperger's Disorder

- A. Qualitative impairment in social interaction, as manifested by at least two of the following:
 - (1) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - (2) failure to develop peer relationships appropriate to developmental level
 - (3) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
 - (4) lack of social or emotional reciprocity
- B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
 - (1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - (2) apparently inflexible adherence to specific, nonfunctional routines or rituals
 - (3) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 - (4) persistent preoccupation with parts of objects
- C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
- D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
- E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
- F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism)

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interests, and activities, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes "atypical autism" presentations that do not meet the criteria for Autistic Disorder because of late age at onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

References, Citations and Resources

- American Psychiatric Association, (2000). *Diagnostic and statistical manual (fourth edition), text revision (DSM-IV-TR)*. Washington: American Psychiatric Association.
- Autism Society of America, Autism 101: a free online course. Retrieved May 17, 2008, from Autism Society of America website Web site: http://www.autism-society.org/site/PageServer?pagename=about_course
- Bogdashina, O., (2003). *Sensory perceptual issue in autism and Asperger syndrome: Different sensory experiences – different perceptual worlds*. London: Jessica Kingsley Publishers.
- Brice, J.H., Pirrallo, R.G., Racht, E., Zachariah, B.S., & Krohmer, J. (2003). Management of the violent patient. *Prehospital Emergency Care*. 7(1), 48-55.
- CDC (2006). Mental health in the United States: parental report of diagnosed autism in children aged 4-17 years – United States, 2003-2004. *MMWR*. 55(17), 481-486
- CDC (2007). Prevalence of autism spectrum disorders – autism and developmental disabilities monitoring network, 14 sites, United States, 2002. *MMWR*. 56(SS01), 12-28.
- Cederlund, M., & Gillberg, C. (2004). One hundred males with Asperger's syndrome: a clinical study of background and associated factors. *Developmental Medicine & Child Neurology*. 46, 652-660.
- Cohen D, Pichard N, Tordjman S, Baumann C, Burglen L, Excoffier E, Lazar G, Mazet P, Pinquier C, Verloes A, Heron D. (2005) Specific genetic disorders and autism: Clinical contribution towards their identification. *Journal of Autism & Developmental Disorders*. 35(1), 103-116
- Cunningham, A.B. & Schreibman, L. (2008). Stereotypy in autism: the importance of function. *Research in Autism Spectrum Disorders*. 2, 469-479.
- Dalton, K.M., Nacewicz, B.M., Johnstone, T., Schaefer, H.S., Gernsbacher, M.A., Goldsmith, H.H., Alexanders, A.L., Davidson, R.J. (2005). Gaze fixation and the neural circuitry of face processing in autism. *Nature Neuroscience*. 8(4), 519-526.
- Danielsson, S., Gillberg, I.C., Billstedt, E., Gillberg, C., & Olsson, I. (2005). Epilepsy in young adults with autism: a prospective population-based follow-up study of 120 individuals diagnosed in childhood. *Epilepsia*. 46(6), 918-923.
- Debbaudt, D (2002, Dec 6). A law enforcement handout. Retrieved May 17, 2008, from Avoiding unfortunate situations Web site: <http://policeandautism.cjb.net/handout.html>
- Debbaudt, D. & Rothman, D. (2001). Contact with individuals with autism: effective resolutions. *FBI Law Enforcement Bulletin*. 70(4), 20-24.
- Debbaudt, D., (2002). *Autism, advocates and law enforcement professionals: Recognizing and reducing risk situations for people with autism spectrum disorders*. London: Jessica Kingsley Publishers.
- Eaves, L.C., & Ho, H.H. (2008). Young adult outcome of autistic spectrum disorders. *Journal of Autism and Developmental Disorders*. 38, 739-747
- Engstrom, I., Ekstrom, L., & Emilsson, B. (2003). Psychosocial functioning in a group of Swedish adults with Asperger syndrome or high-functioning autism. *Autism*. 7(1), 99-110.
- Fombonne, E. (2003). Epidemiological surveys of autism and other pervasive developmental disorders: an update. *Journal of Autism and Developmental Disorders*. 33(4), 365-382.
- Fombonne, E., Chakrabarti, S. (2001). No evidence for a new variant of measles-mump-rubella-induced autism. *Pediatrics*. 108(4), e58-e64
- Gillberg, C., & Billstedt, E. (2000). Autism and asperger syndrome: coexistence with other clinical disorders. *Acta Psychiatrica Scandinavica*. 102, 321-330.
- Gurney, J.G., McPheeters, M.L., & Davis, M.M. (2006). Parental report of health conditions and health care use among children with and without autism: National survey of children's health. *Archives of Pediatric and Adolescent Medicine*. 106, 825-830
- Hellemans, H., Colson, K., Verbraeken, C., Vermeiren, R., & Deboutte, D. (2007). Sexual behavior in high-functioning male adolescents and young adults with autism spectrum disorders. *Journal of Autism and Developmental Disabilities*. 37, 260-269.
- Institute of Medicine, (2004). *Immunization safety review: Vaccinations and autism (2004)*. Washington: The National Academies Press.
- Johnson, C. P., Myers, S.M. & the Council on Children with Disabilities (2007). Identification and evaluation of children with autism spectrum disorders. *Pediatrics*. 120(5), 1183-1215.
- Jones, A., Cork, C., & Chowdhury, U. (2006). Autism spectrum disorders. *Community Practitioner*. 79(3), 97-98.
- Kanner L (1943). Autistic disturbances of affective contact. *Nervous Child*. 2, 217-250.
- Kogan, M.D., Blumberg, S.J., Schieve, L.A., et al (2009). Prevalence of Parent-Reported Diagnosis of Autism Spectrum Disorder Among Children in the US, 2007. *Pediatrics*. 124(5), 1395-1403
- Kupas, D.F. & Wydro, G.C. (2002). Patient restraint in emergency medical services systems. *Prehospital Emergency Care*. 6(3), 340-345.
- Lawler, C.P., Croen, L.A., Grether, J.K., & Van de Water, J. (2004). Identifying environmental contributions to autism: provocative clues and false leads. *Mental Retardation and Developmental Disabilities Research Reviews*. 10, 292-302.
- Lovaas, I., Newsom, C., & Hickman, C. (1987). Self-stimulatory behavior and perceptual reinforcement. *Journal of Applied Behavior Analysis*. 20, 45-68.
- Maryland Police & Correctional Training Commission (MPCTC), (2001). *Why law enforcement needs to recognize autism*.
- McDermott, S., Zhou, L., & Mann, J. (2008). Injury treatment among children with autism or pervasive developmental disorder. *Journal of Autism and Developmental Disabilities*. 38, 626-633.
- Ming, X., Brimacombe, M., Chaaban, J., Zimmerman-Bier, B., & Wagner, G.C. (2008). Autism spectrum disorders: concurrent clinical disorders. *Journal of Child Neurology*. 23(1), 6-13.
- Ming, X., Brimacombe, M., Wagner, G.C. (2007). Prevalence of motor impairment in autism spectrum disorders. *Brain & Development*. 29, 565-570.
- Minshew N.J., Hobson, J.A. (2008). Sensory sensitivities and performance on sensory perceptual tasks in high functioning individuals with autism. *Journal of Autism and Developmental Disabilities*. 38, 1485-1498.
- Morton-Cooper, A., (2004). *Health care and the autism spectrum: a guide for health professionals, parents and carers*. London: Jessica Kingsley Publishers.
- Myers S.M., Johnson, C.P. & the Council on Children with Disabilities (2007). Management of children with autism spectrum disorders. *Pediatrics*. 120(5), 1162-1182.

References, Citations and Resources (Continued)

- Newschaffer, C.J., Croen, L.A., Daniels, J., Giarelli, E., Grether, J.K., Levy, S.E., Mandell, D.S., Miller, L.A., Pinto-Martin, J., Reaven, J., Reynolds, A.M., Rice, C.E., Schendel, D., & Windham, G.C. (2007). The epidemiology of autism spectrum disorders. *Annual Review of Public Health*, 28, 235-258.
- Notbohm, E. (2005). Ten things your student with autism wishes you knew. Retrieved Oct. 5, 2008, from The greater Harrisburg chapter of the Autism Society of America: http://autismharrisburg.org/holdarticles/Ten_Things_Your_Student_with_Autism_Wishes_You_Knew_March_2006.pdf
- O'Neill, M. & Jones, R. (1997). Sensory-perceptual abnormalities in autism: a case for more research? *Journal of Autism and Developmental Disabilities*, 27(3), 283-293.
- Realmuto, G.M., & Ruble, L.A. (1999). Sexual behaviors in autism: problems of definition and management. *Journal of Autism and Developmental Disabilities*, 29(2), 121-127.
- Reay, D.T., Flinger, C.L., Stilwell, A.D., & Arnold, J. (1992). Positional asphyxia during law enforcement transport. *The American Journal of Forensic Medicine and Pathology*, 13(2), 90-97.
- Rimland B (1964). *Infantile autism: The syndrome and its implications for a neural theory of behavior*. East Norwalk, CT: Appleton-Century-Crofts.
- Shavelle, R.M., Strauss, D.J., & Pickett, J. (2001). Causes of death in autism. *Journal of Autism and Developmental Disorders*, 31(6), 569-576.
- Stratton, S.J., Rogers, C., & Green, K. (1995). Sudden death in individuals in hobble restraints during paramedic transport. *Annals of Emergency Medicine*, 25(5), 710-712.
- Strote, J. & Hutson, H.R. (2006). Taser use in restraint-related deaths. *Prehospital Emergency Care*, 10(4), 447-450.
- Turner, L.M., Stone, W.L., Pozdol, S.L., & Coonrod, E.E. (2006). Follow-up of children with autism spectrum disorders from age 2 to age 9. *Autism*, 10, 243-265.
- Van Bourgondin, M.E., Reichle, N.C., & Palmer, A. (1997). Sexual behavior in adults with autism. *Journal of Autism and Developmental Disabilities*, 27(2), 113-125.
- Vilke, G.M., Chan, T.C., & Neuman, T. (2003). Patient restraint in EMS. *Prehospital Emergency Care*, 7(3), 417-418.
- Wakefield AJ, Murch SH, Anthony A, Linnell J, Casson DM, Malik M, Berelowitz M, Dhillon AP, Thompson MA, Harvey P, Valentine A, Davies SE, Walker-Smith JA. (1998). Ileal-lymphoid-nodular hyperplasia, non-specific colitis and pervasive developmental disorder in children. *Lancet*. 351, 637-641. (Retracted)
- Yapko, D. (2003). *Understanding autism spectrum disorders: Frequently asked questions*. London: Jessica Kingsley Publishers.

Notes:



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