

***Autism Spectrum Risk Management for Persons with Autism, their Families and People That Care* by Dennis Debbaudt 2008**

Thoughts about personal safety and risk are found high on the list of concerns expressed everywhere in the global autism community. So, just what can we do to increase security and lower the risks? Beyond educating law enforcers, three approaches come to mind. One is to be prepared for an autism emergency. The second is to develop the ability to disclose our need for an accommodation. We can then display our resiliency to address these risks and share our autism spectrum knowledge with those that need to know now. All are proactive options that, with a little effort, can become part of our daily routines.

Now, let's take a look at what some of those options are.

For Parents and Care Providers: Plan Your Response to an Autism Emergency

The past year also brought with it a predictable spate of autism related wandering. Children and adults all over the world wandered from care and into danger.

Wandering should be a cause for concern for every one of us who advocate for people with autism.

Wandering--and other risks associated with autism--should be included with every information packet offered to families who are new to the spectrum. This information can save lives.

To help ensure safety and lower risk for a child or adult with autism, parents and care providers will need to become proactive and prepare an informational handout.

A leading cause for concern are children and adults who run away or wander from parents and care providers. Tragically, children and adults with autism are often attracted to water sources such as pools, ponds, and lakes. Drowning is a leading cause of death for a child or adult who has autism. Wandering can also lead to high risk field contacts with law enforcement or members of the general public.

Preparing for a wandering incident may seem extreme for some families. After all, their child or adult hasn't wandered or bolted. Yet, for many other families, addressing wandering the first time can be the worst time. These preparations will also be invaluable before, during and after a natural or manmade emergency situation. For example, when a parent or care provider has their own medical emergency and becomes quickly incapacitated.

Securing the home & anti-wandering technology

For many families, securing their home to prevent access to dangerous materials and also to address wandering is the first order of preparedness. These efforts may include installing locking systems for cupboards, closets, appliances and utility rooms to prevent access to the stuff of everyday households: medicines, cleaning materials, foods and beverages, lawn and garden products, tools, plug-in electronics, and, of course, firearms, knives, matches, lighters and combustible materials. (<http://autismriskmanagement.com> to download Environmental Modifications for the Home information)

Interior and exterior doors and windows are a favorite escape route for the child or adult who is prone to bolting and wandering. Everything from double key, chain and window locks, electronic alarms that alert to door or window openings, to personal tracking systems, have been used with success. However, there are no 100% fixes. What works for one may not work for another.

Everyone considering home safety should consider consulting with professional home security and burglar alarm, locksmiths, and home improvement companies who are familiar with 21st century technology that can prevent a disaster.

Whenever and wherever either high or low technology is used to secure a home against wandering, fail safes must be in place such as automatic shut off of electronic key and lock systems and additional fire and CO 2 alarms.

Always keep a record of your anti-wandering efforts. You may need to prove to authorities that you are not neglectful parents or care providers. There may be little or no awareness of wandering and autism as an issue among the general public, law enforcement and social service professionals. Equating autism with Alzheimer's disease as a wandering population analogy can be a quick fix for immediate understanding.

Contacting 911 Call Centers

In the U.S., some law enforcement, fire rescue, and emergency 911 call centers are willing and able to proactively place this information into their data base. Although not every system or agency is able to provide this service, it is certainly worthy of inquiring about.

If wandering is a concern, ask your local 911 Call Center to *red flag* this information in their 911 computer data base. When a call comes in for response to Alzheimer's, autism, or medically fragile families who participate--911 telecommunicators can alert the first responder *before they arrive* with key information that was provided. When we provide law enforcement with information before an incident occurs, we can expect better responses.

Autism groups can partner with Alzheimer's disease advocacy organizations to approach local 911 Emergency Call Centers. Single family approaches can also be made for families in more rural areas. Remember that you are volunteering this information and privacy may be a concern. This will be your choice to make. There are model programs. *Take Me Home*, developed by the Pensacola, Florida Police Department is one example (see web site contact information at <http://autismriskmanagement.com>). Cite these examples when you make your approach. You may need to be persistent, but these are reasonable requests.

When Wandering Occurs

When a wandering incident occurs, and you *are* listed in a 911 special needs database, please be aware that the information is typically linked to your home--to help assist during an emergency *at your home*.---and may **not** automatically transfer to identify a person who has wandered away from home and is now out in the community.

Before searching, it will be your responsibility to call 911 and inform them that a family member is missing and needs assistance in the community. Be ready and willing to provide information about the person who is missing, either proactively or on-the-spot, to 911 telecommunicators or field officers. This can make a positive critical difference to the response to the field response.

An Autism Emergency information handout should be developed, copied and carried with you at all times--at home, in your car, purse or wallet (see model below). Also circulate this handout to family members, trusted neighbors, friends and co-workers. The handout will also come in handy if you are in an area other than your neighborhood and are approached by the police.

The Autism Society of America's *Safe and Sound* initiative features autism alert stickers for homes and vehicles--and a handy form example for information that can be developed, photocopied, carried by parents, care providers or persons on the spectrum to produce or be found during an emergency--and shared proactively with law enforcement, emergency response agencies and persons that should be contacted during an emergency. Visit www.autism-society.org and type in Safe and Sound.

Planning checklist:

- Prepare and copy your Autism Emergency information handout (model below)
- Keep a copy on your refrigerator and near your phone
- If wandering has occurred, call 911 before you go off to search
- Alert the 911 telecommunicator if you are listed in the 911 Special needs directory
- If not, be prepared to share with the telecommunicator the information from your Autism Emergency information handout

- Plan and practice your response in the event of a wandering incident
- Plan a mock event and your response as you would plan and practice your response for escape from a fire in your home
- Practice the 911 call with a friend
- Keep a written record of your efforts

Autism Emergency Contact Handout Model

- Name of child or adult
- Current photograph and physical description including height, weight, eye and hair color, any scars or other identifying marks
- Names, home, cell and pager phone numbers and addresses of parents, other caregivers and emergency contact persons
- Sensory, medical, or dietary issues and requirements, if any
- Inclination for elopement and any atypical behaviors or characteristics that may attract attention
- Favorite attractions and locations where person may be found
- Likes, dislikes--approach and de-escalation techniques
- Method of communication, if non-verbal sign language, picture boards, written word
- ID wear jewelry, tags on clothes, printed handout card
- Map and address guide to nearby properties with water sources and dangerous locations highlighted
- Blueprint or drawing of home, with bedrooms of individual highlighted (Debbaudt, 2004-07)

ID Options

Some type of ID wear is essential for those with autism, especially if they are non-verbal or are unable or become unable to respond to questions about their identity if they are found.

- MedicAlert style bracelet or necklace
- Joggers shoe tags
- ID information laminated card: on belt loops and belt, sewn into pants, sewn into jackets
- hang from zippers
- silk screened into undergarments
- non permanent tattoos

Bracelets, anklets, necklaces, shoe or jacket tags, ID cards, clothing labels or permanent ink ID on t-shirts or undergarments are all good options. The problem with some of these is they may be removed by the person with autism who has sensory issues. An innovative option is the use of prepared, washable tattoos that bear ID information (tattooswithapurpose.com).

If ID wear is used, first responders may not know what autism is. More specific language should be considered in addition to name, address and phone number, such as, non-verbal, sensitive to light, sound or touch, possible seizure activity, or may not seek help. (Debbaudt, 2002).

Alert Your Neighbors

The behaviors and characteristics of autism have the potential to attract attention from the public. Law enforcement professionals suggest that you reach out and get to know your neighbors.

- Decide what information to present to neighbors
- Plan a brief visit to your neighbors
- Introduce your child or adult or a photograph
- Give your neighbor a simple handout with your name, address, and phone number
- Ask them to call you immediately if they see your son or daughter outside the home

This approach may be a good way to avoid problems down the road and will let your neighbors:

- Know the reason for unusual behaviors
- Know that you are approachable
- Have the opportunity to call you before they call 911

Knowing your neighbors can lead to better social interactions for your loved ones with autism. (Debbaudt, 2004)

NOTE: This article recommends reaching out to and alerting neighbors about a child or adult. Parents have expressed their concerns about doing this. The fear, not unfounded, is stranger abductions or abuse. While these incidents can and do occur, physical and sexual abuse is oftentimes perpetrated by persons well known to the victim families.

Below is a link to information that parents can become familiar with in the area of victim selection and modes of operation of child abusers. Risks are dealt with best when we know about them.

I interviewed Ken Lanning for my 1994 booklet, *Avoiding Unfortunate Situations*. His advice and information is essential for every parent to know.

Child Molesters: A Behavioral Analysis

http://www.missingkids.com/missingkids/servlet/ResourceServlet?LanguageCountry=en_US&PageId=469

Authored by Kenneth V. Lanning and produced in cooperation with the FBI, the fourth edition of this book is an investigative tool for law enforcement officers and child-protection professionals handling cases of children who are sexually exploited. It provides investigative strategies, the characteristics of a pedophile, and the difficulties often encountered in cases of sexual exploitation. It introduces a typology that places sex offenders on a continuum, from preferential to situational. 160 pp.

Whether we develop an Autism Emergency Plan ourselves or use a template, what's important is our ability, willingness and preparation to use it during an emergency.

For Persons Who Have Autism

Make safety a part of the daily routine

Learning to recognize that men and women in uniform are people you can go to and stay with during an emergency is a lesson we all learn. Persons who have autism can learn these lessons when we teach these safety skills at home, reinforce them at school and practice them in the community. They are learned best when they are delivered early and often, and are suited to a child or adult's age and ability levels.

Plan cross educational opportunities for students with autism and law enforcement professionals. Provide them in a safe, non-threatening environment. These opportunities can result in improved field interactions and develop skills that will last throughout careers and lifetimes for both populations. Students with autism will learn that law enforcers in uniform are safe "go to" people in times of emergency. This can help demystify police in uniform, and teach that inside the uniform are good people who are also neighbors and friends. Law enforcers who have had a basic training about autism can learn for themselves, for example, what communications in the field with persons who have autism will look and sound like and when to use the specialized autism-related tactics they learned during training. Most importantly, police officers will get the opportunity to meet the children and adults who have autism that live in their community. Best of all, the initial contact will be in a safe, relaxed, controlled environment, not during the oftentimes emotionally charged atmosphere of a sudden field contact.

Building skills for children and less independent adults

To establish these life skills education for children or less independent adults who have autism, form partnerships with teachers and law enforcement professionals to help develop a simple curriculum that helps expand skills that will enhance their safety in the community and build personal resilience to risk. Formally or informally, invite a variety of law enforcers to sit among, not stand in front of, the students. The session should be designed to last about ten minutes, be delivered as frequently as possible, and by as many different officers as possible. Rotation of officers reinforces the message to students that police officers can and will look and sound differently. Rotation also makes the skill easier to generalize for the student and will allow more officers to participate without generating extraordinary time constraints for one particular officer. Officers can be asked to talk in their own words about the life skill that is being taught at the time.

For example:

1. Recognize and respond as best they can to law enforcers, their uniforms, badges and vehicles
2. Stay with--not run from--safe, "go to" police or other uniformed first responders
3. Keep an appropriate distance when interacting with a law enforcer--or anyone else
4. To avoid making sudden movements, i.e. hands into pockets
5. Carry and safely produce an ID card
6. Disclose their autism, carry and/or produce an autism information card
7. Recognize inappropriate touching or sexual come-ons directed at them
8. Effectively report bullying or other incidents
9. Tell someone they need help, or use the phone to request it (Debbaudt and Coles, 2004 b)

Further, officers can participate in mock interviews, for example, by asking the student what their name is and if they have an ID card. With permission from all involved, consider videotaping the visits then using the videotape as a learning tool whenever possible.

These life skills lessons will be learned best when they become part of our daily routine. Augment the skills by practicing them at school and at home. Ultimately, plan field tests in the community to gauge progress.

Building skills for the more independent adolescent or adult who has autism or Asperger Syndrome

Persons with autism who are able to navigate the community without assistance should strongly consider developing a personal handout for the police and develop the skills and resiliency to risk necessary to appropriately disclose their need for an accommodation. Remember that the initial uninformed contact with police presents the highest potential for a negative outcome.

What can and should the independent person living on the autism spectrum expect during sudden or even expected interactions with law enforcement, customs and immigration, first responders such as fire rescue, paramedics, hospital emergency room professionals or other security professionals?

With few exceptions, law enforcers and other first responders will have had little or no training about how to recognize, communicate and respond well when they interact during field contacts with a person on the spectrum. There may be little understanding of the significance of the words Asperger Syndrome, or autism when they hear them.

You can expect a higher level scrutiny from law enforcement and security personnel when traveling in the 21st century community.

Expect public or private sector scrutiny at:

- Airports
- Security checkpoints such as government buildings, schools, any secured facility
- Drive-up or walk-up guard shacks
- Building entrances
- Campus
- Shopping malls or districts

In these days of heightened security? Anywhere!

So, what are the best options for the independent spectrum person during a sudden interaction with a law enforcer during an emergency or non emergency situation?

Should you disclose your autism or AS? When? To whom?

Disclosure tools and options

What's the best tool to use when you make the decision to disclose your autism or Asperger syndrome to a police officer? A handout card.

- 1) Develop a handout card that can be easily copied and laminated
- 2) The handout is replaceable. You can give it away to the officer on the scene
- 3) Carry several at all times
- 4) The handout card can be generic or specific to you
- 5) Work with an AS support organization to develop a generic handout
- 6) Work with persons whose opinions you trust and value to develop a person specific handout

How to present a handout to a police officer

What's the best way to tell the officer that you have a handout?

- (A) Avoid making sudden movements to reach for the handout card
- (B) Obtain permission or signal your intentions before reaching into coat or pants pockets, briefcases or bags, or in to glove compartments of vehicles
- (C) Verbally let officer know you have AS and have an information card for them to read. If nonverbal, or if sudden interactions render you nonverbal or mute, consider using a medical alert bracelet for an officer to read that alerts them to your condition of AS and the fact that you have an information card.

Disclosure to a police officer

The decision to disclose will always be yours to make. If you have learned through experience that disclosure would be helpful, you may decide to disclose to a police officer.

Law enforcers report that they make their best decisions when they have their best information. A good, strong AS disclosure that includes the use of an information card, contact information for an objective AS professional, and proof of diagnosis should be considered.

Here's an example of what a handout card could look like (Debbaudt, 2006 b):

(HANDOUT EXAMPLE--FRONT)

AUTISM/ASPERGER SYNDROME ALERT

I HAVE AUTISM OR ASPERGER SYNDROME

I WILL BE ANXIOUS IN NEW SITUATIONS OR WITH NEW PEOPLE.

PLEASE READ THIS CARD FOR INFORMATION ABOUT HOW TO COMMUNICATE WITH ME AND HOW I COMMUNICATE WITH YOU.

BELOW ARE SOME COMMON CHARACTERISTICS OF AUTISM AND ASPERGER SYNDROME AND SOME TIPS FOR YOU:

USE CONCRETE, DIRECT LANGUAGE. I MAY TAKE YOUR EXPRESSIONS LITERALLY
BE PATIENT. ALLOW ME SUFFICIENT TIME (10-15 SECONDS) TO ANSWER YOUR QUESTIONS
DON'T BE OFFENDED WHEN I REPEAT WHAT YOU SAY. THIS IS COMMON FOR PEOPLE WITH AUTISM AND ASPERGER SYNDROME

I MAY TRY TO CHANGE THE SUBJECT OF CONVERSATION TO A TOPIC OF MY CHOICE

I MAY NOT UNDERSTAND YOUR QUESTIONS OR COMMANDS

MY GOOD VOCABULARY MAY GIVE YOU A FALSE IMPRESSION OF MY COMPREHENSION

TRY TO DISPLAY CALM BODY LANGUAGE. I AM LIKELY TO MODEL YOUR BODY LANGUAGE

I MAY AVOID EYE CONTACT. THIS IS COMMON AND MAY NOT MEAN I HAVE GUILTY KNOWLEDGE

TRY TO IGNORE MY SELF STIMULATORY BEHAVIOR, SUCH AS, PACING OR TALKING TO MYSELF

AVOID SLANG, JOKES OR SARCASM. I DO NOT UNDERSTAND THEM

I MAY MAKE UNINTENTIONAL SOCIALLY INAPPROPRIATE COMMENTS OR GESTURES

I MAY DISPLAY EXTREME DISTRESS FOR NO APPARENT REASON, SUCH AS, SHOUTING, YELLING, CRYING OR PHYSICAL AGITATION

I MAY BE EXTREMELY SENSITIVE TO TOUCH, SOUNDS, LIGHTS OR OTHER SENSORY INPUT

REMEMBER THAT EACH INDIVIDUAL WITH AUTISM OR ASPERGER SYNDROME IS UNIQUE AND MAY ACT OR REACT DIFFERENTLY

CONTACT THE FOLLOWING DOCTOR TO CONFIRM DIAGNOSIS _____

CONTACT THIS ASPERGER SUPPORT GROUP FOR INFORMATION _____

(HANDOUT EXAMPLE--BACK)

RESTRAINT

TRY TO DEESCALATE BEHAVIOR THROUGH GEOGRAPHIC CONTAINMENT. CONSIDER REMOVING PERSON FROM AN AREA WITH MULTIPLE SENSORY INPUTS TO AN AREA FREE OF SENSORY INPUT, SUCH AS, FLASHING LIGHTS, SIRENS, CROWDS, CANINE PARTNERS, PERFUME, SMOKE

IF RESTRAINT OR PHYSICAL CONTACT BECOMES NECESSARY, BE AWARE OF ASSOCIATED MEDICAL CONDITIONS INCLUDING SEIZURE DISORDER AND HYPOTONIA OR WEAK TRUNK MUSCLES

AVOID POSITIONAL ASPHYXIA. AFTER TAKEDOWN, TURN PERSON ON THEIR SIDE OFTEN TO ALLOW NORMAL BREATHING TO OCCUR

ALERT JAIL AUTHORITIES ABOUT MY AUTISM OR ASPERGER SYNDROME.

STRONGLY CONSIDER INITIAL SEGREGATION FROM GENERAL PRISON POPULATION.

I WOULD BE AT EXTREME RISK OF INJURY OR ABUSE WITHIN GENERAL PRISON POPULATION

DOCUMENT ASPERGER SYNDROME IN THE INITIAL REPORT

ALERT SUPERVISOR, DETECTIVE BUREAU AND PROSECUTOR ABOUT THE CONDITION OF AUTISM OR ASPERGER SYNDROME

INTERVIEW

A Person with Autism or Asperger Syndrome:

MAY NOT UNDERSTAND CONSTITUTIONAL RIGHTS OR LEGAL WARNINGS

MAY HAVE DIFFICULTY RECALLING RELEVANT FACTS OR DETAILS OF A SPECIFIC INCIDENT

MAY BE CONFUSED BY STANDARD INTERVIEW OR INTERROGATION TECHNIQUES AND PRODUCE A MISLEADING STATEMENT OR FALSE CONFESSION
MAY NOT FULLY UNDERSTAND THE CONSEQUENCES OF THEIR ACTIONS

CONSIDER CONTACTING A PROFESSIONAL WHO IS FAMILIAR WITH AUTISM OR ASPERGER SYNDROME.
CALL THE FOLLOWING PROFESSIONAL _____
(Debbaudt and Sheri, 2002)

Plan and practice disclosure techniques

Plan your response and practice with others for a sudden encounter. They will happen to all of us. Your preparation is your best chance to have a successful interaction with law enforcement.

1. Discuss these risks with people that you trust
2. Develop a hard person specific disclosure handout
3. Develop a personal plan of how you will use the handout
4. Practice through role playing with people you know and trust
5. Develop disclosure handouts and role play when, where and how you would use them.
6. Adapt and amend disclosure handouts. It's only paper. They're not written in stone.

Further suggestions for you to consider during sudden interactions with police:

- (1) Do not attempt to flee
- (2) Do not make sudden movements
- (3) Try to remain calm
- (4) Verbally let officer know you have autism. If nonverbal, use alternative communication tools, such as a simple sign language card, that indicates the need to write
- (5) Obtain permission or signal intentions before reaching into a coat or pants pocket, or reaching into a car glove box
- (6) If unable to answer questions, consider use of a generic or person-specific autism information card
- (7) If you lose the ability to speak when under stress, consider wearing an alert bracelet or necklace that is easy to see--one that lets the reader know you have an information card
- (8) Ask officer to contact an advocate, if necessary and possible
- (9) If you are a victim or are reporting a crime, you may want the police to contact a family member, advocate or friend who can help you through the interview process
- (10) Carry the phone number of an advocacy organization or personal advocate, relative or friend (Debbaudt, 2006 b)

Avoiding victimization

Everyone should take precautions to avoid becoming victims of criminal activity. Unfortunately, persons with autism may need to take extra precautions. In order to avoid detection, arrest, and prosecution, criminally bent individuals become skilled at picking out easy victims. Robbers and con artists will notice unusual behavior when they select their next victim. An unarmed robber or con artist will operate in public places. Anywhere there's regular pedestrian traffic or large public gatherings will afford a criminal the chance to identify or mark victims. If you are threatened or asked to give up money or valuables, do not

resist. Give them what they want. These things can be replaced. Once in a safe area, call the police.

- To avoid victimization from street crimes or abusers: Avoid areas that are unfamiliar to you
- Consider carrying a cell phone
- Travel in groups if possible or walk with the crowd
- Do not dawdle or appear rushed in a crowd
- Park in a secure area
- Keep car doors locked
- Take a look around the parking lot before unlocking doors and exiting vehicle
- Arrive with the crowd to work, school, events
- Avoid gawking
- Do not maintain eye contact
- Let someone know of your travel plans
- Do not carry large amounts of cash
- Dress to suit the area
- Stay in well lit areas
- Do not wander or explore off well traveled pedestrian walkways or vehicular avenues

Contact your local autism advocacy organization and suggest that they help you to become involved in developing a partnership with police for ongoing law enforcement training sessions.

Ask your support group to assist you in the development a generic handout for law enforcement Also ask for help to distribute the handout to law enforcement agencies, and develop an approved training program for law enforcers.

Encourage your advocacy organizations and persons of trust to create opportunities where you and other persons with autism or Asperger Syndrome can interact with law enforcers in a safe, structured, non threatening and low anxiety environment. You can then can learn from each other how to best interact. These educational opportunities will need to be discussed, planned and carried out. Advocacy groups should be encouraged to embrace these issues and help you form partnerships with law enforcers. Mutual education and information sharing will always be the keys to successful resolution of autism related contacts. (Debbaudt, 2003)

Conclusion

We practice our risk management skills every time we lock a door or put on a car seat belt. Heck, we don't quit wearing seat belts because we don't get into an everyday auto accident. Taking these precautions becomes part of our daily routine.

While developing the resiliency to address the risks of autism and make safety part of our daily routines may not stop an emergency from happening, it becomes our best defense when one does occur.

Be Proactive!

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