



Autism Society Ontario

www.autismsociety.on.ca

Position Paper on the Locating Technology Project for Vulnerable Individuals

July 2005

Executive Summary

Autism Society Ontario (ASO) applauds the Ontario government's initiative in launching a project to test the effectiveness of new technologies in protecting vulnerable people who are at risk of wandering. As the leading source of information and referral on autism, we are uniquely positioned to offer insights regarding the population with autism spectrum disorders (ASD).

ASO has identified the following seven criteria as essential to the success and sustainability of the Locating Technology Project.

1. *Values*

- Any safety devices and support system should be grounded in values of respect for vulnerable people's rights and support for their quality of life, privacy, and desire to enjoy some independence of movement and inclusion in the community.

2. *Technology*

- A variety of responses should be possible (i.e. escalating alerts) dependent upon the individual's circumstances and personal support systems.
- Search and Rescue (SAR) response teams should be certified in the use of the technology.

3. *Training for all 9-1-1 Service Providers*

- Police, fire fighters, and paramedics receive recognition, communication and response training to understand autism spectrum disorders. Without training, well-intentioned emergency personnel may inadvertently escalate the crisis.

4. *Training for all participating parents, families and care providers*

- All participating families receive risk and safety management and emergency preparedness training before participation in, or to receive funding for, the program.

5. *Community awareness*

- Collaboration with various community organizations such as mental health groups, disability advocate associations, service providers, school boards, merchant groups, neighbourhood associations, health organizations, government agencies, recreation facilities, and others is vital to the success of this project.

6. *Electronic Alert*

- There should be an alert in the 9-1-1 response system to provide key medical, communication and behavioural de-escalation information for each participating individual with an autism spectrum disorder.

7. *Ease of administration and funding*

- Utilize existing structures to demonstrate need and determine eligibility as well as provide funding. A streamlined process would reduce the burden on families and administrative systems.
- This program should be supported with new funding and not a reallocation of existing funds and resources.

Introduction

Autism Society Ontario (ASO) is a leading source of information and referral on autism and one of the largest collective voices representing the autism community in Ontario. Members are connected through a volunteer network of 31 Chapters throughout the Province of Ontario. We are dedicated to increasing public awareness about autism and the day-to-day issues faced by individuals with autism, their families, and the professionals with whom they interact.

The Society and its chapters share common goals of providing information and education, supporting research, and advocating for programs and services for the autism community. Our vision is *Acceptance and opportunities for all individuals with Autism Spectrum Disorders (ASD)* and the mission of the ASO is *To ensure that each individual with ASD is provided the means to achieve quality of life as a respected member of society.*

It is estimated that up to 70,000 people in Ontario today have some form of Autism Spectrum Disorder. It is one of the most common developmental disabilities with prevalence estimates as high as 1 in 165 people (Fombonne E. The Prevalence of Autism. JAMA 2003; 289(1):1-3). The number of people being diagnosed with ASD continues to increase dramatically yet most of the public, including many professionals in the medical, educational and vocational fields, are still unaware of how autism affects people and how they can effectively work with individuals with ASD. ¹

Goals of the Project

ASO believes that the Locating Technology Project should have the following three goals:

- a) Primary Safety Device for individuals who run away or wander
- b) Self-Help Device to increase the independence of vulnerable individuals
- c) Reduction of the burden placed on families and caregivers

Key Considerations

1. Values

- Any safety devices and support system should be grounded in values of respect for vulnerable people's rights and support for their quality of life, privacy, and desire to enjoy some independence of movement and inclusion in the community.

2. Technology

- The technology should be able to provide a range of response options both as a primary safety device for those who wander and as a self-help device for those who require support for independence. Refer to *Response Options* included in the appendices.
- The Ontario Provincial Police (OPP) is responsible for security and public safety in the province. The OPP is the first operator for the 911 calls in Ontario; they download the calls to the other appropriate agencies. Their involvement is critical to the successful implementation of any locating technology. Refer to the OPP website at <http://www.opp.ca/>.

- SAR (Search And Rescue) involvement is also essential to the successful implementation of any locating technology. Ground SAR coordination is promoted through the Ontario SAR Advisory Council and carried out through Emergency Measures Ontario. Refer to the Directory of Canadian Search and Rescue (SAR) Organizations for Ontario:
https://www.nss.gc.ca/sar_directory/orgsByProvince_e.asp?province=6
- First alert technology for parents and care providers should be offered for in-home and community building use. The technology should be designed with input from professionals in the fields of home and building security, locksmiths, and builders². Safety systems should prevent day and especially nighttime escape attempts by addressing door and window escape routes.
- Personal tracking technology must be very sensitive, accurate and developed specifically for those who wander. Radio Frequency (RF) technology has a proven track record for recovery of persons who wander but it is limited in geographical range.
- Several transmitter options must be available to accommodate sensory issues, including a selection of size and placements - either on the body (wrist, ankle, waist, etc.), or sewn into or on clothing (shoes, belts, etc.). There should also be a non-removable option.

3. *Training for all 9-1-1 Service Providers*

- Police, fire fighters, and paramedics receive recognition, communication and response training to understand autism spectrum disorders. Without training, well-intentioned emergency personnel may inadvertently escalate the crisis.³
- The above-mentioned training should be part of the mandatory provincial standards in training for all EMS agencies.
- Several training programs and resources specific to autism are available. Refer to the two documents *Contact Information for Training Resources and Programs* and *Autism: Recognition And Response* included in the appendices.

4. *Training for all participating parents, families and care providers*

- All participating families receive risk and safety management and emergency preparedness training before participation in or to receive funding for the program.
- Home security, emergency identification and crisis planning are essential.
- Support groups and service providers should offer safety protocols in information packages sent out to care providers, especially families who have just received an autism spectrum diagnosis.
- Network with the Ontario Association of Access Centres to develop and distribute this information. Contact Chris Symons of Community Services Coordination Network in London: Phone: (519) 438-4783 Ext. 17 Fax: (519) 673-1509 or Email: ChrisSymons@cscn.on.ca
- Refer to the following documents included in the appendices:
 - Protecting the Child or Adult with Autism
 - Person Specific Handout Checklist for 911 Systems
 - Are You Prepared for an Autism Emergency?
 - Crisis Plan

5. *Community awareness*

- The Locating Technology Project should include collaboration with various community organizations such as mental health groups, disability advocate

associations, service providers, school boards, merchant groups, neighbourhood associations, health organizations, government agencies, recreation facilities, and others.

- Provide public education by:
 - Organizing workshops and training events
 - Supplementing inclusion resources in public libraries, recreation facilities, municipal centres, school boards, etc.
 - Developing community projects to promote inclusion and social engagement
 - Promoting research into best practices
- Expand the mandate of the four Community Networks Of Specialized Care (announced May 18, 2005) to include public awareness as outlined above.

6. *Electronic Alert*

- There must be an alert in the 9-1-1 response system to provide key medical, communication and behavioural de-escalation information for each participating individual with an autism spectrum disorder. For an example see the *Vulnerable Persons Name Registry Programme*: <http://www.police.york.on.ca/reporting/>
- The Ontario Policing Technology Information Cooperative (O.P.T.I.C.) Records Management system should store the information and make it readily available to all communications personnel and patrol officers.
- This information must be accessible by all emergency personnel – not only police, but also fire fighters, and paramedics.
- On board (patrol cars) computers should be used to retrieve this information, whenever possible.
- Consult with the National Emergency Number Association (NENA) Ontario about the most current technology: <http://www.nenaontario.com/index.html>

7. *Ease of administration and funding*

- This program should be supported with new funding and not a re-allocation of existing funds and resources.
- Tracking devices and safety protocols should *supplement* rather than supplant existing services.
- Utilize existing structures to demonstrate need and determine eligibility as well as provide funding. A streamlined process would reduce the burden on families and administrative systems.
- ASO recommends Special Services At Home (SSAH) as the best option to provide the funding and administer the safety program for the following reasons:
 1. SSAH is a familiar process to families dealing with autism spectrum disorders.
 2. Families have already submitted the necessary personal information to the ministry.
 3. In the July 15, 2005 press release, the Ministry of Community and Social Services acknowledged the need to eliminate waiting lists for SSAH. We commend this policy.
 4. The Locating Technology Project meets the SSAH criteria for Personal Growth and Development as well as Family Relief and Support. Note particularly section 5 of the SSAH application:
 - 5B Personal Development Support – Community Activities / Involvement
 - 5C Supervision or Attention Provided for Safety – In the Community, At Home
 - 5D Behaviour Needs – *running away* is mentioned specifically

5. Individuals with ASD who do not qualify for SSAH but whose needs still fall within the scope of the project should be eligible to apply directly to the program.
6. Other provincial disability programs such as the Assistive Devices Program, the Ontario Disability Support Program and the Assistance for Children with Severe Disabilities are limited by eligibility restrictions such as age, income level and type of disability. These programs would require significant modification to meet the needs of the population with ASD.

Conclusion

The Locating Technology Project offers great potential to improve the safety and security of individuals with autism spectrum disorders who are at risk of wandering. It can also offer greater independence to individuals living within the community. The burden on families and caregivers will thereby be reduced.

The field of ASD is a highly complex one that requires a deliberate interplay between research, diagnosis, education and treatment and engagement of individuals with ASD and their families.⁴

Autism Society Ontario is willing and able to collaborate with the Ministry of Community and Social Services in its efforts to implement a successful pilot of the Locating Technology Project. We look forward to hearing from ministry staff.

References

1. November 30, 2004 - Autism Society Ontario Response to Preliminary Discussion Paper: *Transforming Services In Ontario for People who have a Developmental Disability*
2. Debbaudt, Dennis. (2002) *Autism, Advocates, and Law Enforcement Professionals: Recognizing and Reducing Risk Situations for People with Autism Spectrum Disorders*. London: Jessica Kingsley Publishers.
3. Ibid.
4. Autism Society Ontario's 2005 Pre-budget Consultation Submission to Ontario's Minister of Finance

Appendices

The following documents are included in the appendices:

1. Response Options
2. Contact Information for Training Resources and Programs
3. Autism: Recognition And Response
(Dennis Debbaudt 2002)
4. Protecting the Child or Adult with Autism
(South Carolina Autism Society)
5. Person Specific Handout Checklist for 911 Systems
(Dennis Debbaudt 2002)
6. Are You Prepared for an Autism Emergency?
(Dennis Debbaudt 2005)
7. Crisis Plan

Contact Information for Training Resources and Programs

This list is a sample of the autism specific resources available.

Autism, Advocates and Law Enforcement Professionals: Recognizing and Reducing Risk Situations for People with Autism Spectrum Disorders

By Dennis Debbaudt, Jessica Kingsley Publishers 2002

ISBN # 1-85302-980-7

Website: <http://www.jkp.com/catalogue/book.php/isbn/1-85302-980-7>

Autism and Informed Response

South Carolina Autism Society has developed curriculum and video geared toward emergency responders, fire, EMS and police.

Phone: 800-438-4790, ext. 102

Email: carol@scautism.org

Website: <http://www.scautism.org/air.html>

Autism and Law Enforcement Roll Call Briefing Video

(2004). Length: 21 minutes. Produced by Dennis Debbaudt. This is an exceptional video to be used in training law enforcement personnel on interacting with people on the autism spectrum. Highly recommended for use in training. For ordering information, call Debbaudt/Legacy Productions at 1-772-398-9756 or online at <http://www.autismriskmanagement.com/id7.html>

Autism Awareness Video for Law Enforcement / Community Service Personnel

(1998). Length: 23 minutes. Developed by the Harrisburg Chapter of the Autism Society of America and funded by the Pennsylvania Developmental Disabilities Council. The video highlights behaviours associated with autism spectrum disorders, and provides recommendations for how community members and law enforcement agencies should interact with these individuals. Recommended as a disability awareness tool for community members and law enforcement personnel. For ordering information, contact the Autism Society of North Carolina at 1-919-743-0204 or online at http://store.appcomm.net/Merchant2/merchant.mv?Screen=SFNT&Store_Code=ASNC

For Safekeeping / First Responder Autism Training

(2003). Length: 21 minutes. Produced by Atlantic Film and Video. This video/DVD provides an overview of the characteristics associated with autism spectrum disorders, highlights four individuals to illustrate these characteristics, and provides useful recommendations for responding and interacting with these individuals. Recommended for professionals who may be involved in responding to emergencies involving individuals across the autism spectrum. For ordering information, contact Autism Alliance of Metro West, Inc. at 1-508-652-9900 or online at <http://www.autismalliance.org/video.htm#video1>

Silent No More, Inc.

The Operation Communication Board is a new tool designed to improve communication between professionals (police officers, fire fighters, hospital staff, and paramedics) and

people who cannot make their circumstances clear due to autism, Alzheimer's syndrome, traumatic head injury, unfamiliar or impaired speech, or other difficulties.

P.O. Box 98

Phone: (610) 274-2364

Fax: (610) 274-2205

Landenberg, PA 19350

Email: SNM@dol.net

Website: <http://www.dol.net/~srz>

Why Law Enforcement Needs To Recognize Autism (2001)

State of Maryland Police and Correctional Training Commissions

Developed in 1999, this is the first and only curriculum developed by a law enforcement agency that solely addresses autism. This document is a model and cited resource for the law enforcement community.

Darla Rothman

State of Maryland Department of Public Safety and Correctional Services

Police and Correctional Training Commissions

6852 4th Street

Sykesville, Maryland 21784

Phone: (410) 875-3526

Fax: (410) 875-3583

Email: drothman@dpscs.state.md.us

This training curriculum is available free of charge from Autism Society Ontario.

AUTISM: RECOGNITION AND RESPONSE by Dennis Debbaudt

Autism is a neurological disorder that seriously affects functioning of the brain and a person's communication, socialization and reasoning skills. The behavioral symptoms persons with autism display under stress are brain-based, not psychological or matters of choice.

Persons with autism will often look perfectly normal. Approximately 50% of people with autism are non-verbal. They may not respond to a 'Stop!' command and may attempt to move or run away when approached. They may cover their ears or look away. They may not recognize a police uniform, badge, or vehicle or may not understand what is expected of them if they do. They may not be able to distinguish between a minor and a serious problem. They may appear as deaf. They may have motor-skill problems that will affect their gait. They may walk pigeon-toed, or on tip-toe, and may have difficulty running. They may be dressed oddly or without regard to the weather conditions.

Persons with autism do not react well to changes in their routine. Unexpected changes in routine, such as having suddenly to interact with law enforcement professionals or a sudden exposure to sensory stimuli, may cause the person's behaviors to escalate. When their routines or atypical behaviors are interrupted, they may respond with aggressive behavior, such as screaming, hitting, biting, and kicking. They may injure themselves or others.

Persons with autism may present as defiant, argumentative, stubborn, and belligerent, or as if they are under the influence of drugs or alcohol. They may be poor listeners, not seeming to care what is said to them. They may be unable to maintain eye contact even when others shift their position to obtain it. They may say 'No', 'Yes', or 'Why' to all questions. When uncomfortable or under stress, the verbal person may persevere on favorite topics as if trying to change the subject, ask repeated questions, engage in arguments or rambling speech, or lose the ability to speak.

Persons with autism may follow or approach children, the elderly, or others that attract them, without an understanding of the social inappropriateness of their behavior. This may occur in stores, parks, airports, train and bus stations, and public restrooms and appear to others as stalking or as a prelude to assault or a sexual advance. Persons with autism may attempt to hug or touch strangers or may sniff all persons and objects that are new to their environment.

Many calls for assistance will involve children who are 'lost & wandering' similar to the wandering Alzheimer's patient. Elopement prevention may include locked doors and windows and may cause first responders to erroneously suspect child endangerment.

SEEING THE SIGNS

Although every individual is unique, a person with the disorder may have one or more of the following symptoms:

- May avoid eye contact
- May prefer to be alone
- Difficulty in expressing needs; does not use gestures
- Insistence on sameness
- Inappropriate response to sound or other sensory input
- Difficulty interacting with others
- No real fear of dangers
- Apparent insensitivity to pain
- Avoidance of touch
- Sustained unusual repetitive play
- Uneven physical skills
- Uneven or missing verbal skills
- Inappropriate laughing or giggling
- Fascination with water, lights, and reflections
- Inappropriate attachment to objects
- Echoes words or phrases
- May seek sensory stimulation, including heavy pressure
- Spins objects or self

VICTIMS WITH AUTISM

Persons with autism, parents, caregivers, and advocates often find it difficult to talk about stories of victimization and abuse. Lack of credibility as a witness or reporter of facts will often leave the person with autism in the unenviable position of being victimized twice: once by the abuser and again by a system that lacks the ability or resolve to understand him or her. More information can be found in *Autism, Advocates and Law Enforcement Professionals* as noted below.

THE FOLLOWING TIPS CAN HELP

- A**pproach the person in a quiet, non-threatening manner. Persons with autism may be hypersensitive to stimuli. Avoid quick motions and gestures that could be, even remotely, seen as threatening.
- U**nderstand that touching the person with autism may cause the protective 'fight or flight' reaction. Never touch the shoulders or near the face. Their hypersensitivity includes being touched and even extends to invasions of their personal space.
- T**alk to the person in a moderated and calm voice. You may have to repeat your directions or questions several times. Be patient and wait for answers that may be delayed. Raising your voice will not help and may be viewed as threatening.
- I**nstructions should be simple and direct, avoiding slang. A person with autism will take what you say literally. 'Do you think that's cool?' 'What have you got up your sleeve?' or 'Are you pulling my leg?' are examples of phrases that probably will cause confusion and may cause an inappropriate response. Directions should be specific, such as 'Stand up' or 'Go to the car, now', and this will reduce the chance of confusion.
- S**eek all indicators to evaluate the situation as it is unfolding and be willing to adjust your actions accordingly. Visually evaluate for injuries because persons with autism can have an extremely high threshold for pain or be unable to ask for help.
- M**aintain a safe distance until any inappropriate behaviors lessen but remain alert to the possibility of outbursts or impulsive acts. Be able to appear to retreat, if necessary, to de-escalate the situation until you can determine what is going on at the scene.

From: Debbaudt, Dennis, 2002 *Autism, Advocates, and Law Enforcement Professionals Recognising and Reducing Risk Situations for People with Autism Spectrum Disorders*, Jessica Kingsley Publishers, ISBN 1-85302-980-7

Debbaudt, a Florida-based licensed private investigator and dad of a young man who has autism, conducts autism workshops nationwide for law enforcement, first response, criminal justice, and private security professionals. He has written about autism for Sheriff Magazine and the FBI Law Enforcement Bulletin. He can be reached at 772-398-9756 ddpi@flash or through his website www.policeandautism.cjb.net

This book can be ordered at www.jkp.com or by calling 1-800-634-7064

Make Sure Your Loved One Wears or Carries Identification

The importance of a bracelet, wallet card or other I.D. cannot be overstated for children and adults with autism. Here's why:

Many cannot speak – or speak well. Even the person who speaks may be too frightened to answer questions.

The I.D. can state that the person has autism, which may help to explain odd behaviors.

The best person to assist is someone who knows the individual well. The I.D. lists this person(s).

MedicAlert (www.medicalert.org) provides low-cost bracelets and medallions. They are imprinted with the wearer's name, key details (autism, seizures, etc.) and a toll-free, 24-hour number for more information. On file will be contact information, medications, and any other information you want to provide. Stores for runners also have I.D. tags.

If you think your loved one won't wear I.D., try it anyway. Be creative. **Don't give up!** Put a tag on a shoe or belt. Sew information inside a shirt collar. Masking tape works temporarily.

Don't dismiss I.D., thinking it will make your loved one a victim. It's more likely to help than hurt. However, avoid too blatant I.D. – such as "I have autism" in big letters across a T-shirt. But, a shirt with other information on it, like your pager or cell number, may relieve your anxiety on a beach or amusement park trip.

Important! Even with I.D. in place, teach your loved one how to draw attention to it or answer questions.

It's worth the challenge.

Get to Know Your Local Agencies

To prepare for a possible emergency, get acquainted with your local police or sheriff's department, fire department and emergency medical service. Visit a fire station with your loved one or ask for someone to come to your home. Have a firefighter "dress out" so your child can see what full gear looks like. (It can look scary in an emergency.) Ask the fire and police departments to inspect your home and suggest safeguards. Wherever you meet, introduce your loved one and talk openly about the risks you believe he or she faces. Just having public safety agencies know where you live – and that your loved one with a disability lives there too – could be helpful in an emergency.

Contact your community's 911 center. It may have the capability of documenting that someone with a disability lives at your home.

It's a good idea to acquaint neighbors with your loved one's tendencies, especially if wandering off is one of them. Some families prepare flyers with a photo, description, emergency contact information, and details like what may upset, and calm, the individual. If your loved one has odd behaviors in stores, talk to employees where you regularly shop. Tell them about autism. If a behavior may cause problems, like the individual's way of handling items, put it into perspective for them. If you are open and positive, you will probably find that people want to help.

Become an Autism and Informed Response trainer. Parents and caregivers like you have trained more than 2400 emergency responders in South Carolina. The S.C. Autism Society will prepare you, provide materials and even sit in on your first class. Call 800-438-4790 for more information. Parents find this is a great way to teach responders not just about autism, but how it affects their loved one. Call soon!

Protecting the Child or Adult with Autism

Information for Parents and Other Caregivers

WHAT YOU NEED TO KNOW

WHAT YOU CAN DO



Autism and Informed Response

Awareness for emergency responders

Funded by a grant from the S.C. Developmental Disabilities Council

Wanders away **Doesn't fear danger**
Upset by new situations **Public outbursts**
Can't I.D. self or explain what's wrong
Dangerous obsessions
Crime victim **Crime suspect**

As parents and caregivers, we may not want to think about possibilities like these. But, there is no escaping the fact that children and adults with autism are at increased risk for many emergencies. Compared to others their age, they are more likely to wander off and may be drawn to bodies of water, tall structures or busy streets. In any crisis, they may be less likely to help themselves.

Because people with autism have no identifying physical characteristics, their disability may not be immediately apparent to others. This means that police, firefighters and the general public may expect responses that the child or adult with autism may not be capable of making. In fact, odd behaviors can be misunderstood and actually **lead to** an emergency.

Everyone with autism is different. Individuals may respond differently to the same situation, and what helps one person may not help someone else. You know your loved one's strengths and weaknesses better than anyone, and you are therefore the best person to safeguard him or her. We hope this brochure will help you to identify potential threats to the safety of your loved one and help you not only to prevent, but to prepare for, potential emergencies.

Wandering Off

Wandering is a common and very serious problem. Try door alarms, I.D., and familiarizing neighbors and public safety agencies with your child (see center back panel). Secure pools and teach your loved one how to swim. Look into electronic tracking or a guard dog. Wandering may become less of a problem over time, but it remains one for some adults. Your best defense? Close supervision.

In the Car

Some individuals with autism remove their seat belts. Check baby stores for buckle guards; local schools can recommend what is used on buses. To alert emergency crews, some families use bumper stickers with the words, "I love someone with autism." In an accident, be prepared for the possibility that your loved one may wander off. Medics may need instructions. If a borderline injury, question the necessity of treatment. It could be more upsetting than it is worth.

School Issues

Behavior problems in schools have resulted in police intervention. What was tolerated in a younger child may no longer be accepted when he or she gets bigger. Be sure to address these issues in your child's IEP. It may be your best protection.

School resource officers can learn what is normal for your child, which may help in a crisis. Students may need special protection from bullies—a downside to inclusion. Inappropriate touching of self or others is common, with innocent acts magnified in puberty. Teach your child what is appropriate and what isn't. Rather than trying to eliminate a behavior like masturbation, teach that it is limited to the bedroom.

Fire Safety

It's difficult to predict how someone with autism will act in a crisis. For example, we believe the individual will leave a smoky house, but then he runs into the bathroom and locks the door. This is why advance preparations—especially drills—are critical.

Don't assume what was taught at school will be applied at home. Teach what to do at home. Make instructions and drills as simple as you can—for instance, when smoke is seen or smelled, or an alarm sounds, exit to a designated spot, such as a tree.

Try to foresee where your loved one will go if confused or afraid. Any child may try to go to a "safe place." In a real emergency, assign a family member to guard your loved one, who may panic in the commotion or try to go back inside.

Safeguard your home without creating traps. Bars have been put on windows to keep children in, only to entrap them when they needed to get out. Use smoke detectors and check batteries. Replace hollow core doors with solid doors, and shut them every night. Use a monitor if closing the door worries you.

Children and adults with autism often lack an understanding of danger. Obsessions with materials like matches need to be taken seriously. Keep them out of sight and reach, and consult a professional about how to change such behaviors.

Some individuals can call 911, while others may turn it into a game. Use your best judgment about teaching this skill. 911 systems can locate users of regular phones, so help may be dispatched without details being provided. Calls from cell phones are not as easily traced. (See center back panel about working with public safety agencies.)

Below Excerpted from: Autism, Advocates and Law Enforcement Professionals: Recognizing and Reducing Risk Situations for People with Autism Spectrum Disorders, by Dennis Debbaudt, Jessica Kingsley Publishers, London UK-Philadelphia, 142 Pages, ISBN #1-85302-980-7, Copyright 2002. Used with permission.

A good handout would include all the information necessary for a responder to know about the person with autism if the caregiver were to become incapacitated or become unable to communicate.

Person Specific Handout Checklist for 911 System, First Responders & Emergency Room Staff

- Name of child or adult
- Current physical description of child or adult, including height, weight, eye and hair colour, any scars or other identifying marks
- Recent photograph
- Name of parents or care providers
- Address
- Phone numbers--home & emergency, work, cell, pager
- Emergency contact person information
- Sensory, medical or dietary issues, if any
- Description of behaviours or characteristics that may attract attention
- Favourite attractions and locations where person may be found
- Likes, dislikes and approach techniques for the individual
- Method of communication, if non-verbal--sign language, picture board, written word
- ID wear--jewelry, tags, on clothes, non-permanent tattoo
- Map and address guide to nearby properties with water sources, dangerous locations highlighted
- Blueprint or drawing of home with bedrooms of autistic individuals highlighted

Circulate this information to trusted neighbours, and keep multiple copies handy for whenever shopping, traveling, or in the community with a person with autism.

A sample person-specific handout might look like this:

Michael Bradley

Male, seven years old, three feet, ten inches, 75 pounds, blonde hair, blue eyes, one inch scar at hairline on left forehead, slight gap between upper front teeth

Photograph

Parents are Susan (mother) and John (father) Bradley

1234 Maple Street

Phone numbers: home (313) 555-1111, Father's work (248) 555-2222; pager (313) 555-3333 Mother's cell phone (313) 555-4444

Emergency contact person: Kathy Avery (aunt) (248) 555-6666; Rita Jones (neighbour) 1256 Maple Street (313) 555-7777

Michael may be attracted to the church steeple and bell at St. Mark's church located at 788 Elm north of the Franklin senior citizen's complex. He will follow garbage trucks and ice cream trucks whenever he sees or hears them in the neighbourhood. He loves water and could be found at the fishpond near 1122 Maple or at the above ground swimming pool in the back yard of 1088 Maple. He cannot swim. Michael also has asthma. At times he needs an inhaler to breathe. He is allergic to penicillin and dairy products.

Michael is fascinated with circles and will search for any item with a circular shape, such as, car taillights, balls, rings, can lids, coins. These items can lure him into potentially dangerous situations, a coin or bottle cap in the street, for instance. Any circular item could also be used to gain his attention and compliance.

Michael also likes Matchbox miniature toy cars and will comply with simple requests when one is offered to him to play with. Michael will typically follow simple instructions from anyone who talks about fire engines or Winnie the Pooh characters or when an apple is offered as a reward.

Michael is afraid of dogs and balloons and would run into oncoming traffic if in the presence of or faced with either.

Michael will flap his hands rapidly and sometimes chews the lapels of clothes. He may open the doors of neighbour's homes and likes to turn on water hoses at nearby homes. He is not afraid of dangerous high places and has been found trying to balance himself at the top of monkey bars and swing sets located in the playground behind the Franklin senior citizen's complex one block west of Maple at the corner of Main.

Do not attempt to retrain him when he is involved in these behaviours. Control his behaviours by providing him with a quiet space where he can calm down. He will not tell you if he is hurt. Michael cannot tell you his name, address and phone number. Michael will repeatedly ask what your name is and your birth date. Those who consistently and repeatedly answer these questions will continue to hold his attention. Engaging in this repeated conversation allows Michael to calm down.

Michael has a laminated ID card sewn into the back pocket of his jeans and his t-shirts have permanent ink ID information printed on them at the lower left back section. The eyelets of his running shoes have an ID tag affixed.

Michael may find his way to the wooded park section located at 760 Elm directly to the north of the Franklin senior citizen's complex. He has been found in the past playing with pines cones at this location. He is also attracted to the door chimes of the home at 1134 Maple. The intersection of Maple and Main is a high traffic area and located one block east of a curve in the road. Michael is sometimes lured to this location to watch for passing fire engines, ice cream or garbage trucks.

Michael sleeps in the upstairs bedroom located in the northeast corner of our home. A yellow "occupant with autism" decal is affixed to this window. During a storm, he would be found in the basement of our home.

Response Options

In order to meet the needs of the diverse population with autism spectrum disorders, the purpose of the Locating Technology Project should be two-fold:

- A. Primary safety device
- B. Self-help device

Below are several essential features for each purpose.

A. *Primary Safety Device*

- Geographical range of less than 1 kilometre
- Compatibility with in-home security devices (doors, windows, etc.)
- Audio/visual alert to primary caregivers
- Immediate 9-1-1 alert to emergency personnel

B. *Self-Help Device*

- Geographical range of at least 20 kilometres
- Extremely accurate mapping system
- Compatibility with other communication equipment such as desktop or laptop computers, cell phones, pagers, BlackBerry® devices, etc.
- Escalating alert system:
 - 1) Audio/visual alert to let the individual know the pre-determined safety zone has been exceeded
 - 2) Audio/visual alert to primary caregivers
 - 3) 9-1-1 alert to emergency personnel

Are You Prepared for an Autism Emergency?

by Dennis Debbaudt © 2005

To 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 is 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 occur anywhere at anytime. The first time is often the worst time.

Another concern is preparation in the event that you become incapacitated or injured while caring for a person with autism at home or in the community.

An informational handout should be developed, copied and carried with you at all times--at home, in your car, purse or wallet. 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.

If wandering is a concern, contact law enforcement, fire and ambulance agencies.

Ask your local 911 call center to "red flag" this information in their 911 computer data base. Dispatchers can alert patrol officers about your concerns before they arrive. When we provide law enforcement with key information before an incident occurs, we can expect better responses.

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.

Prevention

If wandering is an issue for your family, consider contacting a professional locksmith, security company or home improvement professional.

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

CRISIS PLAN

Name	Health Card number				
Address	How can you be contacted? Phone number				
Describe your living situation	Permission to call? <input type="checkbox"/> No <input type="checkbox"/> Yes Comments				
Family doctor	Phone number				
Psychiatrist	Phone number				
Name of pharmacy	Phone number				
Emergency contact(s)	Phone number				
Relationship					
Support Coordinator/PSW/Counsellor	Phone number				
MEDICAL/HEALTH CONCERNS (i.e. allergies, sensitivities, physical and mental health issues)					
PHYSICAL DESCRIPTION (i.e. hair, eye and skin colour, distinguishing features, gender)					
PARTICIPANTS IN THE CREATION OF THIS PLAN					
Name	Date	Name	Date	Name	Date
Date of last update					
WHAT IS YOUR DEFINITION OF A CRISIS?					

CRISIS PLAN

LIST TRIGGERS (i.e. problems due to medical condition, medication issues/changes, times, dates, season, birthday, anniversary, visual images, social situations, family gatherings, places, people, large group situations, meetings with certain professionals, etc.)

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EARLY WARNING SIGNS (i.e. wringing hands, confusion, etc.)

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WHAT USUALLY HAPPENS WHEN YOU'RE IN A CRISIS (usual response without interventions)

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WHAT I WOULD NOT FIND HELPFUL DURING TIMES OF DISTRESS (i.e. what is least helpful, what actions do you not want to take place if possible)

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ADDITIONAL COMMENTS

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