Welcome!

This guide has been designed to help provide basic information for a parent whose child has been recently diagnosed with an Autism Spectrum Disorder or who has recently moved into the York County area. After a child is diagnosed with an Autism Spectrum Disorder, parents are often bombarded with information and ideas from doctors, media, friends and parents of other children living with Autism. This book does not contain everything there is to know about Autism. To gain further information every parent is encouraged to conduct further research by looking at the websites, calling the phone numbers listed, contacting their medical providers and attending Autism York meetings.

Please be sure to discuss any therapy or treatment plan with your child's treatment team, including pediatrician, teacher and service provider. Autism York does not endorse any treatment option over another. The information provided here is meant to give a basic understanding and help direct you to find more in-depth details. Autism York strongly recommends that before obtaining any treatment you research each topic, speak to your doctor and gain the appropriate medical guidance.

Autism does not change who your child is. He or she is still the same person they always have been and still needs your love most of all. A diagnosis and information can help you see your child and his/her world in an entirely new way. Be patient, active and persevere in this journey with your child and your family. You are not alone. Don’t hesitate to come to our meetings and events so that you can network with other families living with ASD and experience things with your child that you might not otherwise be able to enjoy.

Note that there are many places in this guide that assume you reside in York County. If you reside outside of York County, please find the appropriate agency in your home county. The term “Autism Spectrum Disorder”, “Autism” and “ASD” are used interchangeably in this guide. Please personalize this guide to suit your child’s and family’s needs. For further help or assistance, contact Autism York at 717-801-1272 or info@autismyork.org.

Our Best Wishes,
Autism York Board of Directors

What Is Autism? What is Autism Spectrum Disorder?

Excerpts from www.autismspeaks.org

Autism spectrum disorder (ASD) and autism are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors. With the May 2013 publication of the DSM-5 diagnostic manual, all autism disorders were merged into one umbrella diagnosis of ASD. Previously, they were recognized as distinct subtypes, including autistic disorder, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS) and Asperger syndrome.

ASD can be associated with intellectual disability, difficulties in motor coordination and attention and physical health issues such as sleep and gastrointestinal disturbances. Some persons with ASD excel in visual skills, music, math and art.

Autism appears to have its roots in very early brain development. However, the most obvious signs of autism and symptoms of autism tend to emerge between 2 and 3 years of age.

What Causes Autism?

Excerpts from www.autismspeaks.org

Not long ago, the answer to this question would have been “we have no idea.” Research is now delivering the answers. First and foremost, we now know that there is no one cause of autism just as there is no one type of autism. Over the last five years, scientists have identified a number of rare gene changes, or mutations, associated with autism. A small number of these are sufficient to cause autism by themselves. Most cases of autism, however, appear to be caused by a combination of autism risk genes and environmental factors influencing early brain development.

In the presence of a genetic predisposition to autism, a number of nongenetic, or “environmental,” stresses appear to further increase a child’s risk. The clearest evidence of these autism risk factors involves events before and during birth. They include advanced parental age at time of conception (both mom and dad), maternal illness during pregnancy and certain difficulties during birth, particularly those involving periods of oxygen deprivation to the baby’s brain. It is important to keep in mind that these factors, by themselves, do not cause autism. Rather, in combination with genetic risk factors, they appear to modestly increase risk. Increasingly, researchers are looking at the role of the immune system in autism.

What Does It Mean to Be “On the Spectrum”?

Excerpts from www.autismspeaks.org

Each individual with autism is unique. Many of those on the autism spectrum have exceptional abilities in visual skills, music and academic skills. About 40 percent have average to above average intellectual abilities. Indeed, many persons on the spectrum take deserved pride in their distinctive abilities and “atypical” ways of viewing the world. Others with autism have significant disability and are unable to live independently.

Prevalence of ASD

Excerpts from www.cdc.gov

- About 1 in 68 children has been identified with an autism spectrum disorder (ASD) according to estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network.
- ASDs are reported to occur in all racial, ethnic, and socioeconomic groups.
- ASDs are almost 4 times more common among boys (1 in 42) than among girls (1 in 189).
- About 1 in 6 children in the U.S. had a developmental disability in 2006-2008, ranging from mild disabilities such as speech and language impairments to serious developmental disabilities, such as intellectual disabilities, cerebral palsy, and autism.

More Facts & Stats from www.nationalautismassociation.org

- Autism greatly varies from person to person (no two people with autism are alike)
- The rate of autism has steadily grown over the last twenty years
- Comorbid conditions often associated with autism include Fragile X, allergies, asthma, epilepsy, bowel disease, gastrointestinal/digestive disorders, persistent viral infections, PANDAS, feeding disorders, anxiety disorder, bipolar disorder, ADHD, Tourette Syndrome, OCD, sensory integration dysfunction, sleeping disorders, immune disorders, autoimmune disorders, and neuro-inflammation.
- Children with autism do progress – early intervention is key
- Autism is treatable, not a hopeless condition

Do we have to seek a diagnosis for our child?

Every parent has the freedom to make all decisions regarding their children. Autism York encourages parents to educate themselves about the choices and options available to them before making any decisions. The goal of this booklet is to help provide parents with information and resources to help make informed decisions on what is best for their child and family. It is important to remember that an official diagnosis is often needed to gain services such as special education or wraparound services. However a parent can still treat present symptoms without a diagnostic label. This can be done through speech services for a speech delay, occupational therapy or sensory activities for sensory issues, diet changes for intestinal issues, etc.

Getting a Diagnosis

Excerpts from www.cdc.gov

Diagnosing autism spectrum disorders (ASDs) can be difficult, since there is no medical test, like a blood test, to diagnose the disorders. Doctors look at the child’s behavior and development to make a diagnosis. ASDs can sometimes be detected at 18 months or younger. By age 2, a diagnosis by an experienced professional can be considered very reliable. However, many children do not receive a final diagnosis until much older. This delay means that children with an ASD might not get the help they need. Diagnosing an ASD takes two steps:

Developmental Screening

Developmental screening is a short test to tell if children are learning basic skills when they should, or if they might have delays. During developmental screening the doctor might ask the parent some questions or talk and play with the child during an exam to see how she learns, speaks, behaves, and moves. A delay in any of these areas could be a sign of a problem. All children should be screened for developmental delays and disabilities during regular well-child doctor visits. Additional screening might be needed if a child is at high risk for developmental problems due to preterm birth, low birth weight or other reasons.

Additional screening might also be needed if a child is at high risk for ASDs (e.g., having a sister, brother or other family member with an ASD) or if behaviors sometimes associated with ASDs are present.

If your child's doctor does not routinely check your child with this type of developmental screening test, ask that it be done. If the doctor sees any signs of a problem, a comprehensive diagnostic evaluation is needed.

Comprehensive Diagnostic Evaluation

The second step of diagnosis is a comprehensive evaluation. This thorough review may include looking at the child's behavior and development and interviewing the parents. It may also include a hearing and vision screening, genetic testing, neurological testing, and other medical testing.
In some cases, the primary care doctor might choose to refer the child and family to a specialist for further assessment and diagnosis. Specialists who can do this type of evaluation include:

- Developmental Pediatricians (doctors who have special training in child development and children with special needs)
- Child Neurologists (doctors who work on the brain, spine, and nerves)
- Child Psychologists or Psychiatrists (doctors who know about the human mind)

Contact Early Intervention(EI), Lincoln Intermediate Unit(LIU) or your School District

If you think your child might have an ASD or you think there could be a problem with the way your child plays, learns, speaks, or acts, you can call these agencies to request a free evaluation to find out if your child qualifies for intervention services. <u>You do not need to wait for a doctor's referral or a medical diagnosis to make this call.</u> Services may include speech therapy, occupational therapy, physical therapy and special instruction.

Where to call for a free evaluation from the state depends on your child's age:

- If your child is not yet 3 years old, contact the York & Adams County Early Intervention at 717-771-9618.

- If your child is at least 3 years old but not school age yet, contact the Lincoln Intermediate Unit #12 (LIU 12) at 717-624-4616.

- If your child is school age, contact your local public school district.

Educate Yourself

You will be your child's best advocate. There is an incredible amount of information about Autism Spectrum Disorder out there. We hope that this guide is a starting point for you to discover and learn the possible causes, treatments, resources and services available. Remember that nobody knows and loves your child like you do.

We encourage you to ask the doctors, therapists, counselors and teachers any questions that you have when you meet with them for evaluations or treatment.

In addition to this guide, Autism York has an extensive Lending Library. The library is located at Rebecca's Place, 1805 Loucks Road, Suite 800 in York. To browse our selection of books, attend one of our Monthly Meetings or visit Rebecca's Place during regular operating hours. They are generally open between 9:00am – 6:00pm weekdays (some nights later).

You can also find websites later throughout this guide that may be helpful to you as you learn about ASD and the options available to you.

Get Organized

At times, it can be overwhelming to keep track of everything that is going on. Do yourself a favor and start a file or three ring binder now! As a rule of thumb, <u>YOU</u> should keep all original documents when at all possible. Items you may want to include are:

- Correspondence
- Evaluations
- Treatment Plans
- Contact names, numbers & email addresses
- Progress Notes
- Beginning & ending dates of services authorized
- Medication or supplement information
- Individualized Education Program (IEP) or 504 Plan documents
- School Progress Reports

Network with other Parents

Autism York provides lots of opportunities for you to connect with other parents. Take advantage of our monthly meetings and social events. You can find a schedule of activities and sign up to receive our newsletters on our website at www.autismyork.org.

Consider a Case Manager

A Case Manager(CM) can provide services to children and adults with ASD. They can provide referrals and coordination of appropriate services including, but not limited to, BHRS, Family Based Services, speech, occupational, outpatient therapies, and a residential treatment facility (when needed). Case Managers can also provide respite care, family driven funding and waiver funding (when the person qualifies for the IDD system). Case Managers are not required but can be helpful in coordinating and locating services for those with ASD. There is no charge to the family for these services.

These are the agencies in the York area that provide Case Management:
- York/Adams MH-IDD Autism Case Management Unit 717-771-9618 or 1-800-441-2025 ext.9618
- Service Access Management (SAM) 717-848-8744
- The Arc of York County 717-846-6589

PA Autism Insurance Act (Act 62)

PA Act 62 changes to the way autism services are covered through the Medical Assistance program and private health insurers. <u>If you have private insurance, it is important that you know whether or not Act 62 applies to your plan.</u>

The Autism Insurance Act:
- Requires many private health insurance companies to cover the cost of diagnostic assessment and treatment of autism spectrum disorder and services for children under the age of 21, up to $36,000 per year;
- Requires the Pennsylvania Department of Public Welfare, DPW, to cover the cost of services for individuals who are enrolled in the Medical Assistance program and do not have private insurance coverage, or for individuals whose costs exceed $36,000 in one year; and
- Requires the Pennsylvania Department of State to license professional behavior specialists who provide services to children.

Who is covered by the Autism Insurance Act?
- Children or young adults under age 21 with a diagnosis of an autism spectrum disorder who:
- Are covered under an employer group health insurance policy (including HMOs and PPOs) that has more than 50 employees and the policy is not a "self-insured" or "ERISA" policy;
- Are on Medical Assistance; or
- Are covered by Pennsylvania’s Children’s Health Insurance Program (CHIP).

For additional information, check out www.PAAutismInsurance.org.

Apply for Medical Assistance

The Medical Assistance (MA) Access card is the insurance card used for Medical Assistance. This is the insurance provided through the Department of Public Welfare (DPW). Although this is often associated with persons receiving welfare monetary assistance, this is not the only way to obtain the MA card. <u>Almost all children with an Autism Spectrum Disorder qualify for the MA card regardless of parent income.</u> It is highly recommended that you obtain an MA card for your child, as many services are only covered through Medical Assistance. Wraparound services are not covered by private insurance (except if you qualify under Act 62) and most providers do not accept private pay. Many social skills programs are also only paid for by the MA card. MA will also cover most copays and deductibles not covered by your private insurance if you have one.

A Medical Assistance Access card can be obtained by:

- Calling or visiting York County Assistance Office
  130 N. Duke Street
  P.O. Box 15041
  York, PA 17405-7041
  Phone: 717-771-1100 or 800-991-0929
- Applying online at www.compass.state.pa.us
- Downloading a paper application and mailing it
  English http://www.dhs.state.pa.us/cs/groups/webcontent/documents/form/p_014338.pdf
  Spanish http://www.dhs.state.pa.us/cs/groups/webcontent/documents/form/p_011870.pdf

Consider “Wraparound” Services

Behavioral Health Rehabilitative Services (BHRS) are often called wraparound services. Treatment and therapeutic interventions are prescribed by a psychologist or psychiatrist and are provided on an individual basis in the person’s own environment such as home, school, and community. These services include Therapeutic Support Staff (TSS), Behavioral Specialist Consultants (BSC), and Mobile Therapists (MT). Children/adolescents within the BHRS system are referred for services because they are experiencing behavioral and/or emotional difficulties in their home, school and/or community. Services are paid for only by Medical Assistance (MA) Access card and are not covered by self-pay or private insurance (unless your insurance falls under Act 62).

BHRS supports the philosophy that children/adolescents with serious behavioral or emotional issues due to mental health diagnosis, medical conditions or Autism Spectrum Disorders, can be supported within their natural settings. Wraparound services may enhance or supplement services offered by your intermediate unit, early intervention provider, or school district.

Agencies in the York area that provide Wraparound services can be found throughout our Local Service Provider Guide. See that guide for contact information to request services.

Every treatment has its own unique pros and cons. At this point there is no research to show that any one treatment has been proven to work for each and every child. Autism York suggests that you carefully research different treatments and decide on what best fits your child and family. This can be done through reading, on-line research, working with various professionals and talking to other parents. Although input from others will be helpful, only you know the specific needs of your child and can determine what treatment will be most successful. Please note that many families successfully use programs that are made up from parts of several different methods. By carefully monitoring the program, you can determine if your child is making progress and if there are any changes that need to be made to their treatment.

BEHAVIORAL INTERVENTIONS

Applied Behavior Analysis (ABA)

This is the systematic and scientific study of behavior. Behaviors are defined in measurable and observable terms. This may include both behaviors of concern (such as screaming and hitting) as well as functional behaviors of language, social skills and self-help skills.

As this is an "applied" science, therapy occurs in a natural setting (such as home, school and community) rather than a scientific "laboratory" type setting. ABA therapists strive to develop skills that will enable an individual to function as independently as possible and to fully participate in the life of their family and community.

The analysis term refers to the fact that data is taken during all steps of treatment to ensure that progress is being made. A baseline of behaviors and skills should be taken before starting any intervention. Data is used to make revisions as needed to the program. A functional behavior assessment (FBA) is conducted on behaviors of concern (such as physical aggression and self-injury) to determine the function of the behavior. After the function has been determined, the team can research the interventions that will be most appropriate.
For additional information see www.abainternational.org.

Verbal Behavior (VB)

Also known as Applied Verbal Behavior (AVB), this is a program under the guidelines of applied behavior analysis. Based on Skinner's analysis of verbal behavior, this approach states that language is a behavior that is under control of the same conditions as other behaviors. This approach focuses on teaching language through structured techniques and exercises. Data is taken to measure a child's progress and determine the skills that need to be taught. An assessment is used to determine a baseline of the child's language skills and the skills that need to be taught next. Two of the most common assessments are the: Assessment of Basic Language and Learning Skills (ABLLS) or the Verbal Behavior Milestones Assessment and Placement Program.

Floortime/Difference Relationship Model

This therapy was originally developed by Dr. Stanley Greenspan based on the belief that an adult can help a child expand communication by "entering their world". Therapy usually includes play activities on the floor or in a natural setting. These activities focus on helping the child to develop an interest in the world around them by having the adult join in their activities and interests. This technique focuses more on building healthy foundations for social, emotional and intellectual capacities rather than focusing on skills and isolated behaviors. For more information please visit www.stanleygreenspan.com.

Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH)
TEACCH is a North Carolina program administered through the University of North Carolina at Chapel Hill, but because of its training activities and publications the TEACCH approach is widely known, nationally and internationally. The long-term goals of the TEACCH approach are both skill development and fulfillment of fundamental human needs such as dignity, engagement in productive and personally meaningful activities, and feelings of security, self-efficacy, and self-confidence. To accomplish these goals, TEACCH developed the intervention approach called "Structured Teaching" that includes using visual supports and structuring the physical environment. For more information please visit www.teacch.com.

SPEECH, LANGUAGE & MOTOR INTERVENTIONS

Speech-Language Therapy
From www.autismspeaks.org
Most autism behavioral intensive therapy programs include speech-language therapy. With a variety of techniques, speech-language therapy addresses a range of challenges often faced by persons with autism. For instance, some individuals on the autism spectrum do not speak, while others love to talk but have difficulty using conversational speech and/or understanding the nuances of language and nonverbal cues when talking with others.

Speech-language therapy is designed to coordinate the mechanics of speech with the meaning and social use of language. Such a program begins with an individual evaluation by a Speech-Language Pathologist (SLP) to assess an individual's verbal aptitudes and challenges. From this evaluation, the SLP sets goals that may include mastering spoken language and/or learning nonverbal communication skills such as signs or gestures. In each case, the goal is to help the person communicate in more useful and functional ways. The Speech-Language Pathologist can provide therapy one-on-one, in a small group or in a classroom setting. For more information, visit the America Speech-Language Hearing Association's AAC webpage www.asha.org.

Augmentative and Alternative Communication (AAC)
From www.autismspeaks.org
Nonverbal persons with autism can benefit from a variety of augmentative and alternative communicative (AAC) devices and methods. The Picture Exchange Communication System (PECS) is among the most commonly used with children and adults who have little or no verbal ability. Therapists, teachers and parents help the child or adult build a vocabulary and consistently articulate desires, observations and feelings through pictures. This system can be taught and used at home, in the classroom and a variety of other settings.

At the start of a PECS program, the instructor teaches the child or adult to exchange a picture for an object—for instance, a picture of an apple for an actual apple. With instruction, the person learns to distinguish pictures and symbols and use both to form sentences. Although PECS is based on visual tools, the program emphasizes and reinforces verbal communication. Caregivers can purchase standard PECS images as a part of a manual or simply gather photos from everyday sources such as newspapers, magazines and books. Other augmentative and alternative communicative devices include specially programmed computers, iPads, and iPhones. For more information, visit the America Speech-Language Hearing Association's AAC webpage www.asha.org.

Occupational Therapy (OT)

From www.autismspeaks.org

Occupational therapy (OT) addresses a combination of cognitive, physical and motor skills. Its goals include helping a child or adult gain age-appropriate independence and participate more fully in life. For a person with autism, occupational therapy often focuses on skills for appropriate play or leisure skills, learning and self-care skills.

Therapy begins with a certified Occupational Therapist evaluating the person's developmental level as well as related learning styles, social abilities, and environmental needs. Based on this evaluation, the therapist determines goals and selects strategies and tactics for enhancing key skills. For instance, goals may include independent dressing, feeding, grooming and use of the toilet, along with improved social, fine motor and visual perceptual skills. Typically, occupational therapy involves half-hour to one-hour sessions with a frequency determined by the individual's needs. In addition, the person with autism practices strategies and skills—with guidance—at home and in other settings including school. For more information, visit the American Occupational Therapy Association webpage www.aota.org.

Sensory Integration Therapy (SI)

From www.autismspeaks.org

Many children and adults with autism have challenges in processing sensory information such as movement, touch, smell, sight and sound. Sensory integration (SI) therapy identifies such disruptions and uses a variety of techniques that improve how the brain interprets and integrates this information. Occupational therapy often includes sensory integration. Other times it is delivered as a stand-alone therapy.

Certified Occupational and Physical Therapists provide sensory integration therapy. They begin with an individual evaluation to determine a person's sensitivities. From this information, the therapist plans an individualized program that matches sensory stimulation with physical movement to improve how the brain processes and organizes incoming information. As such, the therapy often includes equipment such as swings, trampolines and slides.

Sensory integration therapy can allow a child or adult with sensory integration difficulties to become more "available" for learning and social interactions. Family members and teachers often find that its techniques can help calm an affected child or adult, reinforce positive behavior and help with transitions between activities. For more information about sensory integration or sensory processing, check these websites: www.spdfoundation.net www.out-of-sync-child.com

Physical Therapy (PT)

From www.autismspeaks.org

Many children and adults with autism have challenges with motor skills such as sitting, walking, running and jumping. Physical therapy (PT) focuses on problems with movement that cause real-life limitations. In particular, physical therapy can improve poor muscle tone, balance and coordination.

Certified physical therapists deliver physical therapy beginning with an evaluation of a person's physical abilities and developmental level. They then design programs of activities that target areas of challenge. Typically therapy sessions run a half hour to an hour and include assisted movement, various forms of exercise and the use of orthopedic equipment. The needs of the child or adult receiving services should determine the frequency of these sessions.

OTHER INTERVENTIONS

Music Therapy

Music Therapy is an established health profession in which music is used within a therapeutic relationship to address physical, emotional, cognitive, and social needs of individuals. After assessing the strengths and needs of each client, the qualified music therapist provides the indicated treatment including creating, singing, moving to, and/or listening to music. Through musical involvement in the therapeutic context, clients' abilities are strengthened and transferred to other areas of their lives. Music therapy also provides avenues for communication that can be helpful to those who find it difficult to express themselves in words. Research in music therapy supports its effectiveness in many areas such as: overall physical rehabilitation and facilitating movement, increasing people's motivation to become engaged in their treatment, providing emotional support for clients and their families, and providing an outlet for expression of feelings. For additional information see www.musictherapy.org.

Art Therapy

Art therapy is a mental health profession in which clients, facilitated by the art therapist, use art media, the creative process, and the resulting artwork to explore their feelings, reconcile emotional conflicts, foster self-awareness, manage behavior and addictions, develop social skills, improve reality orientation, reduce anxiety, and increase self-esteem. A goal in art therapy is to improve or restore a client's functioning and his or her sense of personal well-being. Art therapy practice requires knowledge of visual art (drawing, painting, sculpture, and other art forms) and the creative process, as well as of human development, psychological, and counseling theories and techniques. For additional information see www.americanarttherapyassociation.org.

Diet

Some families have found that dietary intervention may be helpful in treating individuals affected by autism. There are many diets that are being used to deal with the variety of physical and behavioral symptoms displayed by those affected. The following are some of the diets presently being used: the Gluten-Free, Casein-Free diet (GF/CF diet), the Specific Carbohydrate Diet, the Feingold diet, the Low-Oxalate diet, and for those with intractable seizures, the Ketogenic Diet. The most commonly known and used diet is the GF/CF diet.

It is strongly recommended before you attempt any dietary changes for your child, that you research the topic carefully and work closely with a medical professional. Just like any treatment, specialized diets do not work for every child, while for some they are very effective.

For more information on specialized diets please visit the following websites:

- The GF/CF Diet eliminates gluten (protein found in most grain products) and casein (protein found in milk products). It is thought that when these proteins are not fully digested they can cross the lining of the gut and cause neurological problems. Sensitivities to gluten and casein can be seen as behaviors, rashes, constipation, diarrhea, bloated belly, nasal congestion, and/or ear infections. Elimination of gluten and casein may decrease some of your child's symptoms. www.gfcfdiet.com www.tacanow.org
- The Specific Carbohydrate Diet is a scientific diet based on chemistry, biology and clinical studies. It is detailed in the book, "Breaking the Vicious Cycle", written by Elaine Gottschall. It was designed for patients with intestinal diseases. Many individuals with autism suffer from inflammatory bowel diseases including Colitis and Crohn's Disease. www.pecanbread.com www.breakingtheviciouscycle.info
- The Feingold Diet involves the elimination of artificial colors and flavors as well as other food additives as a potential way to resolve a number of behavioral and cognitive difficulties. This diet is based on the premise that allergic reactions or sensitivities to certain components of foods may contribute to the symptoms of certain medical conditions. www.feingold.org

Medications

www.nimh.nih.gov

Some medications can help reduce symptoms that cause problems for your child in school or at home. Many other medications may be prescribed off-label, meaning they have not been approved by the U.S. Food and Drug Administration (FDA) for a certain use or for certain people. Doctors may prescribe medications off-label if they have been approved to treat other disorders that have similar symptoms to ASD, or if they have been effective in treating adults or older children with ASD.

Some medications that may be prescribed off-label for children with ASD include antipsychotic, antidepressant and stimulant medications to treat some of the specific symptoms or behaviors of ASD. You should work with a doctor who has experience treating children with ASD. The doctor will usually start your child on the lowest dose that helps control problem symptoms. Ask the doctor about any side effects of the medication and keep a record of how your child reacts to the medication. The doctor should regularly check your child's response to the treatment.

You have many options for treating your child's ASD. However, not all of them have been proven to work through scientific studies. Read the patient information that comes with your child's medication. Some people keep these patient inserts along with their other notes for easy reference. This is most useful when dealing with several different prescription medications. You should get all the facts about possible risks and benefits and talk to more than one expert when possible before trying a new treatment on your child.

It is also important to track which medications or supplements your child is using. See the appendix for a sample medication log that you can use.

Biomedical Treatments

Research shows that many individuals with autism spectrum disorders have underlying medical issues that frequently go undiagnosed and can cause or exacerbate symptoms of autism. Treating these underlying medical issues can greatly improve some of the behaviors and symptoms associated with autism.

Treatment options may include:

- vitamin and mineral supplementation
- immune system support
- anti-inflammatories
- neurofeedback
- chelation/detoxification therapy
- hyperbaric oxygen therapy
- anti-fungal and anti-viral therapies
- dietary intervention
- methyl B-12 therapy

Patients should undergo diagnostic testing and consult with a licensed physician to develop an individualized treatment plan. There are a number of physicians in the U.S. who specialize in treating children and adults with autism. Until recently, the Autism Research Institute (ARI) maintained a list of clinicians who attended DAN! (Defeat Autism Now!) physician training seminars. This list is no longer actively maintained. A new effort is now underway to educate, train and board certify physicians treating individuals with autism. Here are some informative websites you might want to visit: www.medmaps.org www.tacanow.org. www.autism.com

OTHER SERVICES & STRATEGIES

This list is certainly not “all-inclusive” but includes some commonly-used terms, services and strategies that you might hear other parents discuss, see in our Local Service Provider Directory or find in our Lending Library.

Educational Advocate

An Educational Advocate is someone who is knowledgeable about the Federal & State laws protecting children with disabilities. They will work with the student, parents and the school to ensure that appropriate plans are put in place so that student can work to his full potential in school.

Respite Services

Trained caregivers provide temporary care to children or adults with disabilities, giving the main caregiver or parent a break.

Summer Therapeutic Activity Program (STAP)

A Behavioral Health Rehabilitation Service that provides therapeutic support through a structured summer day camp setting.

Family Based Mental Health Services (FBMHS)

Family-Based Mental Health Services provides intervention, support services and therapy in the home and community for families and their children or adolescents who have significant emotional disturbances. It is a short term, yet intensive program aimed to keep children from needing out-of-home placement.

Therapeutic Listening *from* www.vitallinks.net

Therapeutic Listening is an evidence-based auditory intervention intended to support individuals who experience challenges with sensory processing dysfunction, listening, attention, and communication. Clients listen to specifically recorded and enhanced music via headphones as a part of an in-clinic and/or home therapy program. Therapeutic Listening is implemented as part of a home program designed by a trained therapist to suit the unique needs of each client.

Tomatis Method *from* www.tomatis.com

This method can be used when the sound message is correctly heard but poorly analyzed in an emotional framework. The TOMATIS Method is an auditory therapy that stimulates the brain. You can do the listening sessions repeatedly by using specially designed devices that stimulate the brain and progressively help it more effectively analyze the sensory message.

Social Stories *from* www.thegraycenter.org

A Social Story™ describes a situation, skill, or concept in terms of relevant social cues, perspectives, and common responses in a specifically defined style and format. The goal of a Social Story™ is to share accurate social information in a patient and reassuring manner that is easily understood by its audience.

EDUCATION

Promoting Awareness & Advocating For Your Child at School

Teacher(s) and classmates spend a significant amount of time with your child each week. Here are some ways that you can help them work, learn and have fun with your child.

1. Request to meet the teacher prior to the start of the school.
2. Take a tour of the classroom and school (if new) with your child prior to the start of school.
3. Provide written information specifically about your child to the teacher.
4. Provide general autism information to the teacher and possibly the classmates.
5. Contact the school to review your child's IEP or 504, if applicable.
6. If not provided for in the IEP or 504, establish a communication method or system with the teacher.
7. Maintain regular contact with your child's teacher.
8. Volunteer in your child's classroom.
9. Consider if it would be helpful and appreciated for someone from Autism York to do an "Understanding Autism" awareness presentation.
10. Thank your teacher regularly! They need understanding, encouragement and appreciation as much as you do.

Sample child information forms and worksheets to share with teachers are included in the Appendix.

Individualized Education Program (IEP)

An Individualized Education Program (IEP) describes the educational program that has been designed to meet that child's unique needs. Each child who receives special education and related services must have an IEP. Each IEP must be designed for one student and must be a truly individualized document. The IEP creates an opportunity for teachers, parents, school administrators, related services personnel, and students (when age appropriate) to work together to improve educational results for children with disabilities. The IEP is the cornerstone of a quality education for each child with a disability and is a legally binding document.

504 Plan

A 504 Plan refers to Section 504 of the Rehabilitation Act and the Americans with Disabilities Act, which specifies that no one with a disability can be excluded from participating in federally funded programs or activities, including elementary, secondary or postsecondary schooling. "Disability" in this context refers to a "physical or mental impairment which substantially limits one or more major life activities." This can include physical impairments; illnesses or injuries; communicable diseases; chronic conditions like asthma, allergies and diabetes; and learning problems. A 504 plan spells out the modifications and accommodations that will be needed for these students to have an opportunity perform at the same level as their peers, and might include such things as wheelchair ramps, blood sugar monitoring, an extra set of textbooks, a peanut-free lunch environment, home instruction, or a tape recorder or keyboard for taking notes.

A chart showing the similarities and differences of an IEP versus a 504 Plan is in the Appendix.

Extended School Year (ESY) Services

Excerpts from Education Law Center publication on ESY services – see www.elc-pa.org
ESY services are specialized instruction and related services such as therapies provided to a child with a disability when the school or preschool program is not normally in session - for instance, in the summer or during school vacations. Preschoolers and school-aged children with disabilities are eligible for ESY services if the IEP Team determines that the services are necessary to provide the child with a free appropriate public education. Most often, it is children who lose skills or behaviors relevant to the child's IEP goals or objectives during program breaks (called "regression"), and who have difficulty catching up (called "recoupment"), who are eligible for ESY. At the annual IEP meeting for every child with a disability, the IEP Team must raise and discuss whether the child needs ESY services. The IEP meeting to consider ESY for children with severe emotional disturbances, autism, moderate and severe levels of retardation or multiple disabilities must occur no later than February 28 of each school year. The IEP that should accompany the Notice of Recommended Educational Placement (NOREP) contains the IEP Team's ESY determination for these children. The NOREP must be issued by March 31 of the school year.

TRANSITION & ADULT SERVICES

There are many things to consider for an individual with ASD as they approach the teen years and adulthood. It is recommended that transition planning start at age 14 and be included in the IEP (if applicable). There are also guardianship decisions, post-school education, Social Security benefits (at age 18), vocation and housing to consider. The Department of Public Welfare also has a few Medicaid programs available to help adults with ASD.

Autism York has created a guide for Transition to Adulthood. You may pick up at copy at our Lending Library, download a copy from our website or contact us to get one.

ADVOCATING FOR YOUR CHILD

(Note: These are simply suggestions. Don't feel that you must do all of them. This is written in relation to school, however, it is true for other services and organizations that you will work with.)

Be Informed

- Know the facts of your child's situation, including his/her strengths and weaknesses and how they affect your child in the applicable environment.
- Know the applicable laws and your rights.
- Know your school - including teachers, administrators, therapists and other personnel.
- Understand your role and responsibilities as a parent.
- Take the time to learn the real facts – don't rely on gossip or hearsay.

Be Involved

- Volunteer at your child's school as you are able. Some parents may be able to volunteer weekly; others may only be able to volunteer a few times. Either way, it shows that you appreciate what they do and that you are all on the same team.
- Build positive relationships with school personnel and other parents.
- If you will be attending a longer meeting, consider bringing some type of treat (i.e. salty snacks, baked goods, chocolate). Food is a great way to create common ground and show appreciation for those that make the effort and time to attend.

Be Organized

- Make requests in writing even if you have also spoken directly to school personnel.
- Keep copies of everything you get from or send to the school.
- Keep a record of conversations noting the date, time and names/positions of school personnel and any decisions reached.
- When possible, ask for written confirmation of what is promised to you.
- Organize your records. A notebook or binder can be helpful.

Be Prepared

- Decide what you think the school could do to solve the problems you've identified. If you are prepared to offer solutions or work as a team to determine them, there is a much better chance of a successful outcome.
- If you are attending a meeting, know why the meeting is being scheduled. Don't be afraid to ask so that you can be prepared and able to fully participate in the discussion.
- Bring materials that you think will help the group come to a decision: evaluations, report cards, copies of the law, private evaluations, and notes from your own observations.
- Decide what you want to accomplish. Prioritize and be selective with the things that you think will most impact your child's progress. It may be helpful for you to write this list down prior to the meeting so that you can stay on track.
- Bring someone with you to the meeting – an advocate, family member, friend, etc.
- If necessary, bring other professionals who have worked with your child.
- Network with other parents about what has worked and not worked for their children. It might not necessarily work in your situation but you can still learn from their experiences to gain insight on how to advocate for your child.

Be Intentional & Respectful

- Be polite, courteous and on time. Respect the schedules of the others involved.
- Be ready to talk and to listen.
- Acknowledge the good things that have happened and special efforts that have been made.
- If there is something important that you want to say at the meeting, bring notes. It will help you feel confident as you share this information.
- Be concise and clear.
- Ask questions when you don't understand.
- Take the time to make good decisions. Don't feel pressured to rush things if you feel that the situation hasn't been adequately addressed.
- End meetings with a plan of action. Set deadlines and get a summary of what was agreed to and who was present.
- Make sure that you do the actions you promised in the meeting. Respectfully follow-up with others as needed.
- Thank those that met with you either in person, via email or with a note.

Always Remember:

- YOU are an expert on your child and know him/her the best.
- Focus on the problem, not the people. Avoid getting sidetracked by personal conflicts so that the focus can remain on the child.
- Other personnel and professionals may come and go but you will be the best person to understand the "big picture".
- Focus on the present and the future. Work first to address the present problem; address remedies for the past second.
- Be flexible and creative! There may be more than one way to get what your child needs. Work toward mutually agreeable solutions.
- Remember what is truly important to you and your child. If you don't try to effectively advocate for your child, nobody else may either.

SAFETY

Wandering & Elopement

Excerpts from www.autismsafety.org
In 2008, Danish researchers found that the mortality rate among the autism population is twice as high as in the general population. In 2001, a California research team attributed elevated mortality among people with autism in large part to drowning. Drowning, prolonged exposure, and other wandering-related factors remain among the top causes of death within the autism population. In a 2007 online poll through the National Autism Association, 92% of parents reported that their children with autism have a tendency to wander. In 2011, preliminary data from an Interactive Autism Network study found that almost half of all children wander.

Wandering: Wandering means to move about from place to place with or without a fixed plan.
Elopement: The act of running away, wandering away, walking away, escaping, or otherwise leaving a safe setting unsupervised or unnoticed.

About Autism Wandering / Elopement

- *Goal-Directed Wandering:* Wandering with the purpose of getting to something (water, train tracks, park, an item or place of obsession, etc.), or getting away from something (noise, bright colors, clutter, commotion, etc.).
- *Non Goal-Directed Wandering:* Wandering with seemingly no purpose; random and aimless movement from one place to another.
- *Wandering – Other:* Any other type of wandering – nighttime wandering, or wandering due to disorientation or confusion.
- *Bolting / Fleeing:* The act of suddenly running or bolting, usually to quickly get away from something, or in negative reaction to an event, anxiety, excitement or stress.

If your school-age child is at risk of wandering and/or elopement, you may want to consider including it in their IEP if they have one. For a sample letter on how to request this of your school, see http://www.awaare.org/IEPletter.htm.

Teach your Child to Swim

Children with ASD are attracted to water. Swimming lessons are <u>highly</u> recommended and available at most YMCA and YWCA locations. This is a great preventative measure!

ALERT First Responders, ER Room Staff and other Medical Professionals

There are some simple ways to alert emergency workers that there is someone with autism involved in the situation.

- Place some type of Autism awareness magnet on your vehicle.
- Window clings for car or home to alert first responders that someone in the vehicle or home may need special assistance in the event of an emergency.
- Safety or Autism alert cards carried by the individual with ASD

INFORM First Responders, ER Room Staff and other Medical Professionals
Many safety organizations highly recommend having some type of information/contact form prepared for your child in case of emergency and/or to help medical professionals work with your child. Keep it in a convenient place so that you can access it in an emergency such as near your medications, on your refrigerator or by the phone. Autism York has created a form that you can use and copy is included in the Appendix.

REQUEST Accommodations at a Medical Facility
If your child is in a medical facility, you may want to assess and consider requesting one or more of these accommodations based on the situation:

- Alert the intake staff or receptionist that the patient has ASD.
- Request a quiet place to wait if the waiting area is congested and noisy.
- Consider sensory sensitivities to light, sound, touch and smell.
- Make sure the medical staff is aware if your child has a low or high pain tolerance or if they are sensitive to hot or cold temperatures.
- Request a private exam area if possible.
- If paper gowns or exam table coverings are a problem for your child, request a cloth one.
- Alert them if your child does not like to be touched so that they can proceed carefully.
- Request that the staff explain in simple language what they are doing before they do anything to your child so that the child knows what to expect.
- Tell them to allow extra time for the child to respond to questions.

AVAILABLE from Autism York! **Autism Alert Cards**
We are now able to provide Autism Alert cards that you can use with your child, teen or adult with ASD. These business-sized cards were developed to be carried in a car, purse or wallet for older teens and adults along with their driver's license or state ID. The cards can also be placed in a child's backpack. If you are traveling on vacation or at a crowded location like an amusement park, you may want to punch a hole in them, laminate them and add them to a carabineer that can be attached to your child. We also have a second – extended version for individuals that have more information to include on the card. Cards are available at our meetings or they can be mailed to you upon request.

Safety through the years
You may want to consider how to build safety skills in your child, teen or adult with ASD. This is particularly important if they are fairly independent or driving themselves around the community. The Appendix includes a great article on various skills needed around law enforcement officers, first responders and security checks as well as disclosure tips and ways to avoid street crime and abusers.

For more information about Safety & Autism, see these websites:
www.awaare.org www.autismsafety.org www.autismriskmanagement.com

HELPFUL TIPS

Medical Assistance Transportation Program (MATP)

Individuals who are receiving Medical Assistance may be eligible to receive transportation assistance through the MATP program. This can take the form of mileage reimbursement, help paying for public transportation or paratransit services.

To access MATP services:

- Contact your local MATP provider. In York, contact rabbittransit 717-845-7553 or toll free 1-800-632-9063
- A one-time MATP application must be completed and signed.
- The MATP provider will give you information about how to schedule transportation, request mileage reimbursement and use the local program.

Women, Infants and Children (WIC) Program

The WIC program provides free food and nutrition education to low-income women who are pregnant, breastfeeding for up to 12 months after giving birth, non-breastfeeding for up to 6 months after giving birth, and children ages birth-5 years. WIC is particularly helpful if your child is prescribed a special formula or nutritional supplement. Vouchers for food purchases are distributed every two months at WIC offices. Pennsylvania women who meet income guidelines and have a nutritional or medical problem are eligible. *Children who have Medical Assistance may automatically qualify for WIC, regardless of parent income.*

An application must be completed and signed by a physician and updated periodically to re-qualify. More information is available at www.pawic.com by calling 800-942-9467.

Diapers

If your child is over the age of 3 and still not potty trained, you may be eligible to receive free diapers or pull-ups shipped to you each month. Check with your MA Insurance provider to see if they will cover them. You will need a prescription from your primary care physician that includes the size, quantity and any type of allergy that needs to be considered.

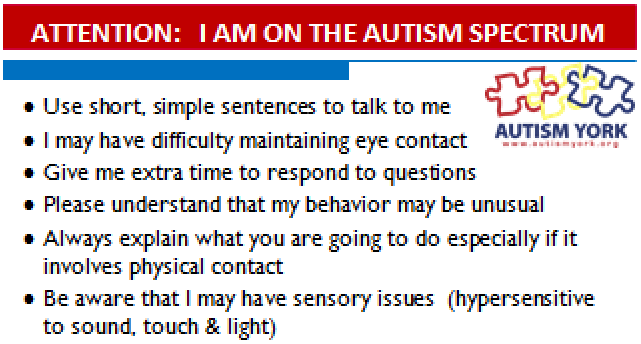
Amusement Parks

If your ASD child has significant difficulty waiting in line, contact customer/guest services to learn about accommodations that they can offer those with disabilities. We encourage you to use this option only if your child cannot enjoy the park otherwise. It is also advisable to contact the park in advance or check their website to see what services they provide and what, if any, documentation you may need to provide to get the accommodations.

Autism “Business Cards”

To help increase awareness and understanding, some parents/caregivers carry business cards that contain a message about autism as well as contact information for a local or national autism advocacy group. When out in the community, these cards can be shared to help provide an explanation about autism or when you feel you need to explain your child's behavior. Autism York does have a few versions of this card. Feel free to ask for some at one of our meetings.

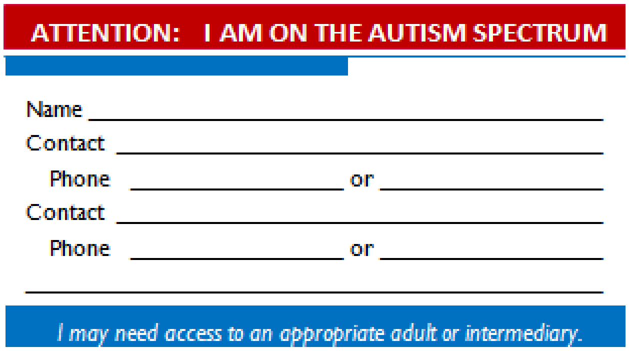
front



ATTENTION: I AM ON THE AUTISM SPECTRUM

- Use short, simple sentences to talk to me
- I may have difficulty maintaining eye contact
- Give me extra time to respond to questions
- Please understand that my behavior may be unusual
- Always explain what you are going to do especially if it involves physical contact
- Be aware that I may have sensory issues (hypersensitive to sound, touch & light)

back



ATTENTION: I AM ON THE AUTISM SPECTRUM

Name ______________________________
Contact ______________________________
Phone ______________ or ______________
Contact ______________________________
Phone ______________ or ______________
____

I may need access to an appropriate adult or intermediary.

AAC	Augmentative and Alternative Communication
ABA	Applied Behavior Analysis
ADA	Americans with Disabilities Act
ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
BAS	Bureau of Autism Services
BCBA	Board Certified Behavior Analyst
BHRS	Behavioral Health Rehabilitative Services
BSC	Behavioral Specialist Consultant
CCBH	Community Care Behavioral Health (managed care organization commonly used by MA)
CDC	Centers for Disease Control and Prevention
CM	Case Manager
DPW	Department of Public Welfare
EI	Early Intervention
FAPE	Free Appropriate Public Education
FBA	Functional Behavior Assessment
FBMHS	Family Based Mental Health Services
GF/CF	Gluten Free/Casein Free
IDD	Intellectual and Developmental Disabilities (replacing the term MR in some agencies)
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Plan
LCSW	Licensed Clinical Social Worker
LIU	Lincoln Intermediate Unit
LRE	Least Restrictive Environment
MA	Medical Assistance
MATP	Medical Assistance Transportation Program
MH	Mental Health
MR	Mental Retardation
MT	Mobile Therapist
NAA	National Autism Association
OCD	Obsessive Compulsive Disorder
OT	Occupational Therapist/Therapy
OTR/L	Occupational Therapist – Registered, Licensed
OVR	Office of Vocational Rehabilitation
PECS	Picture Exchange Communication System
PDD	Pervasive Developmental Disorders
PT	Physical Therapist/Therapy
RTF	Residential Treatment Facility
SAM	Service Access Management
SI	Sensory Integration
SLP	Speech-Language Pathologist
SSI	Supplemental Security Income
ST	Speech Therapy
STAP	Summer Therapeutic Activities Program
TA	Teacher’s Assistant
TSS	Therapeutic Support Staff

Items included in the appendix:

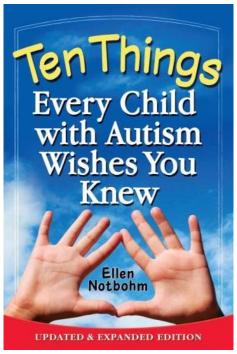
Title	Source
10 Things Every Child with Autism Wishes You Knew	Ellen Notbohm www.ellennotbohm.com
Comparison of an IEP and a 504 Plan	Autism York with sources listed
Student Info Sheet: An Introduction to My Child (open ended format for a parent to complete)	Autism York*
Student Info Sheet: 12 Things to Help you Understand (fill in the blank format for a parent to complete – boy version included, girl version available on our website)	Autism York*
Student Info Sheet: Things About Me (short answer format for student to complete)	Autism York*
Autism & Wandering	www.awaare.org
Autism Spectrum Disorder – Emergency Contact Form	Autism York*
Plan Your Response for an Autism Emergency	Dennis Debbaudt www.autismriskmanagement.com

All items are reprinted with permission of the authors. We appreciate their willingness to help us support families. Please visit their websites and contact them for more information.

* Electronic versions of these forms can be downloaded at www.autismyork.org.

Ten Things

Every Child with Autism Wishes You Knew



by Ellen Notbohm

from the book *Ten Things Every Child with Autism Wishes You Kn*ew, 2nd edition (2012, 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. Autism can be 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 labeled an "incurable disorder," but that notion has crumbled in the face knowledge and understanding that increase even as you read this. Every day, individuals with autism show 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 basic elements has a tremendous impact on their ability to journey towards productive, independent adulthood.

Autism is a complex disorder but for purposes of this 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.

My autism is part of who I am, not all of who I am. Are you just one thing, or are you a person with thoughts, feelings, preferences, ideas, talents, and dreams? Are you fat (overweight), myopic (wear glasses) or klutzy (uncoordinated)? Those may be things that I see first when I meet you, but you're more than just that, aren't you?

As an adult, you have control over how you define yourself. If you want to single out one 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. If you think of me as just one thing, you run 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 senses are out of sync.

This means that ordinary sights, sounds, smells, tastes, and touches that you may not even notice can be downright painful for me. My environment often feels hostile. I may appear withdrawn or belligerent or mean to you, but I'm just trying to defend myself. Here's why a simple trip to the grocery store may be agonizing for me.

My hearing may be hyperacute. Dozens of people jabber at once. The loudspeaker booms today's special. Music blares from the sound system. Registers beep and cough, a coffee grinder chugs. 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 three with ammonia. I feel like throwing up.

And there's so much hitting my eyes! The fluorescent light is not only too bright, it flickers. The space seems to be moving; the pulsating light bounces off everything and distorts what I am seeing. There are too many items for me to be able to focus (my brain may compensate with tunnel vision), swirling fans on the ceiling, so many bodies in constant motion. All this affects how I feel just standing there, and now I can't even tell where my body is in space.

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

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, I hear "*&^%$#@, Jordan. #$%^*&^%$&*." Instead, come over to me, get my attention, and speak in plain words: "Jordan, put your book in your desk. 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's much easier for me to comply.20 21

4. I'm a concrete thinker. I interpret language literally.

You confuse me by saying, "Hold your horses, cowboy!" when what you mean is, "Stop running." Don't tell me something is "a piece of cake" when there's no dessert in sight and what you mean is, "This will be easy for you to do." When you say, "It's pouring cats and dogs," I see pets coming out of a pitcher. Tell me, "It's raining hard."

Idioms, puns, nuances, inferences, metaphors, allusions, and sarcasm are lost on me.

5. Listen to all the ways I'm trying to communicate.

It's hard for me to tell you what I need when I don't have a way to describe my feelings. I may be hungry, frustrated, frightened, or confused but right now I can't find those words. Be alert for body language, withdrawal, agitation or other signs that tell you something is wrong. They're there.

Or, you may hear me compensate for not having all the words I need by sounding like a little professor or movie star, rattling off words or whole scripts well beyond my developmental age. I've memorized these messages from the world around me because I know I am expected to speak when spoken to. They may come from books, television, or the speech of other people. Grown-ups call it echolalia. I may not 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. Picture this! I'm visually oriented.

Show me how to do something rather than just telling me. And be prepared to show me many times. Lots of patient practice helps me learn.

Visual supports help me move through my day. They relieve me of the stress of having to remember what comes next, make for smooth transition between activities, and help me manage my time and meet your expectations.

I need to see something to learn it, because spoken words are like steam to me; they evaporate in an instant, before I have a chance to make sense of them. I don't have instant-processing skills. Instructions and information presented to me visually can stay in front of me for as long as I need, and will be just the same when I come back to them later. Without this, I live the constant frustration of knowing that I'm missing big blocks of information and expectations, and am helpless to do anything about it.

7. Focus and build on what I can do rather than what I can't do.

Like any person, 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. I avoid trying anything new when I'm sure all I'll get is criticism, no matter how "constructive" you think you're being. 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 it may be that I simply do not know how to start a conversation or join their play. Teach me how to play with others. Encourage other children to invite me to play along. I might be 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. Coach me. 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 what to say. Talk to me about Emily's feelings and teach me to ask, "Are you okay?"

9. Identify what triggers my meltdowns.

Meltdowns and blow-ups are more horrid for me than they are for you. They occur because one or more of my senses has gone into overload, or because I've been pushed past the limit of my social abilities. If you can figure out why my meltdowns occur, they can be prevented. Keep a log noting times, settings, people, and activities. A pattern may emerge.

Remember that everything I do is a form of communication. It tells you, when my words cannot, how I'm reacting to what is happening around me.

My behavior may have a physical cause. Food allergies and sensitivities sleep problems and gastrointestinal problems can all affect my behavior. Look for signs, because I may not be able to tell you about these things.

10. Love me unconditionally.

Throw away thoughts like, "If you would just—" and "Why can't you—?" You didn't fulfill every expectation your parents had for you and you wouldn't like being constantly reminded of it. I didn't choose to have autism. Remember that it's happening to me, not you. Without your support, my chances of growing up to be successful and independent are slim. With your support and guidance, the possibilities are broader than you might think.

Three words we both need to live by: Patience. Patience. Patience.

View my autism as a different ability rather than a disability. Look past what you may see as limitations and see my strengths. I may not be good at eye contact or conversation, but have you noticed that I don't lie, cheat at games, or pass judgment on other people?

I rely on you. All that I might become won't happen without you as my foundation. Be my advocate, be my guide, love me for who I am, and we'll see how far I can go.

Award-winning author and mother of sons with ADHD and autism, Ellen Notbohm's books and articles have informed and delighted millions in more than nineteen languages. Her work has won a Silver Medal in the Independent Publishers Book Awards, a ForeWord Book of Year Honorable Mention and two finalist designations, a Mom's Choice Gold Award, *Learning* magazine's Teacher's Choice Award, two iParenting Media awards, and an Eric Hoffer Book Award finalist designation. She is a contributor to numerous publications, classrooms, conferences and websites worldwide. To contact Ellen or explore her work, please visit www.ellennotbohm.com.

Comparison of an IEP and a 504 Plan

	IEP	504
Oversight	Individuals with Disabilities Education Act (IDEA) – Education Law	Americans with Disabilities Act (ADA) – Civil Rights Law
Definition	Individualized Education Program: student program or curriculum that is essentially different from what peers utilize – fundamentally a special education program at its core	Section 504 of the Rehabilitation Act of 1973: equal opportunity for those students with disabilities – fundamentally a general education program at its core with supports extended to access it
Purpose	Specialized instruction with modification of actual program or curriculum materials	Accommodations for accessing standard program or curriculum materials
Funding	Federal funding	No federal funding
Eligibility	Students ages 3-21 only under specified disability categories: autism, specific learning disabilities, speech or language impairments, emotional disturbance, traumatic brain injury, visual or hearing impairment, etc AND because of that disability needs specialized instruction.	Less discriminatory – available to students with physical or mental impairment substantially limiting at least one major life activity, have a record of such impairment or regarded as having such an impairment
First Steps	Parents can request that the school district conduct a comprehensive evaluation; Parent must consent in writing; school must complete the evaluation and provide a written report with 60 calendar days (not counting summer) of the date the parents signed the consent	Parents should write a letter to the school district explaining the disability and type of assistance needed; Parents can provide evaluations they have had completed; School can accept them or conduct their own; school must respond in 25 calendar days stating whether or not they agree to provide the services
Evaluation	Requires that the student be fully and comprehensively evaluated by a multidisciplinary team; requires informed and written parental consent; requires reevaluation every three years or sooner if warranted; reevaluation is not required before a change in placement	Evaluation draws on information from a variety of sources and is documented; decisions are made by knowledgeable individuals which do not require written consent of parents, only that they are notified; requires periodic reevaluation; requires reevaluation before a significant change in placement
Free And Appropriate Education (FAPE) Responsibility	requires an IEP; “appropriate” education means a program designed to provide “educational benefit” for a person with disabilities; placement may be any combination of special education and general education classrooms; provides related service, if required, which may include speech & language therapy, occupational therapy, physical therapy, counseling services, psychological services, social services and transportation	does not require an IEP but does require a plan; “appropriate” means an education comparable to the education provided to those students who are not disabled; placement is usually in a general education classroom; they can receive specialized instruction, related services or accommodations within that classroom; provides related services, as needed, like the IEP

	IEP	**504**
Due Process	Must provide impartial hearings for parents who disagree with the identification, evaluation, or placement of student; requires written consent; describes specific procedures on the due process; an impartial appointee selects a hearing officer; provides "stay-put" provision (the student's current IEP and placement continues to be implemented) until all proceedings are resolved; parents must receive 10 days' notice prior to any change in placement	Must provide impartial hearings for parents who disagree with the identification, evaluation, or placement of a student; does not require parental consent; requires that parents have an opportunity to participate and be represented by legal counsel – other details are left to the discretion of the school; a hearing officer is usually appointed by the school; no "stay-put" provision; does not require that parents are notified prior to the student's change of placement, but they still must be notified
Testing	Standardized testing accommodations available	Standardized testing accommodations available
Tracking	Progress reporting	No progress reporting
Duration	IDEA covers the special education of students with disabilities from ages 3 to 21	Section 504 covers the lifespan of an individual with disabilities in many areas of their lives, including employment, public access to buildings, transportation and education

Information taken from:

www.edconsult.org
www.elc-pa.org
www.ldonline.org
www.ncld.org

Please access these websites for additional information.

An Introduction to My Child

Name/Nickname:____

History (diagnosis, therapies, family, etc.)

My child’s medications and side effects:

Progress my child has made over the last year(skills gained):

My child’s strengths are:

My child struggles with:

My child’s likes (school subjects, color, toys, characters, hobbies, activities):

My child dislikes (activities, triggers, frustrations):

This is what a meltdown looks like for my child (include any signs that may lead up to a meltdown):

____

____

____

Rewards my child will work for:

____

____

____

Stimulation Behaviors of my child (what, when, and how we redirect):

____

____

____

Our goals this year for our child:

____

____

____

Our concerns about this year for our child:

____

____

____

Our contact information so you can contact us with any questions or concerns:

____

____

____

Additional Information:

12 Things to Help You Understand________________as a Student

1. **________________is on the Autism Spectrum.** Some may say he is "high functioning". While that is true, his level of functioning varies from day to day and from moment to moment. Just like cancer does not define who a person is, autism doesn't either. However, it does change how he views and lives in the world.

2. **Social Communication is difficult**. He does not understand others' points of view, or how what he does impacts other people. It is an intangible concept that is extremely difficult for him to grasp. I constantly have to remind myself that he really doesn't always "know better" just because other kids his age do. He looks like your average_____year old boy on the outside but his brain doesn't always process things like a ______year old.

3. **He reads, listens, speaks and interprets very literally**. If he is thinking it, chances are good that he will say it. Sarcasm, puns and some forms of humor are often not understood. If you say it is "raining cats and dogs", he will look for cats and dogs falling out of the sky.

4. **He has a hard time being creative.** His ability to predict the outcome of things, infer how people are feeling and select a topic for an essay or project are extraordinarily difficult. This is an area where teachers can really help him by simplifying his choices or suggesting topics that other students have used.

5. **Routine and consistency make his life easier.** We have found that a_____picture_______written_______ combined picture/written daily schedule works best. It is helpful for him to know what to expect during the day. Unexpected events, words, etc. are very difficult for him.

6. **He may have difficulty moving to a new topic or accepting he was wrong or lost.** He doesn't like to make mistakes. If he gets into a debate or stuck on a topic, try to redirect him or ask him to write down his question/thought to discuss later. He is rule oriented and has a strong desire to be first or win every single time. He can get upset if someone else does not follow the rules. Sportsmanship does not come easily because he will only see that he lost.

7. **He struggles with receptive and expressive language.** It is difficult for him to remember and understand strings of directions. Break directions down into simple steps. Visual cues (lists, outlines, pictures) will typically work better than auditory alone. When you speak to him, ask him one question at a time and give him a little extra time to answer so he can process what he wants to say.

8. **His brain does not process sensory stimuli as others would expect.** This means that sounds, smells, tastes, touches and sights are received and responded to differently. Here are some sensory things for you to be aware of:

   Sounds:

   Sight:

   Touch:

   Taste:

Pain tolerance:

9. **Think of his responses to things like cell phone reception.** *One minute* you have four bar reception and are having a perfectly wonderful conversation with someone. This is similar to when his brain is not overloaded so it is making the right connections and sending the right signals to the rest of his body. *The next minute*, you go into a building or drive through a tunnel and lose your cell phone signal. Obviously, you cannot continue your conversation until you get to a place with better reception. This is similar to when he experiences something that upsets his brain's ability to regulate his body. It may be a smell, sound, auditory language, a schedule interruption, a complex visual presentation, etc. He cannot proceed, understand or even talk properly most times until his brain gets the signal back and starts to regulate him.

10. **At times, he may experience "meltdowns" when he gets upset.** Please allow a safe and quiet spot where he can "cool off". Try to take note of what occurred before the meltdown. It's best to talk to him after he has calmed down. He cannot process logic or anything you might want to share with him when he is upset.

    When he starts to get upset, he may:

    When he is very upset, he usually:

    He may even try to escape or request permission to:

    Coping skills we encourage him to use:

11. **He doesn't always realize how hard he is working.** Be assured that he really is trying his best. At times, he will need a bit more understanding than others. He may say or do something that isn't appropriate or correct. Try to deal with those situations with him individually rather than in front of other students when at all possible. Autism is considered a disability because there are things his body either cannot do or cannot do without additional support. Any encouragement you can give him will be appreciated.

12. **___________________is loved.** Absolutely anything we can do to help him have a positive experience at school is important to us.
    His strengths are:

    He enjoys:

    We love him so please do not hesitate to contact us with questions, concerns or ideas to help make his school year a great experience. The best way to reach us is below.

THINGS ABOUT ME

Hi, my name is__________________________and I am in your class this year. I want you to know a little about me. I'm nervous to be in your class because it's new and I don't know what to expect. I need some time to adjust and then I will feel comfortable. Please don't judge me on my first few weeks. As the time goes by, you will be amazed by the skills you never thought I possessed.

I sometimes look like I don't understand. That's just because I don't have the same expressions and reactions as other people. I might not look at you when you talk but that doesn't mean I didn't hear you. I did. In fact I usually hear more than most people. As I become familiar with your classroom I will begin to shine. A great way to speed up this process is letting me know what to expect. Written or picture schedules for the day reduce my anxiety. A five minute warning before a change of activity can help me greatly too. You are my teacher and I look up to you.

I want to succeed this year but I can't do it without your help and most importantly, your belief in me that I can do it!

1. What is my general disposition? ____

2. What am I really, really good at? ____

3. What do I absolutely **LOVE** doing? ____

4. What do I absolutely **HATE** doing? ____

5. What academics are my strong areas? ____

6. What academics do I need a lot of extra help with? ____

7. Which skills would my parents really like me to work on this year? _____________________________

8. How do you know when I'm getting frustrated? ____

____

9. What can you do to calm me down before the storm hits? _____________________________________

____

10. Too late! The storm hit! What can you do to calm me down? ___________________________

____

11. What strategies work really well to get me to do something I don't want to do? _____________

____

12. What typically makes me laugh? ____

13. I would also like you to know…____

____

AUTISM & WANDERING

In 2008, Danish researchers found that the mortality rate among the autism spectrum disorder (ASD) population is twice as high as the general population. In 2001, a California research team found that elevated death rates among those with ASD were in large part attributed to drowning.

Drowning often occurs as a result of wandering off. **Drowning, along with prolonged exposure and other factors, remain among the top causes of death within the autism population.** Although there is no known data that recognizes whether deaths associated with wandering are on the rise within the autism population, anecdotal reports suggest an increase.

There are various reasons someone with ASD may wander. Many parents report their child gravitates towards water, so nearby lakes, ponds and creeks may continue to be a desired destination. Too, someone with ASD is likely aware when attention has shifted away from them and will take the opportunity to slip out quickly in order to reach a desired area or item of interest.

Family gatherings or other events may give a false impression of "all *eyes* on" someone with ASD. However, heavy distractions can present opportunities to leave unnoticed. Visiting relatives or episodes of distress also may increase the risk for wandering. This also holds true in warmer months when persons with ASD are more likely to play outside or attend summer or day camps.

WANDERING CAN OCCUR ANYWHERE AT ANYTIME. THE FIRST TIME IS OFTEN THE WORST TIME.

Join Autism Wandering Prevention on Facebook

CAREGIVER RESOURCES

AWAARE COLLABORATION
awaare.org

NAA/UA AUTISM SAFETY TOOLIOT
nationalautismassociation.org/safetytoolkit

AUTISM SPEAKS AUTISM SAFETY PROJECT
autismsafetyproject.org

ASA SAFE & SOUND SAFETY INITIATIVE
autism-society.org

CHILD SAFETY PRODUCTS
mypreciouskid.com
SelectAutismMerchandise.com
tattooswithapurpose.com

SERVICE DOGS
autismservicedogsofarnerica.com
4pawsforability.org

TRACKING SYSTEMS & MEDICAL DEVICES
Project Lifesaver: **projectlifesaver.org**
LoJack SafetyNet: **lojacksafetynet.com**
EmFinders: **emfinders.com**
Caretrak **Systems: caretrak.com**
Alzheimer's Comfort **Zone: alz.org/comfortzone**
Medicalert: **rnedicalert.com**
A Child is Missing: **achildismissing.org**

FOR FIRST RESPONDERS & CAREGIVERS
National Center for Missing and Exploited Children:
missingkids.com | 1-800-THE-LOST
Autism Risk Management:
autismriskrnanagernent.com
The Autism & Law Enforcement Education Coalition:
sncarc.org/alec.htm
The Law Enforcement Awareness Network
leanonus.org
Autism Alliance for Local Emergency Responder Training: **AutismAlert.org**

SUPPORTING ORGANIZATIONS:
Designed & Printed by: National Autism Association & Talk About Curing Autism
Supported By: Age of Autism | Autism One | Autism Research Institute | Autism Speaks | Doug Flutie Jr. Foundation for Autism | HollyRod Foundation | National Autism Association | Safeminds | Talk About Curing Autism

autism & WANDERING

prevention | safety tips | resources

SECURE YOUR HOME

Consider contacting a professional locksmith, security company or home improvement professional to promote safety and prevention in your home. **You may find it is necessary to prevent your loved one from slipping away unnoticed by:**

0 *Installing secure dead bolt locks that require keys on both sides.*

0 *Installing a home security alarm system.*

0 *Installing inexpensive battery-operated alarms on doors and windows to alert you when opened (available at stores like Walmart and RadioShack).*

0 *Placing hook and eye locks on all doors, above your child's reach.*

0 *Fencing your yard.*

0 *Adhering printable STOP SIGNS to doors, windows and other exits, such as gates.*

CONSIDER A TRACKING DEVICE

Check with local law enforcement for Project Lifesaver or LoJack SafetyNet services. These tracking devices are worn on the wrist or ankle and locate the individual through radio frequency. Various GPS tracking systems are also available. *See* the **RESOURCES** section within this pamphlet for more information.

CONSIDER AN ID BRACELET

Medical ID bracelets will include your name, telephone number and other important information. They may also state that your child has autism and is non-verbal if applicable. If your child will not wear a bracelet or necklace, consider a temporary tattoo with your contact information. *See* the **RESOURCES** section within this pamphlet for more information.

TEACH YOUR CHILD TO SWIM

Swimming lessons for children with special needs are available at many YMCA locations. The final lesson should be with clothes **on. REMEMBER:**

0 *Teaching your child how to swim DOES NOT mean your child is safe in water.*

0 *If you own a pool, fence your pool. Use gates that self-close and self-latch higher than your children's reach.*

0 *Remove all toys or items of interest from the pool when not in use.*

0 *Neighbors with pools should be made aware of these safety precautions and your child's tendency to wander.*

The American Academy of Pediatrics does not recommend swimming classes as the primary means of drowning prevention. Constant, careful supervision and barriers such as pool fencing are necessary even when children have completed swimming classes. All families are encouraged to seek training in swimming, lifesaving, first aid and cardiopulmonary resuscitation.

ALERT YOUR NEIGHBORS

It is recommended that caregivers plan a brief visit with neighbors to introduce their loved one or provide a photograph. **Knowing your neighbors can help reduce the risks associated with wandering.**

0 Give *your neighbor a simple handout with your nam address, and phone number.*

0 *Ask them to call you immediately if they see your child outside the home.*

0 *Decide what other information to present to neighbors.*

0 *Does your child have a fear of cars and animals or is he/she drawn to them?*

0 *Does your child gravitate towards pools or nearby ponds or creeks?*

0 *Does he/she respond to their name or would a stranger think they are deaf?*

0 *Are there sensory issues or meltdown triggers your neighbors should know about?*

ALERT FIRST RESPONDERS

Providing first responders with key information before an incident occurs may improve response. **Informational handouts should include all pertinent information, and be copied and carried with caregivers at all times.** Circulate the handout to family, neighbors, friends and co-workers, as well as first responders.

0 *Name of child or adult, current photograph and physical description including any scars or other identifying marks*

0 *Identify your child's favorite song, toy or character*

0 *Names, home, cell and pager phone numbers and addresses of parents, other caregivers and emergency contact persons*

0 *Sensory, medical or dietary issues and requirements*

0 *Favorite attractions and locations where the person may be found*

0 *Likes, dislikes, fears, triggers, and de-escalation techniques*

0 *Method of communication: note if nonverbal uses sign languag picture boards, or written words*

0 *ID wear, jewelry, tags on clothes*

0 *Map and address guide to nearby properties with water sources and dangerous locations highlighted*

1

Additional tips can be found at **autismriskmanagement.com** **(above information courtesy of Dennis Debbaudt)**

For a generic form that can be used by any caregiver, regardless of city or state, visit AWAARE.org.

AUTISM YORK
www.autismyork.org

AUTISM SPECTRUM DISORDER

EMERGENCY CONTACT FORM

Date Completed ______________________

Attach current photo here

Name: ____

Address: ____

____

Date of Birth: ____________________ ☐ Male ☐ Female Eye Glasses: Yes / No

Height: ____________ Weight: ____________ Eye Color: ____________ Hair Color: ____________

Scars or other identifying marks: ____

Other Relevant Medical Conditions	Prescription Medications	Sensory/Dietary Issues

Method of Communication: ☐ Verbal ☐ Sign Language ☐ Picture boards ☐ Written Words

Favorite attractions/locations: ____

Atypical behaviors that may draw attention: ____

Favorite toys, discussion topics

Individual carry ID Information? ____

EMERGENCY CONTACT INFORMATION

First Contact:	*Alternate Contact:*	*Medical Care Providers:*
Name:	Name:	Name:
Phone:	Phone:	Phone:
Phone:	Phone:	
Address:	Address:	Name:
		Phone:
Relation:	Relation:	

Plan Your Response for an Autism Emergency
Dennis Debbaudt 2012

Thoughts about personal safety and risk are found high on the list of concerns expressed by 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.

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 become 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 items 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 other combustible materials.

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.

Keep Records

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 and dementia 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 you 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 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 for the the field response.

Emergency 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

An Autism Emergency Contact Form 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.

Consider Autism Icons

When traveling in vehicles, consider prominently placing disclosure tools and icons such as autism car magnets, autism alert decals, autism puzzle ribbon magnets, “I Love Someone With Autism” bumper stickers, at home on the front door and on vehicle bumpers and windows. Law enforcement and first response professionals are being trained to look for these icons and search for autism handouts based on this information. Also consider using autism awareness specialty license plates that are now becoming available in the U.S. As a precaution, always check appropriate laws regarding decal placement on vehicle windows and bumpers.

Autism Emergency Contact Form 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

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 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:

- Security checkpoints such as airports, government buildings, schools, any secured facility
- Drive-up or walk-up guard shacks
- Building entrances
- Campus, shopping malls and 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

What are the best ways to tell the officer that you have a handout? One is to verbally let the 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.

Avoid making sudden movements to reach for the handout card. Obtain permission or signal your intentions before reaching into coat or pants pockets, briefcases or bags, or in to glove compartments of vehicles

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(Debbaudt, 2006 b).

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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