

Search Management *Autism*

Autistics is one of 41 categories of lost or missing subjects now categorized with statistical information in the book titled *Lost Person Behavior – A Search & Rescue Guide on Where to Look – for Land, Air and Water* by Robert J. Koester, 2008.

This article will highlight a recent study released this year regarding developmental disabilities, a brief review of autism, its inclusion into the categories of lost person behavior and some of the important considerations for search management and searchers when receiving notice of a lost/missing autistic and searching.

In May 2011, it was announced that the CDC's National Center on Birth Defects and Developmental Disabilities had completed a 12 year study using data of children, ages 3-17 to determine the prevalence of developmental disabilities in the United States.

Practicing search planners and managers can appreciate the availability of any new information and its potential value for use in the field especially when faced with the challenge of searching for an autistic individual.

The study, titled *Trends in the Prevalence of Developmental Disabilities in US Children, 1997-2008*, appeared in the June journal of *Pediatrics* and indicated that for the first time nationally representative data on developmental disabilities had been collected. This writer obtained a copy of this article and notes are included below.

The information for the study was collected from National Health Interview Surveys (NHIS) from 1997-2008. These ongoing surveys are conducted through in person interviews with a knowledgeable adult family member.

The study looked at a group of developmental disabilities that included attention deficit hypersensitivity disorder, cerebral palsy, *autism*, seizures, stammering or stuttering, intellectual disability (mental retardation), moderate to profound hearing loss, learning disorders and other developmental delays. The study indicated:

- Developmental disabilities are common and were reported in ~1 in 6 children from 2006-2008.
- Boys had twice the prevalence of any developmental disability and excess prevalence for ADHD, autism, learning disabilities, stuttering or stammering and other developmental delays.
- Autism, attention deficit hyperactivity disorder and other developmental delays increased.
- Autism showed, by far, the largest relative increase while moderate to profound hearing loss decreased.
- Factors that may have influenced the prevalence of developmental disabilities included the improved survival of the growing number of children born preterm with birth

defects or genetic disorders whose improved survival may be offset by a disproportionate burden of neurologic and other impairments.

~1 in 110 children in the United States has an Autism Spectrum Disorder

Autism Spectrum Disorders (ASD's) are a group of developmental disabilities that can cause significant social, communication and behavioral challenges. People with autism handle information in their brain differently than other people.

There are three types of Autism Spectrum Disorders (ASD)

- Autistic Disorder
People with Autistic Disorder usually have significant language delays, social and communication challenges, and unusual behaviors and interests and may have an intellectual disability.
- Asperger Syndrome
People with Asperger Syndrome usually have some milder symptoms of autistic disorder. They might have social challenges and unusual behaviors and interests. They typically do not have problems with language or an intellectual disability.
- Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)
People who meet some of the criteria for autistic disorder or Asperger syndrome, but not all may be diagnosed with PDD-NOS. They usually have fewer and milder symptoms and these symptoms might cause only social and communication challenges.

Facts to know about autism for Search & Rescue

50% of autistics are nonverbal throughout their life and others may present themselves as non-verbal when stressed.

Make no assumption that they don't hear what others are saying.

Determine if the autistic individual uses a communication board.

Autistics may take longer to respond because they don't understand and are afraid. Speak simply and in clear short phrases. Avoid abstract or figurative language. Be patient and wait for the response. If their caretaker is present let them do the talking.

The caretaker is a valuable resource – keep them available.

Autistics can develop a seizure disorder.

Autistics may have a poorly developed upper trunk area. Be mindful of positional asphyxiation and that they may resist restraint. They may have low muscle tone and loose joints.

Ask before touching them or their property.

Autistics may not have a normal range of sensations and therefore may not feel cold, heat or pain. A response to pain could be to laugh, hum, sing and remove clothing.

Autistics engage in self stimulating behavior (motor mannerisms) such as hand flapping, finger flicking, eye blinking, string twirling, rocking, pacing, making repetitive noises or saying repetitive words that have no relation to what is happening. They may repeat something that someone says over and over. They are not being a “smart aleck.” This is called *echolalia* and can have a calming effect on the individual.

They may have an averted gaze.

There are various types of alert stickers to identify an individual with ASD. Due to sensory issues, individuals with ASD may not wear an ID bracelet. Parents may weave the ID into a child’s shoe lace or attach it to a zipper of a garment. Are they carrying a small pack and inside there is information about them.

Autistic individuals are attracted to water, reflections and lights.

Search and rescue personnel should avoid the use of flashing lights and sirens.

Do not rush at an autistic individual. Approach calmly and speak in a soft tone of voice.

In the case of a lost/missing autistic be mindful they may have wandered away, stepped away from a stressful situation or “ran ahead” of others; became lost and unable to orientate to where they are in respect to where they need or want to be.

Autistics are resilient.

Search Management

Autistics are included as one of the forty-one categories of lost persons in the most recent publication of Lost Person Behavior by Robert Koester (2008). It is not unusual today to read or hear about a search for an autistic individual or for that matter other developmental disabilities to include traumatic brain injury disorder.

Data for the publication came from the International Search & Rescue Incident Database (ISRID) which collected 50,692 cases. Of these cases 30,708 were considered unique reflecting individual case data. The data was organized into 76 fields with the most important field described found in the comment section. In 39% of the cases valuable information was included that provided insight into what actually occurred at a search.

Sixty-two cases of autistics met the criteria for data inclusion and were distinguished for population density (urban versus non-urban).

The distances from the initial planning point, find location, survivability and scenario were collated into tables and are displayed below.

Distance from Initial Planning Point		
	Temperate	Urban
	Miles	Miles
n	20	16
25%	0.4	0.2
50%	1.0	0.6
75%	2.3	2.4
95%	9.5	5.0

Survivability		
	Wilderness	Urban
Uninjured	88%	96%
Injured	10%	4%
Fatality	2%	
Survivability	Alive	n
<24 hours	100%	51
>24 hours	67%	3
>96 hours	50%	2

Find Location (%)		
	Temperate	Urban
n	11	10
Structure	45%	70%
Road	18%	20%
Water	9%	10%
Scrub	9%	
Woods	9%	
Field	9%	

Scenario (%)	
n	35
Investigative	3%
Lost	89%
Medical	6%
Overdue	3%

Statistical data alone will not resolve locating the subject of any search. In combination with distance theory, evaluation of the location of the incident and facts and evidence, it supports defining the search area.

Each and every search requires an appropriate response that begins with the very first person to speak with the reporting party. The gathering of information must begin immediately and detailed interviewing of all parties involved must follow. Best practices in interviewing are essential. The interviewer needs to place those ill at ease and under stress in a position to share information and be as detailed as possible.

Once the initial report has been received and pertinent information has been gathered it is essential that a resource skilled in searching for lost/missing persons be contacted at minimally to be made aware of a possible SAR activation and thus utilizing the time following notification to anticipate and prepare for an appropriate response.

Searching for lost/missing subjects is science and art. A skilled and experienced individual, such as a search manager, should be able to suggest to the local first response the actions and tactics that can be taken immediately that may resolve the incident in a very short period of time. The early notification of a potential search incident would allow adequate time for the

search planner to evaluate and plan for a future need to conduct a ground search and would allow others to be notified and prepare for the potential activity.

Search management will have experience in conducting a search urgency evaluation whether woodland or urban, emphasize the need to initiate a lost person questionnaire and remind others that the Point Last Seen (PLS - the single most important clue) should be located and protected. They are knowledgeable in reading topographical maps, terrain analysis, how to apply the appropriate resources (trained and untrained), reflex tasking, where best to direct hasty searching and progressive search work. As well, they will be mindful of passive search tactics in order to limit the size of the search area thereby creating confinement.

The incident command system should be activated, an incident action plan is required and a search plan and search plan map should follow.

Search management will brief teams with relevant information regarding the subject of the search and available clues. Of the many absolutes in this business of search and rescue there are no two searches alike.

Search and Rescue Preplanning

Continuing education is a necessity in search and rescue and is part of preplanning. Although the recent study mentioned in the beginning of this article did not gleam the notion that autism was on the increase nor did it hint at the possibility that searches for autistics would increase, it however did hint at how much is being done to support all developmental disabilities.

Here are possible suggestions for continuing education.

First – Realize autism and planning searches for lost/missing autistics is a special education topic for SAR and other public safety personnel. Imagine that you are an official with delegated responsibility to search for a missing person and what will be expected of you or imagine you are a member of a search team that locates a lost autistic subject. Are you prepared and what will you do?

This past October a search for an 8-year old autistic child occurred in Doswell, Virginia in the 80 acre North Anna Battleground Park. The child who wandered away from his family while they hiked in the park was found 5 days later following an extensive search with reports of more than 3000 volunteer searchers participating. The child was found alive and curled up in a fetal position and located less than a mile from the point last seen. After 3 days of searching with night time temperatures in the 40's, physicians and professional rescue personnel indicated the child might still be alive and officials did not give up.

- Consider having someone give a presentation on Autism Spectrum Disorders. Contact a state agency or organization that offers training to first responders about autism spectrum disorders.

- Contact your local or regional school district. Every child with a developmental disability receives support and schools are required by law to provide each student with an Individualized Education Program, commonly known as an IEP. Special education teachers, speech pathologists, occupational therapists, social workers, school nurses and others will be involved. Ask if a specialist can give a presentation and learn if they are a resource to be considered who may be able to assist if the time comes.
- First responder agencies or departments should consider having a SAR for First Responder presentation. This program provides first responders with information on what initial steps they can take if someone goes missing in their hometown, how they might resolve the incident, what search management does and SAR resources capabilities. The program can highlight what subject categories are most frequent to the area.
- As an agency or department with delegated responsibility for conducting searches, consider contributing data from a search to the International Search & Rescue Incident Database. The contact information can be found at the following website www.dbs-sar.com

Preventive SAR

If you know of someone in your area who cares for an individual with a propensity to wander let them know about a program called CareTrak. This is a program that makes available tracking devices that a subject can wear or can be attached to clothes. In the event that an individual wanders away they can be located quickly with a special receiver. In Vermont the Sheriff departments across the state and the Vermont State Police Search and Rescue Team have trained and have the receivers. This program is known to be successful in saving lives, providing peace of mind and saving money. The website is www.caretrak.com

This writer has included an article written by Ellen Notbohm, author of Ten Things Every Child With Autism Wishes You Knew. The author has graciously given permission to reprint the article here.

Ten Things

Every Child with Autism Wishes You Knew

by Ellen Notbohm

from the book *Ten Things Every Child with Autism Wishes You Knew* (2005, Future Horizons, Inc.)

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Some days it seems the only predictable thing about it is the unpredictability. The only consistent attribute—the inconsistency. There is little argument on any level but that autism is baffling, even to those who spend their lives around it. The child who lives with autism may look “normal” but his behavior can be perplexing and downright difficult.

Autism was once thought an “incurable disorder,” but that notion is crumbling in the face knowledge and understanding that is increasing even as you read this. Every day, individuals with autism are showing us that they can overcome, compensate for and otherwise manage many of autism’s most challenging characteristics. Equipping those around our children with simple understanding of autism’s most basic elements has a tremendous impact on their ability to journey towards productive, independent adulthood.

Autism is an extremely complex disorder but for purposes of this one article, we can distill its myriad characteristics into four fundamental areas: sensory processing challenges, speech/language delays and impairments, the elusive social interaction skills and whole child/self-esteem issues. And though these four elements may be common to many children, keep front-of-mind the fact that autism is a spectrum disorder: no two (or ten or twenty) children with autism will be completely alike. Every child will be at a different point on the spectrum. And, just as importantly – every parent, teacher and caregiver will be at a different point on the spectrum. Child or adult, each will have a unique set of needs.

Here are ten things every child with autism wishes you knew:

1. **I am a child first.** My autism is only one aspect of my total character. It does not define me as a person. Are you a person with thoughts, feelings and many talents, or are you just fat (overweight), myopic (wear glasses) or klutzy (uncoordinated, not good at sports)? Those may be things that I see first when I meet you, but they are not necessarily what you are all about.

As an adult, you have some control over how you define yourself. If you want to single out a single characteristic, you can make that known. As a child, I am still unfolding. Neither you nor I yet know what I may be capable of. Defining me by one characteristic runs the danger of setting up an expectation that may be too low. And if I get a sense that you don’t think I “can do it,” my natural response will be: Why try?

2. **My sensory perceptions are disordered.** Sensory integration may be the most difficult aspect of autism to understand, but it is arguably the most critical. This means that the ordinary sights, sounds, smells, tastes and touches of everyday that you may not even notice can be downright painful for me. The very environment in which I have to live often seems hostile. I may appear withdrawn or belligerent to you but I am really just trying to defend myself. Here is why a “simple” trip to the grocery store may be hell for me:

My hearing may be hyper-acute. Dozens of people are talking at once. The loudspeaker booms today’s special. Musak whines from the sound system. Cash registers beep and cough, a coffee grinder is chugging. The meat cutter screeches, babies wail, carts creak, the fluorescent lighting hums. My brain can’t filter all the input and I’m in overload!

My sense of smell may be highly sensitive. The fish at the meat counter isn't quite fresh, the guy standing next to us hasn't showered today, the deli is handing out sausage samples, the baby in line ahead of us has a poopy diaper, they're mopping up pickles on aisle 3 with ammonia. . .I can't sort it all out. I am dangerously nauseated.

Because I am visually oriented (see more on this below), this may be my first sense to become overstimulated. The fluorescent light is not only too bright, it buzzes and hums. The room seems to pulsate and it hurts my eyes. The pulsating light bounces off everything and distorts what I am seeing -- the space seems to be constantly changing. There's glare from windows, too many items for me to be able to focus (I may compensate with "tunnel vision"), moving fans on the ceiling, so many bodies in constant motion. All this affects my vestibular and proprioceptive senses, and now I can't even tell where my body is in space.

3. Remember to distinguish between *won't* (I choose not to) and *can't* (I am not able to).

Receptive and expressive language and vocabulary can be major challenges for me. It isn't that I don't listen to instructions. It's that I can't understand you. When you call to me from across the room, this is what I hear: "*~%\$#@, Billy. #%^*~%\$~* . ." Instead, come speak directly to me in plain words: "Please put your book in your desk, Billy. It's time to go to lunch." This tells me what you want me to do and what is going to happen next. Now it is much easier for me to comply.

4. I am a concrete thinker. This means I interpret language very literally. It's very confusing for me when you say, "Hold your horses, cowboy!" when what you really mean is "Please stop running." Don't tell me something is a "piece of cake" when there is no dessert in sight and what you really mean is "this will be easy for you to do." When you say "Jamie really burned up the track," I see a kid playing with matches. Just tell me "Jamie ran very fast."

Idioms, puns, nuances, double entendres, inference, metaphors, allusions and sarcasm are lost on me.

5. Be patient with my limited vocabulary. It's hard for me to tell you what I need when I don't know the words to describe my feelings. I may be hungry, frustrated, frightened or confused but right now those words are beyond my ability to express. Be alert for body language, withdrawal, agitation or other signs that something is wrong.

Or, there's a flip side to this: I may sound like a "little professor" or movie star, rattling off words or whole scripts well beyond my developmental age. These are messages I have memorized from the world around me to compensate for my language deficits because I know I am expected to respond when spoken to. They may come from books, TV, the speech of other people. It is called "echolalia." I don't necessarily understand the context or the terminology I'm using. I just know that it gets me off the hook for coming up with a reply.

6. Because language is so difficult for me, I am visually oriented. Show me how to do something rather than just telling me. And be prepared to show me many times. Lots of consistent repetition helps me learn.

A visual schedule is extremely helpful as I move through my day. Like your day-timer, it relieves me of the stress of having to remember what comes next, makes for smooth transition between activities, helps me manage my time and meet your expectations.

I won't lose the need for a visual schedule as I get older, but my "level of representation" may change. Before I can read, I need a visual schedule with photographs or simple drawings. As I get older, a combination of words and pictures may work, and later still, just words.

7. Focus and build on what I can do rather than what I can't do. Like any other human, I can't learn in an environment where I'm constantly made to feel that I'm not good enough and that I need "fixing." Trying anything new when I am almost sure to be met with criticism, however "constructive," becomes something to be avoided. Look for my strengths and you will find them. There is more than one "right" way to do most things.

8. Help me with social interactions. It may look like I don't want to play with the other kids on the playground, but sometimes it's just that I simply do not know how to start a conversation or enter a play situation. If you can encourage other children to invite me to join them at kickball or shooting baskets, it may be that I'm delighted to be included.

I do best in structured play activities that have a clear beginning and end. I don't know how to "read" facial expressions, body language or the emotions of others, so I appreciate ongoing coaching in proper social responses. For example, if I laugh when Emily falls off the slide, it's not that I think it's funny. It's that I don't know the proper response. Teach me to say "Are you OK?"

9. Try to identify what triggers my meltdowns. Meltdowns, blow-ups, tantrums or whatever you want to call them are even more horrid for me than they are for you. They occur because one or more of my senses has gone into overload. If you can figure out why my meltdowns occur, they can be prevented. Keep a log noting times, settings, people, activities. A pattern may emerge.

Try to remember that all behavior is a form of communication. It tells you, when my words cannot, how I perceive something that is happening in my environment.

Parents, keep in mind as well: persistent behavior may have an underlying medical cause. Food allergies and sensitivities, sleep disorders and gastrointestinal problems can all have profound effects on behavior.

10. Love me unconditionally. Banish thoughts like, "If he would just. . . and "Why can't she. . ." You did not fulfill every last expectation your parents had for you and you wouldn't like being constantly reminded of it. I did not choose to have autism. But remember that it is happening to me, not you. Without your support, my chances of successful, self-reliant adulthood are slim. With your support and guidance, the possibilities are broader than you might think. I promise you, I am worth it.

And finally, three words: Patience. Patience. Patience. Work to view my autism as a different ability rather than a disability. Look past what you may see as limitations and see the gifts autism has given me. It may be true that I'm not good at eye contact or conversation, but have you noticed that I don't lie, cheat at games, tattle on my classmates or pass judgment on other people? Also true that I probably won't be the next Michael Jordan. But with my attention to fine detail and capacity for extraordinary focus, I might be the next Einstein. Or Mozart. Or Van Gogh.

They may have had autism too.

The answer to Alzheimer's, the enigma of extraterrestrial life—what future achievements from today's children with autism, children like me, lie ahead?

All that I might become won't happen without you as my foundation. Be my advocate, be my friend, and we'll see just how far I can go.

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Ellen Notbohm is author of *Ten Things Every Child with Autism Wishes You Knew*, *Ten Things Your Student with Autism Wishes You Knew*, and *The Autism Trail Guide: Postcards from the Road Less Traveled*, all ForeWord Book of the Year finalists. She is also co-author of the award-winning *1001 Great Ideas for Teaching and Raising Children with Autism or Asperger's*, and a contributor to numerous publications and websites around the world. To contact Ellen or explore her work, please visit www.ellennotbohm.com

