Welcome!

This guide has been designed to help provide basic information related to teens and young adults who are diagnosed with an Autism Spectrum Disorder. There are many things to consider and plan for as you approach these new phases in life. This guide does not contain everything there is to know about autism and the transition to adulthood. To gain more information you are encouraged to conduct further research by looking at the websites, contacting the resources listed, talking to your current team of service providers and attending Autism York meetings.

If you are an older teen or adult looking for information on diagnosis of ASD, we would encourage you to obtain a copy of our Resource Guide. Our Resource Guide also includes a full local service provider directory that can help you locate offices that evaluate and diagnose. Both resources are available for download on our website and hardcopies can be picked up at our Lending Library.

Autism York does not endorse any one specific path for transition. The information provided here is meant to give a basic understanding and help direct you to find more in-depth details.

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 needs.

Our Best Wishes,
Autism York Board of Directors

Other Transition Resources from Autism York:

- Autism York's Teen Meet Up Group is a support group that offers monthly social outings for individuals with ASD who are ages 13-17.
- Autism York's Adult ASD Meet Up Group is a support group that offers monthly social outings for individuals with ASD who are around age 18 and up.

What is "Transition" Planning?

According to the Pennsylvania Training and Technical Assistance Network (PaTTAN)
Secondary transition is the process of preparing students for life after they leave high school, including participation in post-secondary education or training, employment, and community living. These three areas are often referred to as "post-secondary outcomes" and are the driving force behind Individualized Education Programs (IEPs) written for students in high school.

Transition planning begins no later than age 14, in middle school or early high school, as students explore what they want their post-school outcomes to be through career awareness exploration activities. It continues through high school as instruction and community experiences support these outcomes.

Transition planning involves a partnership between the student, the family, school-age services and program providers, post-secondary services and program providers, and local community members. Effective transition involves purposeful planning among all these entities. It entails recognizing the student's current strengths, interests, preferences, and needs, and then identifying what services and supports he or she will need to achieve future success.
See www.pattan.net for more information.

Transition and the IEP

Much of the information available outlines how transition planning is an important part of a student's Individualized Educational Program (IEP). If the student receives special education through an IEP, there are specific steps in the transition planning process that should start at the age of 14.

We recognize that not every student with ASD receives special education through an IEP. We hope that this guide will also provide an overview of areas that those students and parents need to be aware of and consider as well.

Timeline for Transition Planning

The timeline below is simply a guide and should not be considered "all-inclusive" by any means. There may be item on this list that is not applicable to your situation or things missing that do apply to you. It is simply meant to provide a basic idea of what is involved in the transition process.

Age 14

- School conducts first IEP/Transition Meeting and starts to consider goals for various aspects of life. These may include:
  - Employment
  - Post-secondary Education
  - Living Arrangements
  - Community Participation & Mobility
  - Financial Independence

  - Recreation and Leisure
- If you believe your son/daughter with ASD will need support from various government agencies after graduation, you should contact the York/Adams Mental Health Program if you do not already have a Case Manager at (717) 771-9618. You should also ask them when and if it would be appropriate to contact York/Adams Mental Retardation (or IDD) for services.

Age 16

- All transition plans in the IEP should be in full effect by this age.
- Consider when the student will be graduating. Will it be at age 18 fulfilling school district requirements or later (as late as 21) at the completion of the IEP?
- If graduation will be at age 18, contact the Office of Vocational Rehabilitation (OVR) to see what support they may be able to provide. In York, you can reach them at 1-800-762-6306. Regardless of whether or not the student has an IEP, 504 Plan, GIEP or no accommodations at all in high school, the OVR still encourages you to apply for their services.
- If appropriate, the student may start working to obtain a driver's license. Most school districts offer classes and assistance on this.
- If the individual will not be working to get a driver's license, they should consider obtaining a state photo ID. http://www.dmv.state.pa.us/home/index.shtml

Age 17

- Issues such as guardianship, health care and emancipation should be addressed.
- Student should start visiting colleges/technical schools or other post-secondary educational opportunities as appropriate.

Age 18

- Apply for Social Security Benefits as an adult (check for eligibility) http://www.socialsecurity.gov/
- Apply for Vocational Rehabilitation, Independent Living Services, and other services as applicable and not already completed.
- Male students should register with the Selective Service, regardless of the level of functioning, within 30 days before/after their 18th birthday. http://www.sss.gov/default.htm
- Review health insurance needs
- Register to vote http://www.votespa.com/
- If graduation will be later than age 18, contact the Office of Vocational Resources two years prior to graduation.

Age 18-21

- Under a Special Education IEP, notice will be given one year before the student reaches the age of majority (21 years in PA for Special Education) informing the student and the parents of his/her IDEA rights and that they will transfer from the adult to the student.

The End of Special Services under IDEA

"The purpose of the Individuals with Disabilities Education Act (IDEA) is to ensure that all children with disabilities receive free appropriate public education (FAPE) in the least restrictive environment (LRE). The education should emphasize special education and related services to meet their unique needs and prepare them for "further education, employment and independent living." At the end of the school year when a student reaches the age of 22, or when they graduate with a regular diploma, the entitlement to a Free and Appropriate Public Education ends."
From www.autismhandbook.org, see more information on this website.

Section 504 of Vocational Rehabilitation Act & the Americans with Disabilities Act (ADA)

"Section 504 and ADA ensure that an individual with disabilities has access to supportive services such as an aid in a classroom setting, accessibility to extracurricular activities, and protections in employment. These two civil rights laws protect individuals with disabilities from disability-related discrimination whether it is in education, the workplace or public accommodations (such as a restaurant or public building). Section 504 is more limited in that it only applies to institutions that receive Federal Funds such as schools, while the ADA's broader scope applies to state and local government services as well as a number of public services, whether or not they are federally funded. They both require that individuals with disabilities not be denied access to appropriate services or supports that may be necessary to meet their needs. Importantly, these two laws protect individuals with ASD when their protections are no longer in effect under IDEA, that is, once they turn 22."

The major difference is that the responsibility of getting needed accommodations and supports from high school to post-secondary schooling is that it becomes the student's responsibility to see and request necessary accommodations.
From www.autismhandbook.org, see more information on this website.

Long-Term Planning for the Post 21 Years

While attending school, your child is covered under the IDEA laws that <u>entitle</u> him/her to a Free Appropriate Public Education. After graduation, the adult service system provides benefits on a <u>needed</u> or <u>eligible</u> basis. If you are seeking services with the adult I/DD system you may find the following definitions useful as you navigate the system. In all likelihood you and your child's Supports Coordinator will prepare an Individual Support Plan (ISP), which may access a wide array of support services.

Adult Medicaid Waivers

The term "waiver" actually means the Medicaid Home and Community Based Waiver Program. Waivers represent a primary funding source for Intellectual and Developmental Disabilities (I/DD) supports and services which can help an individual live in his/her home and community. There are different kinds of waivers and each one has its own set of eligibility requirements. Waivers can provide funding for the supports and services needed in order for you to remain in your home and community.

The PA Bureau of Autism Services administers two programs for adults with autism, the Adult Autism Waiver (AAW) and the Adult Community Autism Program (ACAP). These two programs are designed to help adults with autism live in their communities the way they want to, based on their identified needs. A few documents summarizing and comparing Pennsylvania's Adult Waiver programs are included in this folder. More information can be found at http://www.dpw.state.pa.us/foradults/autismservices/index.htm.

If you think you may be eligible, you are encouraged to request an application. To request an application for either program, you can call toll-free in PA: 1-866-539-7689. Applications may not be requested by email and are not available on-line.

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 Teenager/Young Adult to Swim
Individuals with ASD are attracted to water. Swimming lessons are highly 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.

Now 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. A sample of the small card is included with this guide. Additional cards are available at our meetings or 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. This folder includes a great article "Developing Risk and Safety Life Skills for Persons with Autism" by Dennis Debbaudt. It covers 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.

PA Yellow Dot Program

Pennsylvania's Yellow Dot Program was created to assist citizens in the "golden hour" of emergency care following a traffic accident when they may not be able to communicate their needs themselves. The program is a cooperative effort among the Pennsylvania Departments of Transportation, Health and Aging; the Pennsylvania State Police, the Pennsylvania Turnpike Commission and First Responders and local law enforcement.

Participants complete a personal information form, which includes the participant's name, contact information, emergency contact information, medical history and medications, allergies and the participant's doctors' names. A photo – showing only the participant's head and shoulders – is then taped to the front of the completed information sheet.

The yellow dot decal provided is placed in a specific spot on the participant's car. This decal alerts first responders to check your glove compartment for vital information to ensure you receive the medical attention you need.
For more information see http://www.yellowdot.pa.gov/.

York County Special Needs Registry (formerly ECRIN)

This is a free, voluntary, and confidential program, open to all York County residents to provide assistance to those with special needs in the event of an emergency. It is designed to help identify those who have no reliable source of assistance in the event of an evacuation. Those who would benefit the most include Individuals those with mental disabilities along with many other types of disabilities and special needs. The program was developed by the York County Human Services Department in conjunction with the York County Office of Emergency Management and all necessary tools are provided free of charge to each municipality.
For more information:
http://yorkcountypa.gov/health-human-services/human-services-division/programs/york-county-special-needs-registry-1.html
Email: humanservices@yorkcountypa.gov
Phone: Kelly Blechertas, York County Human Services, (717) 771-9347
Shen Kreiser, York County Emergency Management, (717) 840-2990

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 717-846-RIDE (7433) 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.

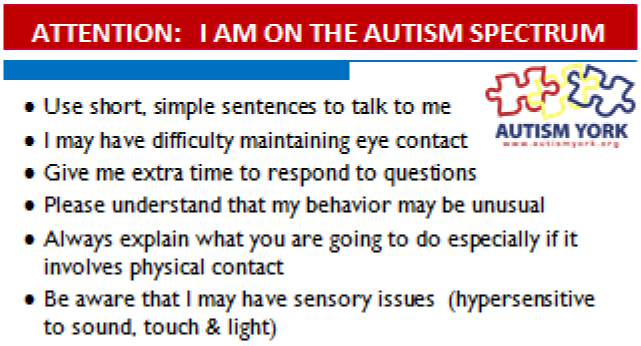
Amusement Parks

If someone with ASD 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 the individual 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 unusual behavior. Autism York does have a few versions of this card. Feel free to ask for some at one of our meetings.

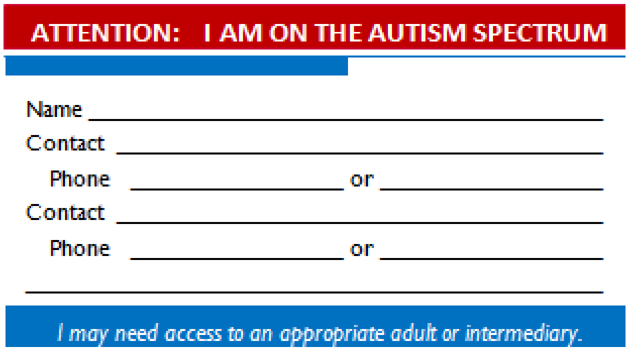
front



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.

Additional Transition & Adult Resources can be found at or by contacting:

ASERT (state-wide resource funded by the Bureau of Autism Services, PA Dept of Public Welfare)
www.PAautism.org
877-231-4244 info@PAautism.org

Pennsylvania Training and Technical Assistance Network (PaTTAN)
www.pattan.net
(717) 541-4960 or (800) 360-7282 in PA only

Pennsylvania Secondary Transition Guide
www.secondarytransition.org

Autism Transition Handbook (specifically written for PA & DE)
www.autismhandbook.org

Autism Speaks (See the Tool kit area for a Transition Tool Kit)
www.autismspeaks.org

Pennsylvania Youth Leadership Network
www.pyln.org
This is a group of youth/young adults with disabilities that has written some great toolkits for other youth with disabilities. These are worth a look if your teen might respond well or be encouraged by hearing how their peers have adapted and learned to be more independent.

do2Learn – Job Tips
www.do2learn.com then select the “Job Tips” along the top of the screen
JobTIPS is a free program designed to help individuals with autism spectrum disorder and other learning differences explore career interests, seek and obtain employment, and successfully maintain employment. JobTIPS addresses the social and behavioral differences that might make identifying, obtaining, and keeping a job more difficult for you.

Penn State University – Office for Disability Services
http://equity.psu.edu/ods
This site includes some great information and resources not only for students planning to attend Penn State but for any student with a disability planning to attend a college. Don’t miss checking the resources under the “Considering Penn State” menu item on the left-hand side.

National Center on Secondary Education and Transition (NCSET)
www.ncset.org

Items included in the appendix:

Title	Source
Strategies for Surviving Middle School with an Included Child with Autism	Ann Palmer TEACCH Autism Program www.teacch.com
Preparing for College: Tips for Students with HFA/Asperger's Syndrome	Gladys Williams & Ann Palmer TEACCH Autism Program www.teacch.com
Ten Tips That May Help Your Child's Transition To Adulthood	Pacer Center www.pacer.org
How You Can Help Your Child Learn to be a Good Self Advocate	Pacer Center www.pacer.org
Tips for Teens: Use Your IEP Meetings to Learn How to Advocate for Yourself	Pacer Center www.pacer.org
Be Your Own Best Advocate	Pacer Center www.pacer.org
Post-Secondary Educational Opportunities	Autism Speaks www.autismspeaks.org
The Disclosure Dilemma For Advocates	Laverne A Buchanon, Ed. D. GW HEATH Resource Center www.heath.gwu.edu
Comparison of Medicaid Programs that Serve Adults with ASD	PA DPW - Bureau of Autism Services www.dpw.state.pa.us
Autism & Wandering	www.awaare.org
Autism Spectrum Disorder – Emergency Contact Form	Autism York
Developing Risk and Safety Life Skills for Persons with Autism	Dennis Debbaudt www.autismriskmanagement.com

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TEACCH Autism Program

Strategies for Surviving Middle School with an Included Child with Autism by Ann Palmer

I began worrying about my son's future transition to middle school about the time he first started full inclusion in the third grade. Elementary school was hard enough. How was he going to survive complicated schedules, more difficult academics, and the social pressures so problematic in middle school? Eric did survive, and so did I as his parent. It was by far our hardest years in school, but they were much easier than I imagined they would be. His success through middle school can be attributed to many things, but I am most appreciative to his guidance counselor and teachers for supporting him in so many ways and for allowing me to be a contributing partner in school decisions. Every child with autism is unique, with different strengths and needs, and though these strategies worked for my son, they may not for others.

1. Prepare as early as possible. Start thinking about the organizational and academic issues BEFORE transition to middle school, preferably in 4th or 5th grade. Talk to the guidance counselor at the middle school or to parents of middle school students to find out what skills a student will need when entering middle school. Use this information to prepare IEP goals to work on in the 4th or 5th grade. Invite someone from the middle school to attend the IEP meeting if possible. When having the IEP meeting for the transition to middle school, have the meeting at the middle school, not the elementary school, and make sure a regular education teacher is present. Take your child to tour the school the week before school starts and walk him through his schedule, preferably not at an open house with lots of people, but on an individual tour.
2. Organization issues are often one of the hardest parts of middle school for our kids. Ask the school if your child can have one notebook for all classes rather than a different notebook for each one. This notebook can have subject dividers with pockets between each class section. (I found them at Office Depot.) One pocket can be designated for things to come home: assignments, notes to parents, etc., and one pocket for things to go to school: homework, notes to teachers, etc. A notebook with a clear cover was also very helpful because a copy of the schedule can be placed in it so that it is visible from the outside of the notebook and can be referred to as needed.
3. Individualize the schedule. Eric's middle school had a very complicated schedule and no consecutive days had the same time schedule for classes. There would be "block" days where certain classes were extended and certain classes were omitted. To help with this, I made a simple, easy to read schedule that included each day of the week and placed this schedule on the outside of his notebook. You can even color code each class, for example, green for science, blue for English, etc. I even individualized the schedule by including when to go to the locker and when to go to the bathroom. This involves researching when classes are located nearer each other and therefore would allow a stop at the locker or bathroom. Sometimes you can find a teacher willing to allow a student to go to the restroom or locker during class which helps avoid the crowds.
4. Lockers can be adapted to the needs of your child. There was a requirement at our middle school for each student to have a spin dial lock, bought from the school. This kind of lock was too difficult for my son to use and we got them to approve his use of a lock where the combination numbers are rolled in

place to open the lock. Of course, you have to give the school office the combination for the lock. The location of the locker can also be important. Try to have the locker located outside of a supportive teacher's classroom. We found that most of the teachers stand at the door of their classrooms or in the halls between classes and would be able to keep an eye out for problems. Get an outside locker so that there won't be students on both sides of your child's locker crowding him or making access to the locker more difficult. Organize the locker if needed. You can buy locker organizers that compartmentalize the locker so things can be found easier. Try the Hold Your Own store for these. Post a locker schedule inside of the door to the locker that the student can refer to. This would include what should be put in the locker at each visit and what to remove from the locker. Between classes at the lockers is a very loud, hurried time and this helps the student who may have trouble with these distractions.

5. Getting homework assignments home with the correct books and notebooks can be a difficult task. To help solve this problem, we asked for an extra set of textbooks for home. You can have this included in the modifications part of the IEP. Or for the student who has trouble with bringing the right books to class, the school textbook can be kept in the classroom in a safe place designated by the teacher and accessible to the student. Highlighted textbooks were also an option at our middle school. They really help students to know what is important in a chapter when studying for a test. Parents can offer to highlight the textbooks if they aren't already done by the school. At our middle school, the PTA highlighted a certain number of textbooks that were primarily used by LD students but would be very appropriate for some of our kids as well. This too can be put in the IEP.
6. Many of the modifications available to students with learning disabilities can be accessible to autistic students. At our middle school, the LD students were all located on a particular hall with typical kids as well as Academically Gifted students. An extra LD Resource teacher was assigned to this hall and would "float" between classes as needed. This hall was a good placement for Eric because of the extra teacher and because all the teachers were prepared to make modifications for these students. Check to see if your school has a similar situation.
7. Social difficulties can be a problem in middle school. Eric is very passive and withdrawn socially, like some children with autism. On the other hand, many of you may have autistic children who may be very social and want and need social acceptance by their peers. My concerns for Eric were more around his getting "lost in the shuffle" so to speak, and luckily he has never been bothered by not having friends or not being popular. I think he frequently was oblivious to what the other students thought of him or said about him. There were a few students who took an interest in him, or were helpful to him in elementary school. The middle school counselor had the idea to place these students in some of Eric's classes when possible. Teachers can also suggest possible peer buddies with students who have shown they want to be helpful to your child.
8. One of the hardest social situations for my son in middle school was the Physical Education classes. He hated sports and had motor delays that made sports difficult for him and therefore made him more of a target for other students. The locker room situation was especially difficult and there was little adult supervision there to protect him. After a couple of incidences, we were able to arrange that he wouldn't go into the locker room at all, and instead would wear appropriate clothes on P.E. days and would leave his backpack in the P.E. teacher's office. We had him exempted from the 8th grade P.E. requirement. I wrote a letter to the principal and included a letter from a developmental pediatrician who knew my son and was very knowledgeable about autism. We had no problem getting him exempted. I would only suggest this option if your child gets nothing positive from P.E. or suffers anxiety related to it. High School gives you many more options for Physical Education classes that can be used to satisfy the requirements for graduation, such as weight lifting, track, and other more individualized sports. You can also request Adaptive PE help in an IEP.
9. Communication is so important in middle school and unfortunately you will probably find it harder to communicate with your child's teachers on the middle school and high school levels than in elementary school. Educating seven teachers instead of one about your child and autism is much harder for parents. These teachers may have over a hundred different students each day and finding the time for

daily communications home is impossible. I would have a meeting with as many of my son's teachers as possible before the school year began, often bringing my son in for them to meet. I also met with them as much as possible during the year to find out how things were going. The teachers on each hall function as a team and meet regularly and you may be able to attend some of these meetings. The guidance counselors should be able to help you arrange this. If you have at least one teacher on the team who is especially interested in helping your child, that teacher will probably be willing to keep up a good communication line between the other teachers and report to you about any concerns that may come up. We also found that teachers appreciate having a resource in the school available to them who is knowledgeable about autism, maybe an autism class teacher or another special education teacher, someone they know they can contact if your child has a "meltdown" or if they just have questions about autism.

10. Communication from your child about school is also very important. My son was never one to initiate telling me things that happened at school. I more or less interrogated him when he arrived home, not one of his favorite activities, but one I felt was necessary. If I didn't ask the right questions, I often wouldn't find out about important things that happened. After years of these question sessions, Eric has learned what kind of information I need to know and will now (most of the time) tell me things about school. I continue to remind teachers each year that Eric does not report back to me well and that I need for them to let me know about things and not rely on him to relay messages home.

Good luck to all of you who read this and are planning future transitions to middle school for your children. Remember, most typical middle school students have times when they may struggle with staying organized, with making friends, and with dealing with the academic pressure. This is a hard time for all adolescents. The staff at your middle school is prepared for these events and should have strategies to help. Your role as a parent, I believe, is to develop a good working relationship with your child's school and teachers so that all of you, together, can combine your knowledge and experiences to make the middle school years as successful as possible.

Ann Palmer

TEACCH Autism Program

Preparing for College: Tips for Students with HFA/Asperger's Syndrome * NEW * by Gladys Williams and Ann Palmer

These ideas have been compiled from our work with students with high functioning autism/Asperger's Syndrome who were thinking about or attending college. Each student has a unique profile of strengths and needs, so each recommendation should be considered with the specific student in mind.

Gladys Williams and Ann Palmer
Chapel Hill TEACCH Center

Selecting a College

When considering which colleges to apply to, there are many dimensions to consider. Many of these dimensions are relevant for all students: a curriculum of interest to the student, location and cost, etc. Some other characteristics that may be particularly important for students on the autism spectrum include a clearly structured academic program, a good disabilities services program (or its equivalent), willingness to provide modifications and support for learning needs, and a counseling center with support services. Experience with autism might be helpful, but the most important characteristics of the disabilities services program and counseling center are the commitment to providing individualized support and a willingness to learn about each student's disability and needs. Because of the learning differences of students with high functioning autism/Asperger's Syndrome, they often benefit from tutoring, organizational, and personal support services. On many campuses, organizational and personal support services are not offered; families and advisors may need to work together to identify ways to meet these needs.

Sometimes, a smaller school is easier for students who learn better in small classes and quiet settings, or who can become overwhelmed in a complicated environment. For students who will find the degree of independence and organization required for living at college to be daunting, it can be helpful to live at home for the first year or two of college, and gradually make the transition to more independent living.

Some colleges offer cooperative education programs, in which students alternate between taking academic courses and working in related jobs. Such programs have the potential to help students explore potential careers and develop essential work skills.

Academic Support and Accomodations

1. In college, students are given the responsibility of advocating for themselves. If they wish, they can receive support from the disabilities services program, but they will have to be able to make many decisions for themselves, and talk to their professors.

2. In many colleges, the disabilities services program will write a letter to relevant professors, indicating that a student has a disability and may need accommodations. This letter might be the student's responsibility to give to the professor, or it might be sent out to each professor. In either case, it is then likely to be the student's responsibility to follow up with the professor and request specific accommodations (e.g., seating, time on tests, material in writing). Many students will need coaching and support in order to do this. Some counselors may be willing and able to help with this if asked. Others may not be able to do so.

3. A tutor may be helpful, especially for the more challenging courses and for courses that require students to write papers and do independently structured projects. Tutorial services are often available; the program that provides disabilities services will be able to provide information about what is available and how to access these services. A student may then need guidance about how and when to make use of a tutor.

4. Academic accommodations that have been helpful for some students with Asperger's/ High Functioning Autism follow.

- Many students need a little longer to process information and organize responses. This can mean that they will take a little longer in responding to questions in class. It also means that he or she should receive the accommodation of extra time on tests.
- Due to difficulties in processing and screening sensory information, a distraction free environment may be important for ongoing studying, and for taking tests.
- In lecture halls, seating can be important. Sitting at or close to the front, and sometimes in the center of the row, can make it easier to hear and understand a lecture. Some students find it easier to sit near the front but in an aisle seat, so that they have a bit more room to spread out and are less likely to be bumped. Sometimes seating is on a first come, first served basis all semester. In this case, students should get to the first class early! Other professors assign seating or have students remain in the same seat all semester. In this case, students may need to talk to the professor in order to arrange for seating needs.
- Some classes include projects on which students work together in small groups. Sometimes talks must be given in front of the classes. Some professors include class participation as a component of the grade. These requirements can be challenging for students with difficulties in oral communication or in working as part of a group. When this is the case, the student should be advised to talk to the professor about his or her disability early in the semester. In some cases, accommodations may be appropriate. In others, the professor's understanding and support might suffice.

Organization

It is important to be aware that most students with autism spectrum disorders need clear, systematic organizational strategies for academic work and probably for aspects of daily living. Calendars, checklists, and other visual strategies for organizing activities should be developed with the student.

Selecting Courses

Many students with Asperger's/High Functioning Autism will do best in courses that draw on factual memory and/or visual perceptual skills. A sensitive counselor or academic advisor can help guide him or her to a curriculum that will capitalize on his or her strengths and interests.

Courses that require abstract verbal reasoning, flexible problem solving, extensive writing, or social reasoning are often challenging. Such courses may be valuable to take, but could require extra time and support. In her book, Pretending to be Normal, Liane Willey, an adult with Asperger's Syndrome, recommends taking courses in communication and psychology in order to improve social understanding and skills. She comments that sometimes it might be wise to audit a course if it would take a long time to master the material.

Course load is an important issue, especially during the first year when everything is new.
For some students, a reduced course load can help keep the stress levels more manageable. A related issue is that many students with autism need extra time for thinking about problems and for completing work. This means that they may need longer than most students for reading and doing assignments. This should be taken into account in planning a student's course load so he or she will not be overwhelmed.

Social Life

For some students with autism, living on one's own may be overwhelming at first. They often need more support than most college freshman for making social connections. All campuses have organized social groups and activities; most students with high functioning autism/Asperger's will enjoy participating in some of these, but will need guidance in finding the right groups and getting introduced. Consider the student's strengths and interests when looking for groups and activities. It might be beneficial to have someone, perhaps an older student or an advisor, point out groups that would be of interest, and help with the initial steps of becoming a participant. It may also be possible to mobilize other resources through the student counseling services, residence advisors, and service organizations on campus.

Living in the Dorms

For many students with high functioning autism, it is preferable to have a single room. This provides them with a sanctuary where they can control their environment, focus on their work and daily activities without distraction, and not be forced to engage in social interaction all the time. Having a roommate can be highly stressful. On the other hand, it is often helpful to have a mentor nearby. When the student is in agreement, it can be helpful to inform the residence staff of the student's disability and areas in which support may be needed. If the student is comfortable about talking with peers about his disability, it can also be helpful to meet (with support) with some of the students who live in adjacent rooms, and talk with them about the student's strengths and interests, and why she or he might do some things a bit differently.

Daily Living

Try to think through various aspects of daily life on campus, to figure out the likely pitfalls, and provide written guidelines, checklists, or advance training/preparation. Here are some examples: meal plans and their rules; where to eat at non meal times; laundry; spending money; budget; using a campus ID and charge card; dorm rules; handling fire drills in the middle of the night; using communal bathrooms; transportation; campus maps; finding rest rooms; using the alarm clock; e mail and instant messaging; library hours and how to get help from a librarian; how lectures work; learning about and participating in dorm activities; and student health services and medical emergencies (and non emergencies). First aid and how to take care of oneself during a minor illness (including how to get liquids and food when feeling under the weather) are important. Building in time for physical exercise (perhaps through courses) is important for many individuals, not only for health reasons but also as a factor th at helps with stress management.

Prepare in Advance

Thinking about these issues well in advance is important. As part of the IEP process, each student should have a transition plan. Learning the skills necessary for college should be part of this plan. Many important skills that will facilitate success in college can be taught and practiced, at home as well as at school, while the student is in high school. It is important that the student understand what his or her learning needs are, and the types of accommodations that are helpful. In college, he or she will probably find it helpful to talk to advisors and professors about these issues. This will be easier to do when it has been practiced in the more supportive environment of high school. At home, high school students should be learning and practicing daily living and independence skills they will need to live successfully at college.

Resources

There are brief discussions of college related topics in Liane Willey's book, Pretending to be Normal, and in A Parent's Guide to Asperger Syndrome & High Functioning Autism, by Sally Ozonoff, Geraldine Dawson, and James McPartland. Aquamarine Blue 5: Personal Stories of College Students with Autism, edited by Dawn Prince Hughes, has 12 essays and an appendix of tips. A recent addition is Succeeding in College with Asperger Syndrome: A Student Guide, by John Harpur, Maria Lawlor, and Michael Fitzgerald.

There are a number of websites with advice for students with disabilities (and occasionally autism specifically!), about preparing for or being in college. Some are:

Eric Clearinghouse on Disabilities and Gifted Education, One of their many useful articles, ERIC EC Digest #E620, is "Selecting a College for Students with Learning Disabilities or Attention Deficit Hyperactivity Disorder (ADHD)".

A web site from the United Kingdom, University Students with Autism and Asperger's Syndrome, has many helpful links and some interesting articles by university students with autism spectrum disorders.

North Carolina State University has a usesful guide on transitioning from high school to college on their web site.

Gladys Williams and Ann Palmer

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INFORMATION SHEETS

Ten Tips That May Help Your Child's Transition To Adulthood

Planning for your child's transition from adolescence to adulthood is one of the most important things you can do to pave the way to a successful future. In Minnesota, transition planning and services required by the Individualized Education Program (IEP) begin when your child with a disability isin the ninth grade or before if needed. You and your child will start learning new skills side-by-side. As your child begins to take on more responsibility, you will find new ways to provide support. Regardless of physical or cognitive ability, your child can play an active role in the transition journey, and in determining his or her own life, if you provide encouragement and guidance along the way.

This transition period can be a challenge. Depending on your child's disability, you may need to consider everything from postsecondary education and employment to housing and finances. As you and your son or daughter plan for the future, consider these tips to help build a successful transition.

You can help your son or daughter:

1. Develop self-determination and self-advocacy skills.

All young people need a strong sense of their strengths, abilities, interests, and values. If students have a disability, they should also be aware of how it might affect them at work, in the community, and in their educational pursuits, and should be able to explain it to others. Helping youth speak with understanding about their disability is one step to empowering them as they take on adult responsibilities of work, education, andindependent living.

Many young adults know that they have received special education services but do not understand why. They may ignore the supports they need in employmentor independent living, which may cause unnecessary frustration and low self-esteem. It is important for young adults to have knowledge about themselves and their skills. If they do not know this, they can be at risk. Transition is a wonderful time to explore how youth will talk about their disability in different settings and ask for any support or accommodation they will need. You can make sure your child has a variety of opportunities to learn and practice advocacy and self-determination skills in the classroom, at student work sites, and in the community. The IEP could provide some of these opportunities. It is important for students to develop the skills to talk about their disability before they enter the workforce and postsecondary education. In order to be protected from discrimination under the Americans with Disabilities Act, the individual must disclose information about his or her disability to an employer or educational institution and explain the need for specific accommodations.

2. Expand social and community support networks.

Social and community networks are more than fun; they are important tools that help tie people into the community and provide a wider network of support. As children with disabilities become adults with disabilities, they may need support from a variety of sources. Start now to develop helpful social and community support networks for your child. Who do you know in your family, social group, professional circle, faith-based community, or other sphere who could help providesocial, recreational, work, orvolunteer experiences for your young adult? Transition planning that addresses opportunities for social relationships and recreation can build a bridge to new friendships, potential employment opportunities, and a wide range of natural community supports. Consider contacting adults in the community who have the same disability as your child to

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learn what kinds of supports they use. Peer mentoring opportunities are sometimes available through disability organizations such as the Center for Independent Living (http://www.virtualcil.net/cils/). Parents may feel there is a risk in allowing their son or daughter to develop new relationships and friendships, but building natural and shared relationships is an important first step for all young adults.

3. Build a work résumé.

Many young people struggle to find work experiences that help them compete in the job market. Summer jobs, helping neighbors, and volunteering are great solutions. Traditional summer jobs such as mowing lawns or dog walking can be described on résumés as self-employment enterprises if your child creates business cards and flyers on a computer or demonstrates other business skills. By taking part in a variety of community activities, young adults can develop employment and social skills while building a résumé and increasing their network of potential employer contacts. Your son or daughter is more likely to find future paid employment if he or she demonstrates interests, abilities, initiative, and dedication to work through community and volunteer activities. The participation of a parent, friend, or group of peers may help enrich the experience. Many summer jobs and volunteering experiences can be found through your network of friends, family, and social organizations. Also check out The Community Living webpage for volunteering opportunities in Minnesota: www.c3online.org/commLiving.html

4. Learn “soft” employment skills.

In addition to the work skills people need for their jobs, they also need “*soft skills*.” These include such things as being able to accept direction, return from breaks on time, deal with conflict, have the confidence to make decisions, and engage in appropriate personal communication. *Soft skills* also include dressing properly for the workplace, focusing on the job at hand, asking for help when needed, calling in when ill, and using typical responses such as “good morning” and “thank you.” Many of the rules of the workplace are unspoken or assumed. An employer is more likely to be patient with an employee learning the technical aspects of a job if basic soft skills are in place. You can help your young adult develop these skills by teaching them at home, and then providing opportunities for practice at school and in social situations. Additional information on soft skills is available online at http://www.ncwd- youth.info/information-brief-28 and on a CD available from PACER Center, Top Secret Job Skills: Declassified, www.pacer.org/publications/transition.asp

5. Practice money management skills.

Financial education is an important part of transition. Children need the self-determination skills developed through saving, spending, gift giving, and budgeting. Parents can begin by opening a savings account and taking their son or daughter to the bank regularly to deposit part of his or her allowance, earnings, or cash gifts so that he or she becomes familiar with financial institutions. Learning how to use an ATM card for saving and withdrawals might be appropriate for many youth. Your child can practice their skills if you include him or her in budget decisions concerning birthday parties, holiday dinners, or family vacations. As youth transition to independent living and adult responsibilities, their previous experience with spending and saving will allow them to participate more fully in their own quality- of-life decisions. Additional information is available at www.pacer.org/publications/possibilities/

If your son or daughter qualifies (or may qualify as an adult at the age of 18) for State or Federal benefits due to disability and limited financial resources, planning ahead is important. The Minnesota Disability Linkage line at 1-866-333-2466 and the Disability Benefits 101 link at http://mn.db101.org provide information on benefit programs, work incentives and benefit estimators.

6. Connect with adult service providers.

Upon graduation from high school, IDEA special education services end. This means that the IEP team will no longer be available to coordinate disability-related services that your child may need, such as accommodations, transportation, physical or speech therapy, and job development services. All of these services and others, if available, will very likely be provided by different agencies, each with its own application processes, different eligibility standards, and definitions of disability. No one piece of legislation defines services to youth with disabilities after IDEA services end. Governmental programs, such as vocational rehabilitation services, developmental disabilities administration, public mental health services, and supplemental security benefits, have legal requirements and eligibility guidelines. Young adults, to the extent they are able, will have to take responsibility for evaluating, applying for, and coordinating these services. Confidentiality policies and age of majority (age 18 in Minnesota) may establish a barrier between parents and service professionals. The IEP team can help families determine what adult services are available and initiate connections. It is important for the future success of young adults that these connections are established before graduation whenever possible.

7. Explore housing options.

While some young adults may stay on in the family home at least for the short term, others may live in residential housing with services, cooperative housing, a dormitory at an educational institution, an apartment with or without roommates, or they may own a home. Different types of housing and supervision oversight might be appropriate during different periods of an adult's life. The choice of housing is often dependent upon the community and family's resource and support system. There are both federal and state subsidized housing programs. If your son or daughter receives county services, your social worker can help you explore options. Networking with other families may provide valuable suggestions and contacts. When evaluating possibilities, it is helpful to start with a list of desired criteria that matches your vision for your young adult's future. Does your son or daughter need housing that is close to employment, public or private transportation, a food market and shopping stores, or a medical clinic or facility? Depending on your young adult's needs and desires, you might consider if the area is safe for walking, if pets are allowed, or if family and friends or recreation and social opportunities are nearby. The PACER Housing webpage (PACER.org/housing/resources) has links and updated information on a variety of Minnesota housing options.

8. Plan for health care needs.

Like most people, young adults with disabilities need to begin managing their health care, prescription drug use, and insurance issues. Parents can help youth take on more responsibility as they get older by encouraging them to make their own medical appointments, to speak directly with their doctor, and to take their prescription drugs as directed. Youth may need to learn strategies such as using a pill organizer, starting a filing system for medical records, and keeping a calendar specifically for doctor appointments and prescription refill alerts. When planning for life after high school, it is often helpful for the IEP team to consider how health might affect employment choices, education, and independent living. The lack of attention to health needs and management can jeopardize goals for learning, working, and living safely in the community. For more information, refer to "What Does Health Have to Do with Transition? Everything!" from the National Center on Secondary Education and Transition at: www.ncset.org/publications/parent/NCSETParent_May06.pdf

9. Visit postsecondary training and education programs.

Visiting a college or training program can help your son or daughter visualize the future. Simply call one of the Minnesota state colleges, universities, technical schools, certificate programs, or other schools and ask for a tour. Include a meeting with the school's Disability Services office to find out how to document your student's disability and to inquire about what accommodations are available or could be considered. Postsecondary programs are not required to locate, evaluate, or serve students with disabilities, or to modify course work if it would substantially change program requirements.

Students who receive academic programming and support in high school through their IEPs will not automatically have the same support after they graduate. Although postsecondary institutions are required to provide reasonable accommodations to students with disabilities, it is the student's responsibility to provide appropriate, updated documentation of their disability. The exact accommodations provided in high school may not be available. Postsecondary programs are not required to follow past IEPs, write new ones, or provide student grade information directly to parents. Learn more at the Minnesota State Colleges and Universities website (www.mnscu.edu/collegeforme/youcan doit.html) and find more resources in PACER's handout, "Start Now to Chart Your Youth's Career Path After High School" at www.pacer.org/parent/php/php-c162.pdf

10. Prepare for Change.

Helping your child plan for the future can lead to success, as long as you stay flexible. Plans will change no matter how carefully they are developed, and life includes challenges and stumbling points. To mature, the adolescent brain often has these bumps in the road, which are actually opportunities to make decisions and recover from mistakes. As families help their youth establish healthy living guidelines and values, prepare back-up and safety plans, and provide advice and support, they should also be ready for surprises. Young adults are likely to make multiple changes in their goals, at times confusing family and support people; this is normal. Allowing your son or daughter to be flexible with future plans helps him or her develop the self-determination and self-advocacy skills so important for adult life.

Call PACER Center for information and resources. The staff at PACER Center can help you prepare your son or daughter for the adult world. Trained advocates can help you understand your rights and find resources to help with all aspects of transition. Call PACER at (952) 838-9000 or visit www.PACER.org/publications/transition.htm for online transition resources.

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How You Can Help Your Child Learn to Be a Good Self Advocate

It is never too early to start teaching your child how he or she can advocate for himself or herself. Like many other important life skills, self-advocacy is a critical tool your child needs in order to achieve goals, increase self-sufficiency, and become a successful young adult. It is a life long process that begins with your child learning by watching you, as a parent, be a good advocate.

What exactly does self-advocacy mean?

It means taking the responsibility for communicating one's needs and desires in a straightforward manner to others. It is a set of skills that includes:

- Speaking up for yourself
- Communicating your strengths, needs and wishes
- Being able to listen to the opinions of others, even when their opinions differ from yours
- Having a sense of self-respect
- Taking responsibility for yourself
- Knowing your rights
- Knowing where to get help or who to goto with a question

One of the best places to start teaching your child about self-advocacy is in his or her Individualized Education Program (IEP) meetings. Including your son or daughter in the IEP meeting provides him or her with an opportunity to learn and practice important life skills. Some advantages your child may gain by being involved in the IEP process include:

- learning about the impact of his or her disability
- practicing goal setting
- building teamwork skills
- developing an ability to speak up forhimself or herself
- participating in a process of resolvingdifferences
- gaining an understanding of his or her strengths and needs
- learning how to ask for and accept help from others.

Even very young children can contribute to their IEP meetings. If you feel your child is too young to participate in the entire meeting, you may choose to include him or her just in the opening of the meeting. This helps your child to know the IEP team members better and to start to be more comfortable in a meeting setting. It also ensures that everyone at the meeting starts out with your child as the focus. If your child does not attend the IEP meeting, you can bring a picture of your child to display at the meeting. You can also receive your child's input before you attend the IEP meeting. Ask your child if there is anything he or she would like to share at the meeting or to have you share. It can also be very beneficial to ask each team member to state one positive trait or skill your child has as you begin the meeting. Be sure to include your child in this sharing of positives. After the IEP meeting, sit down with your child and explain the goals and services or answer any questions your child may have.

As your child becomes older, the ways in which he or she can participate in his or her IEP meetings greatly increases. It is important to discuss the meeting process with your child beforehand. Role-playing being in an IEP meeting with your child can be a great teaching tool and may help your child to feelless anxious about participating.

Ways for you child to be involved are not limited to, but include:

- Writing down ideas, questions, and concerns before the IEP meeting
- Rehearsing what he or she wants to say inthe IEP meeting
- Introducing him or herself
- Talking about his or her interests,

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strengths, and desires for the future

- Explaining his or her disability to the team
- Leading all or part of the IEP meeting
- Helping the team develop IEP goal areas
- Asking for explanations if he or she doesn't understand something
- Reviewing what the team has agreed to at the end of the meeting

Some questions you may want to discuss with your son or daughter prior to the IEP meeting are:

- What do you want to learn or work on this year?
- What are your special concerns for the school year?
- How do you learn the best?
- What do you need to be successful?
- What would make learning easier for you?
- What do you wish your teacher and other school staff would understand about you?

Discuss with your child how to handle the situation if something negative or difficult to hear is said about him or her in the meeting. Determine at what point, if any, you would stop the meeting and have your child leave. If the meeting is likely to be too stressful or negative, have your child only attend part of it and determine the agenda ahead of time with the team. Be sure to include your child's input on the agenda. If your child chooses not to attend a meeting, ask if he or she would be willing to share ideas or opinions in writing or on tape to provide to the team.

Federal special education law (Individuals with Disabilities Education Act) requires your child to be invited to the IEP meetings anytime transition services or needs are to be discussed. Transition is about planning for your child's future and taking a look at his or her skills in the five areas of employment, postsecondary education, home living, community participation, and recreation/leisure. In Minnesota, transition must be addressed by age 14 or ninth grade. Also, when your child reaches the age of majority (18 in Minnesota), all parental rights will transfer and he or she will be signing his or her own IEP. Therefore, your child needs as much practice in self-advocacy as possible before turning 18.

Teaching your child self-advocacy skills will benefit him or her throughout the school years and far beyond into adulthood. Knowing and exercising your rights as a parent are the first steps in teaching your child to become a strong self-advocate. For more information on special education rights, please contact PACER at 952-838-9000 or 1-800-537-2237.

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Tips for Teens: Use Your IEP Meetings to Learn How to Advocate for Yourself

Self-advocacy is a key step in becoming an adult. It means looking out for yourself, telling people what you need, and knowing how to take responsibility. No one is born knowing these skills. Everyone has to learn them. Ready to begin learning? Here is some great information from teens, for teens, that can start you on your way.

What is self-advocacy?

Self-advocacy means taking the responsibility for telling people what you want and need in a straightforward way. It is knowing how to:

- speak up for yourself
- describe your strengths, disability, needs,and wishes
- take responsibility for yourself
- find out about your rights
- obtain help or know who to ask if youhave a question

Where can I practice self-advocacy?

A great place to practice self-advocacy is in your Individualized Education Program (IEP) meet- ings. With the support of your team members, you can learn ways to:

- explain your disability to others
- set goals for yourself
- build teamwork skills
- share with teachers what works and does not work for you
- ask for accommodation
- accept help from others
- lead all or part of the IEP meeting

But I don't like going to these meetings!

Understandable. But did you know there are still many ways you can be involved and learn self-advocacy skills? Which of these ideas mightwork for you?

- Come for just a few minutes, instead ofattending the whole meeting.
- Write down your ideas, questions, and concerns before the meeting.
- Practice or role-play ahead of time what you want to say in the meeting.
- Introduce yourself.
- Tell team members about your interests, strengths, and desires for the future.
- Explain to the team what it is like to haveyour disability.
- Help your special education teacher write the agenda.
- Help the team develop IEP goal areas.
- Ask for explanations if you do not under stand something.
- At the end of the meeting, review what theteam decided.
- If you choose not to attend the meeting, share your input with your parent(s) or special education teacher before the meeting and review the meeting's eventsafterward.

Be prepared!

Most people are more comfortable at meetings if they have had some time to think about what they want to say. Before your IEP meeting, youcould think about these questions:

- What do I want to learn or work on this year?
- What are my special concerns for the school year?
- How do I learn the best?
- What do I need to be successful?
- What would make learning easier for me?
- What positive information about myself can I share at the meeting?

What does the law say about my attending IEP meetings?

The federal Individuals with Disabilities Education Act (IDEA) says that you must automatically be invited to all of your IEP meetings once you are 16. (You don't have to go,

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but it’s a good idea. After all, no one knows you better than you.) In Minnesota transition must begin during the ninth grade, so you should be invited then and whenever the team is talking about transition services. You may want to discuss attending your IEP meeting with your parents. Transition is about planning for your future. You will look at your skills in three areas:

- employment
- postsecondary education and training
- independent living, if appropriate (includes recreation and leisure as well as community participation)

All this planning and self-advocacy will serve you well. When you turn 18, you will be considered an adult—and will make lots of decisions on your own unless you have a legal guardian. You will be signing your own IEP. This is why it is a great idea to practice self-advocacy as much as possible before turning 18.

Learning good self-advocacy skills is cool. It will help you while you are in school—and when you become an adult. Knowing and exercising your rights are important steps in becoming a strong self-advocate.

For more information on special education rights, please contact PACER at 952-838-9000 or 800-53-PACER.

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Be Your Own Best Advocate

What does it mean to advocate for yourself? Being your own advocate means that you ask for what you need while respecting the needs of others. For example, if you are at a store and a clerk ignores you, you are able to ask in a polite way to be served. Self-advocacy is asking for what you need in a direct, respectful manner.

Why is this skill important? Self-advocacy helps you:

- Obtain what you need
- Make your own choices
- Learn to say no without feeling guilty
- Express disagreement respectfully

How to Advocate for Yourself

You become a self-advocate by taking the initiative to ask directly and specifically for what you need. When you ask, you are polite. You listen to the other person's response without interrupting. You are patient, knowing that change might take some time.

If you feel nothing is changing despite your best attempts, you ask for help from a parent, teacher, or other adult. Here are a few ideas to help you advocate for yourself. You may want to practice them with a friend or family member.

> **"Asking for help is one way of advocating for yourself."**

1. Take a deep breath. Deep breathing gives your body lots of oxygen, and oxygen helps you feel calmer and think more clearly.

2. Think about what just happened. Before you react to something someone said or did, think about it a bit. Ask yourself questions such as: "Did that person really mean to bump into me, or was it just an accident?" or "Is the clerk really ignoring me or is she just very busy? Maybe I need to be more patient."

3. Think about what you want to be different. Before you talk to the other person, make sure you know what you want to happen. Do you want to be treated differently? Do you want that person to stop doing something?

4. Speak clearly and slowly. Start by saying something like, "I would like to talk with you about…" and then calmly describe how you see the situation.

5. Let the other person speak. Being a self- advocate doesn't mean that only you talk. The other person needs a chance to respond to what you are saying. If that person becomes impatient, try to stay calm and take a deep breath.

6. Don't expect immediate results. Change is not always instant or lasting. Sometimes it takes many conversations with the other person before anything changes. You may even have to remind the person more than once.

7. Ask someone to help. There may be times when you and the other person cannot agree or the other person becomes unreasonable.

One of the best parts of being your own advocate is that you don't have to solve all the problems on your own. You can and should ask for help. Asking for help is also advocating for yourself.

8. Understand your disability. In many school and job situations you may need to take the responsibility for explaining your needs based on your disability to others. Practice speaking openly about your needs and strengths with your family and friends. This will make it easier in new situations and with people who don't know you.

When to Advocate for Yourself

You may need to advocate for yourself in many situations. Here are some times when you might need to stand up for your rights or make sure your voice is heard. You may want

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to role-play these and other scenarios with a family member or friend:

- A substitute teacher hands out a test. You have an accommodation to take your tests in a quiet room, but the substitute does not know this. How do you respond?
- Your bus arrives and someone you don't know offers to help you go up the steps. You don't want to be rude, but you would rather not have help, even if it takes you a fewminutes longer to board and take your seat. How do yourespond?
- You have a reading tutor who works with you in the library's learning center. The tutor has been late three times and is late again. How do you respond?

How to Learn More about Self-advocacy

No one is born knowing how to be their own self-advocate. It is a learned skill. You can find out more about it by watching someone who is a good advocate (a parent, aunt, uncle, or neighbor, for example). What is the tone of their voice? How do they stand? Do they make eye contact? What else do you notice?

You also can check out these helpful resources for teens and families.

For Teens:

www.fvkasa.org

This site is from Kids as Self Advocates (KASA), a national, grassroots network of youth with disabilities and needs speaking out about living with disabilities, health care, transition issues, school, work, and more.

www.mcil-mn.org

This site is from the Metropolitan Center for Independent Living in Minnesota, which helps people with disabilities live independently, pursue meaningful goals, and enjoy the same opportunities and choices as all persons. Programs are often available for transition age self-advocacy training and peer mentors.

For Families:

Developing Positive Assertiveness: Practical Techniques for Personal Success by Sam R. Lloyd, (2001). Crisp Publications, Los Altos, CA

This book is for anyone who wants to take charge of their life. It includes a helpful collection of practice situations. Available at www.amazon.com

Self-Determination Synthesis Projectwww.uncc.edu/home.asp

This project includes information about self-determination resources, such as research references, curricula, Web links, and other materials. From the University of North Carolina, Charlotte, it includes links to many lesson plans.

Promoting Self-Determination in Students with Developmental Disabilities by M.L.Wehmeyer, Ph.D., (2007). Guilford Press, New York, NY.

This book offers practical methods for teaching self-determination, including choice making, problem solving, decisionmaking, goalsetting, self-advocacy, andself-regulated learning. It also provides best-practice recommendations. Special features include reproducible worksheets and forms. Available at www.amazon.com

Self-Determination for Middle and High School Students National Center on Secondary Education and Transition(NCSET)
This NCSET handout is a helpful resource for those addressing self-advocacy and self-determination issues. NCSET coordinates national resources, offers technical assistance, and disseminates information related to secondary education and transition for youth with disabilities. Available at http://ncset.org/topics/sdmhs/default.asp?topic=30.

Post-Secondary Educational Opportunities

There are several post-secondary education models that young adults with autism may want to consider. Each model offers supports and classes that will provide young adults with the skills that they may need to reach their goals and dreams.

Three main types of Post-Secondary Education models include:

1. **Mixed/hybrid model**: Students participate in social activities and/or academic classes with students without disabilities (for audit or credit) and also participate in classes with other students with disabilities (sometimes referred to as "life skills" or "transition" classes). This model typically provides students with employment experience on- or off-campus.
2. **Substantially separate model**: Students participate only in classes with other students with disabilities (sometimes referred to as a "life skills" or "transition" program). Students may have the opportunity to participate in generic social activities on campus and may be offered employment experience, often through a rotation of pre-established employment slots on- or off-campus.
3. **Inclusive individual support model**: Students receive individualized services (e.g., educational coach, tutor, technology, natural supports) in college courses, certificate programs, and/or degree programs, for audit or credit. The individual student's vision and career goals drive services. There is no program base on campus. The focus is on establishing a student-identified career goal that directs the course of study and employment experiences (e.g., internships, apprenticeships, work-based learning). Built on a collaborative approach via an interagency team (adult service agencies, generic community services, and the college's disability support office), agencies identify a flexible range of services and share costs.

As described by the Institute for Community Inclusion:
www.communityinclusion.org/article.php?article_id=178

Different post secondary educational institutions may offer one or more of the models listed above that may meet the needs of a young adult with autism. Post secondary educational institutions include:

Four Year College or University

There are more and more colleges that do provide support services for students with disabilities. However, students and their families are encouraged to research to make sure that the supports offered meet the needs of the student. College students with autism may need assistance learning the advocacy skills required to ask for supports and accommodations. A counselor or peer-counselor may be able to assist with this, or someone from the school's office of disability services.

In rigorous academic classes, a student may want to request the assistance of a tutor. Tutors are often available through the university and can be located through various avenues. A good place to start is the office of disabilities.

Cooperative Education

An option offered at Some colleges and universities is cooperative education. In a cooperative education program, the student alternates between taking academic classes and working in the field of their choice. If available, this type of education can oftentimes be a good choice for students with autism, as it allows them to develop both academic and work skills at the same time.

Community College

Several community colleges are developing programs to meet the needs of young adults with developmental disabilities. For some students this may include life skills such as money management, problem solving, and housekeeping. For others it may be more academic subjects and for others, it is a combination of both. The good news is that community colleges recognize the needs of individuals with developmental disabilities and are tailoring programs to meet these needs. The Consortium of Community Colleges for Autism and Intellectual Disabilities has approximately 40 community colleges in its membership and they are developing best practices in supporting individuals with developmental disabilities.

For a list of some community colleges with programs geared toward individuals with autism and other developmental disabilities, visit the Autism Speaks Resource Guide: AutismSpeaks.org/community/fsdb/search.php

Vocational or Technical Schools

Vocational or technical schools can provide individuals with disabilities with the opportunity to experience hands-on learning in a variety of fields. There are some career and technical education programs that provide this hands-on training along with academic skills such as reading, writing, math and problem solving skills. These programs also provide workplace experience such as internships and mentorships. It has been reported that participating in vocational or technical classes during the last two years of high school, especially classes that offer occupational-specific instruction, is a successful transition strategy. It may be helpful to work with your school district to find out about programs in your area.

Even for those who may not want to attend college fulltime, or who do not possess the standard high school diploma, young adults with autism have the ability to audit classes.

504 Plans

Most colleges and universities have a department that ensures the school's compliance with both the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973. It is important to become familiar with the school's disability-related resources so that your young adult can be sure to advocate for the services and supports they are entitled to.

> ***"The Section 504 regulations require a school district to provide a 'free appropriate public education' (FAPE) to each qualified student with a disabilitywho is in the school district's jurisdiction, regardless of the nature or severity of the disability. Under Section 504, FAPE consists of the provision of regular or special education and related aids and services designed to meet the student's individual educational needs as adequately as the needs of non-disabled studentsare met."***
>
> ***- Free Appropriate Public Education for Students with Disabilities: Requirements Under Section 504 of The Rehabilitation Act of 1973***
> ***www2.ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.html***

Section 504 and ADA are civil rights laws. They are designed to help protect individuals with disabilities from discrimination in school, work and public accommodations. Section 504 applies to any school that gets federal funding. Students with disabilities cannot be denied appropriate services or supports that may be necessary to meet their needs, or that would be available to students without disabilities. In order to be eligible for Section 504 protections, a student has to have a physical or mental impairment that limits at least one major life activity, as well as a history of this impairment in a major life area. Reasonable accommodations can include: taped books, readers or scribes, note-takers, access to the instructors notes, extended time for assignments and tests, the use of a calculator, preferential seating and other similar supports.

You may want to keep in mind that Section 504 does **NOT** require an institution to compose a written plan, but most places will do this. In order for a student with autism to receive accommodations under Section 504, the student or his or her advocate must request them. Even if young adults with autism had services in high school, this does not ensure that they will have them if they go on to a post-secondary educational setting. Some post-secondary educational institutions will provide supports usually through an office set up to aid students with disabilities. However, the level of supports as well as the efficiency and effectiveness vary from school to school. It is important that you and your young adult research the supports available and determine if they will be appropriate for success in this educational setting. It is essential to remember that once your child has left high school and is enrolled in an institution of higher education, IDEA requirements no longer apply. Section 504 and ADA will protect the student, but it is the young adult's responsibility to make sure appropriate accommodations are requested in college.

This is the best opportunity to self-advocate. Young adults with autism would be best served by speaking up for themselves and articulating their needs. College counselors are more readily willing to listen when the student, not their parents, approaches them. Some individuals with autism will go on to college after high school. The number of 2-year and 4-year college opportunities for young adults with autism has been growing in recent years. There may be no greater opportunity for self-advocacy than during this process. You may want to remind your young adult that his or her “voice” will make a difference. It is very important to share anxieties or areas where he or she needs help. You also may want to help your young adult with autism make a list of his or her most significant concerns about college. Young adults should be encouraged to share these concerns with their advisors. Creating a solid support system may lower the chances of future problems.

Differences between High School and College

Adapted from Kay McVey, Faculty Development Specialist, PROJECT CONNECT, Henderson State University (www.uml.edu/student-services/disability/transition2.html)

High School	College
All students have the right to an education	College education is a privilege, not a right
Individuals with Disabilities Education Act Section 504 of the Rehabilitation Act Americans with Disabilities Act	Section 504 of the Rehabilitation Act Americans with Disabilities Act
School district is responsible for identifying the disability	Student is responsible for providing documentation that establishes verification of the learning or other type of disability
School district designs the IEP	Student identifies his/her needs in collaboration with his or her counselor.
School district ensures that the IEP is implemented	Student is responsible for their own progress.
Teacher functions as advocate	Students must advocate for themselves.
Fundamental alterations to program of study are made	Fundamental alterations of programs are not allowed. Classroom accommodations may not alter the fundamental nature of a course of impost an undue burden on an instructor/institution.
Personal services are provided (ex: aide) Success is more of a right	Personal services are student’s responsibility. Only the opportunity to succeed is provided.
Transportation to and from school is provided.	Transportation to and from school is NOT provided.
Parent or guardian is the primary advocate. Students learn ways to become their own advocate	Students are expected to be their own advocates.

Preparing for College While Still in HighSchool

If your young adult is planning to go to college, it is essential to remember that in order for a student to apply to college, he or she will need to obtain a high school diploma or a General Education Diploma (GED). An IEP diploma will not be recognized by institutions of higher education.

Make sure that all standardized tests have been taken, both ACT and SAT, and SAT subject tests. Some colleges will require these for admissions. If you think your child may need extra support taking standardized tests, oftentimes accommodations can be arranged. In order to ensure that the right accommodations are in place, you and your young adult should work with the school to fill out the necessary disability paperwork to make these requests. Be mindful that this needs to be done several months in advance of your child sitting for the examination.

Find out if colleges that your child may be interested in require IQ or achievement test scores to receive accommodations under Section 504 (see below). The high school may be able to arrange for this while the student is still under IDEA.

Assess if the individual needs any remedial classes before going on to college. Some students do this at college, while others spend an extra year in high school. Summer courses may be an option for your student with a college in your area. These classes can help to prepare the student for the upcoming transition.

Work closely with your guidance counselor to begin to explore all available options. One option is *Dual Enrollment*. A dually enrolled student is a student who is still officially a student at high school, but is also taking one or more classes at a college for credit. Transition teachers from the school will work with your young adult outside of school. His or her weekly schedule might include taking classes, looking for a job or working, learning to use public transportation, and working out at a health club. Dual Enrollment allows the student to begin to get used to the college setting, life and workload, while still in high school.

Choosing the Right School

It is essential to ask the right questions as you explore post-secondary education options. *The Autism Transition Guide: Planning the Journey from School to Adult Life* by Carolyn Bruey and Mary Beth Urban gives the following advice:

- Talk to the guidance counselor at your school.
- Attend local college fairs and ask about disability support services.
- Ask your child's teacher about where some of their past students have attended college.
- Ask other parents of students with ASD.
- Consult local autism organizations to see about listings of colleges that offer supports.
- Make sure to arrange visits to any potential schools where you can speak with staff and students. The school may also be able to help connect you to other students with ASD and their families.
- Investigate if the school has the proper supports and services available for your child to have the most successful and rewarding experience possible.
- Keep in mind that there are many different types of institutions that your child could possibly attend. These include: vocational school, community college, technical institutes, state schools, liberal arts schools and also the variation of 2-year versus 4-year programs.
- Factors that come in to play when selecting a college can also include location and finances.
- Students and their parents should not hesitate to visit the selected college and the one they will eventually attend as many times as they need to in order to familiarize the student with the college.

Below is a checklist of topics that families may want to take into consideration when discussing transition from high school to college. The checklist is adapted with permission from Jerri Roach Ostergard, Transition Specialist, Worcester MA Public Schools as found on the *Think College* website. You can also see the checklist at: http://thinkcollege.net/for-families/transition-checklist.

- Help your student know what choices they have. Visit programs, talk to other students, families, watch videos, etc.
- Set post-secondary education and career goals through the use of person-centered planning.
- Ensure that your son/daughter is enrolled in academic courses throughout high school, which will prepare him/her for college courses. While not a requirement, experience tells us that students with more inclusive academic experiences in high school do better once in college.
- Know the difference between the laws that govern education at the secondary level (IDEA = entitlement) and at the college level (ADA = otherwise qualified). Encourage your son/daughter to participate in and, if possible, lead their own IEP. Participation means planning the meeting, working with a teacher to identify their own goals and supports, presenting their goals at the meeting, welcoming the team, learning about the forms.
- Help your son/daughter learn to advocate for him/herself while in high school, which will prepare him/her for when it needs to be done in college.

- Obtain college catalogue(s) and review them carefully with your son/daughter and with support from high school staff (e.g. guidance counselor, transition coordinator) as needed. Visit campus activities while in middle or high school, sports, recreational, entertainment activities. Have a currently enrolled student get involved in the campus visit or activity.
- Ensure that documentation of your son/daughter's disability is up-to-date. This may be required by the college.
- Discuss with your son/daughter the nature of their disability and how it affects their school work. Practice how they refer to their disability and identify what supports they need.
- Encourage teachers to document what accommodations and technology your son/daughter uses now and what they may need in college (e.g. reader, note taker, scribe, books-on-tape, speech-to-text software, screen reader, tape recorder, PDA, etc.) Create a list of these accommodations and supports.
- Visit colleges together so that your son/daughter has good information to make a final choice.
- Your son/daughter should meet with college Disability Services Office (DSO) staff to talk about documentation and learn about how accommodations in college are different from high school.
- If there is a specific program on the campus for students with intellectual disabilities, arrange to meet with the staff. Find out how participants in the program participate in general college life and academics.
- Discuss goals, learning needs, and how to access specific accommodations, including academic supports, that are available for all students (e.g. tutoring, writing support) with your son/daughter and DSO staff before classes begin. Figure out and setup transportation prior to the start of school (e.g. driving, car-pooling, learning to use public transportation, travel vouchers).
- Be aware of financial aid resources available to your family and make sure that funding for all costs is arranged before school starts (e.g. tuition, books, fees, transportation).
  Identify how financial support your child may receive impacts other benefits (e.g. SSI, SSDI).
- Know what services are available through adult human service agencies (e.g. vocational rehabilitation – tuition, books, transportation, employment supports; One-Stop Career Canters, Individual Training Accounts, Developmental Disability agencies). Representatives from these groups should be at the transition IEP, PCP, etc. Your son/daughter should have the phone numbers for relevant agencies in their cell phone.
- Be prepared for the fact that you, the family member, need written consent from the student to obtain access to their records at the college level.

Key Skills, Common Issues and Concerns

Self Advocacy and Post-Secondary Educational Opportunities

Once your young adult with autism had been accepted into an educational institution, he or she needs to start relying on his or her own self-advocacy skills. Most institutions do not have a way for parents to advocate for their young adult. This leaves the responsibility in the hands of the students.

Leaving high school and participating in new educational opportunities may be challenging, partially because the mandatory supports that were in place are no longer there. In addition, as a parent you may have advocated for your young adult throughout his or her school years, and will no longer able to do so. Young adults with autism in college become solely responsible for themselves. It is now up to them to ask for what they need in all situations, both academic and social. It may be a good idea to review the types of services that were helpful in high school to prepare your young adult for what will be helpful in college. This transition is most likely a major change for both you and your young adult, so it’s important to develop self-advocacy skills while still in high school.

Aside from the necessary services, there will be other areas in which young adults with autism need to communicate and advocate for themselves. These areas can include: knowing how and when to disclose their autism diagnosis, understanding their rights, and asking for assistance when necessary.

While in college, the ability to ask for what you need, find out about new situations, and navigate the complex social world can often be difficult. Working on these skills and ideas in advance can help students use them when necessary. Some things that students have found helpful are:

- Creating a disclosure letter with disabled student services.
- Learning when, how, and how often to ask for accommodations.
- Seeing professors during office hours.
- Talking about what is not working, giving/receiving feedback.
- Resolving problems.

Stephen Shore outlines the four main components to think about before entering college and work on while you are there:

- Coursework
- Living
- Organization
- Social

Independent Living Skills

Many students may worry about living skills such as organization and time management upon entering college. It is important for you to work with your young adult to begin to develop these skills in the transition plan while still in high school. These skills can include: managing time, setting priorities and organizing assignments and free time.

It is very important for your young adult with autism to maintain structure in his or her life in college. Structure is still there in college, but it needs to be more self-imposed. There is quite a bit more free time in college. Very often, the amount of time spent on homework and studying exceeds the amount of time spent in the classroom. Young adults with autism need to be able to create new routines to adjust to the many changes in daily life that happen between high school and college. Self-advocacy is essential.

Young adults with autism living on their own may need to cultivate skills relating to independent living skills such as cleaning, managing finances, solving problems and doing laundry. It is essential to note that these types of independent living skills should be worked on prior to leaving high school.

This is a blog entry written by Autism Speaks staffer Kerry Magro. Kerry, an adult who has autism, is a rising senior at Seton Hall University, majoring in Sports Management. He started an Autism Speaks U Chapter: Student Disability Awareness on campus to help spread awareness and raise funds for those affected by autism. Autism Speaks U is a program designed for college students who host awareness, advocacy and fundraising events, while supporting their local autism communities.

One issue, in my opinion, that isn't addressed enough on college campuses, is accommodations within the residence halls for those with disabilities. Yes, from time to time you will see a residence hall with an elevator, maybe bed shakers for those who are hearing impaired, but does that make a residence hall "disability friendly?" I don't think so. A disability friendly residence hall should be accommodating to all disabilities, especially autism.

For people just starting college, living away in a dorm can be a difficult transition. For an individual with autism who is affected drastically by change it can make that transition almost impossible. The argument to this, is that those affected by autism who actually attend college are just a small enough quota where it doesn't really matter. The thing is, most accommodations for those with autism in the dorms just rely on having a good and understanding friend. It's easy in college to fall into a pattern of anti-social tendencies when work builds up on you.

I have seen this from every angle imaginable. My freshman year in the dorms, I was a resident. During my sophomore and half of my junior year, I was a Resident Assistant (RA) who helped residents while living in the dorms. Living in the residence halls wasn't much of a difficulty for me, but that was because I had great friends early on who supported me in everything that I did. Being able to socially get my way through that first year, where I was seen as enough of a leader to be one of the only autistic RA's not only in New Jersey, but in the country.

So what can autistic individuals living in the dorms do to make themselves ready for the transition? Firstly, strongly consider requesting a single room. Most colleges are very willing to give someone with a registered disability a single. I have lived alone and have loved the benefits. Mainly, the best benefit is that you have your own place to unwind. You don't have to worry about whether you get along with other individuals. The pros outweigh the cons in most cases.

Secondly, make sure you get yourself out there. Most residence halls have programs within the first couple of weeks of school to get people meeting your fellow peers. Most residence halls will also have a peer support group for those with disabilities where you can interact with others who have similar difficulties within the dorms. We also live in a technology related world, so if you don't feel comfortable with face to face conversations, virtual communication (Facebook, instant messaging, texting) is a great way to practice your social capabilities. Just make sure it doesn't become a habit, if you are never leaving your room!

Take some time to meet with the director of your dorm. If you are open with them about having a disability, they can't turn you away, and have to give you proper accommodations. You need to force yourself out of your comfort zone because that's where the most progress can be made.

Now, this is a process. There is no game plan to every disability. You have to create your own plan of attack. Independence is not learned overnight either, so take the steps needed to make your own personal plan and then follow through.

Post-Secondary Education Resources

Think College! College Options for People with Intellectual Disabilities
www.thinkcollege.net

College Coach: Excellence in Educational Advising
www.getintocollege.com

WNY Collegiate Consortium of Disability Advocates
www.ccdanet.org

U.S. Department of Education Office for Civil Rights: Protecting Students with Disabilities
http://ed.gov/about/offices/list/ocr/504faq.html#interrelationship

The Autism Transition Guide: Planning the Journey from School to Adult Life
by Carolyn Thorwarth Bruey, Psy.D. and Mary Beth Urban, M.Ed.

Living with Autism: Life After High School
Autism Society
www.education.com/reference/article/Ref_Living_Autism_Life

The Health Resource Center at the National Youth Transition Center
Online Clearinghouse on Post-Secondary Education for Individuals with Disabilities
www.heath.gwu.edu

Free Appropriate Public Education for Students with Disabilities: Requirements Under Section 504 of the Rehabilitation Act of 1973
www2.ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.html

The Syracuse Community-Referenced Curriculum Guide for Students with Moderate and Severe Disabilities
by Alison Ford

Understanding Asperger Syndrome: A Professor's Guide
www.researchautism.org/resources/AspergerDVDSeries.asp

More General Transition Resources

Transition to Adulthood: Guidelines for Individuals with Autism Spectrum Disorders (ASD)
by the Ohio Autism Task Force with the support of the Ohio Center for Autism and Low Incidence (OCALI) Transition to Community Task Force
www.umcard.org/files/Trans_Guide_5.pdf

Guiding Your Teenager with Special Needs Through the Transition from School to Adult Life: Tools for Parents

by Mary Korpi

Life's Journey Through Autism, a Guide for Transition to Adulthood

Organization for Autism Research, Southwest Autism Research and Resource Center and Danya International, Inc.

www.researchautism.org/resources/reading/documents/transitionguide.pdf

Growing Up on the Spectrum: A Guide to Life, Love and Learning for Teens and Young Adults with Autism and Asperger's

by Lynn Kern Koegel, Ph.D. and Claire LaZebnik

Autism Into Adulthood — Making the Transition

by Jennifer Van Pelt, M.A.

Social Work Today

www.socialworktoday.com/archive/090208p12.shtml

GW HEATH Resource Center

The Disclosure Dilemma For Advocates

By Laverne A Buchanan, Ed. D.

Should you? Shouldn't you? When? To whom? Such questions frequently arise for parents, counselors, and teachers whenever the topic of disclosure of a disability arises. Many disabilities, such as certain learning, cognitive, and perceptual disabilities, are not readily apparent. Students and employees with hidden disabilities may be understandably reluctant to disclose information about the presence and nature of a disability for fear of discrimination and negative perceptions.

Many factors can influence the ultimate decision of whether or not disclosure is the best course of action in a given circumstance. Young adults engaged in the transition to postsecondary education and employment will benefit from counsel and guidance about how to make sound judgments regarding disclosure.

Counselors, advocates, and family members should reinforce any advice regarding disclosure with instruction about effective self-determination and self-advocacy, concepts with which students in transition should be familiar. Ultimately, students and employees with disabilities who can articulate their particular needs and objectives, and who have been coached on the selective sharing of personal information, enjoy greater control over their circumstances.

Questions About Disclosure

There are many points of view about whether or not it is necessary or beneficial to disclose information about a disability, and, as noted above, many valid concerns about when, how and to whom such information should be shared. The following questions will guide students and advocates to a clear understanding about this difficult issue.

Why to Disclose?

There may be any number of reasons that an individual is confronted with a decision about disclosure:

- An accommodation is needed
- Legal reasons
- Background check is pending
- Safety or other health related reasons

When the disclosure question arises, individuals with disabilities need to address their own feelings about sharing personal information related to the disability.

When to Disclose?

The choice of when to disclose depends on the type of information being shared. Generally, disclosure occurs:

- When the individual is assured of the confidentiality of the information being shared, and never before.
- During initial contact, such as a job application.
- When an interview is scheduled.
- During an interview.
- Following a job interview or acceptance into a program.
- Any time after employment or program has started.
- Never.

Students and employees may choose never to disclose if no accommodations are needed and their disabilities create no safety issues for themselves of classmates and co-workers.

The George Washington University
HEATH Resource Center
2121 K Street, N.W. Suite 220 • Washington, DC 20037
Voice/TTY: 202-973-0904 • 1-800-544-3284 (toll free) • Fax: 202-973-0908
Email: ask heath@heath.gwu.edu Website: www.heath.gwu.edu

What to Disclose?

Once the decision to disclose is made, one must still consider how much is too little, too much , or just enough personal information to share in light of the desired objective. Always be focused on the *purpose* of disclosing. When providing information about a disability, it is best to:

- Be honest, straight forward, factual, and positive.
- Relate disclosure comments to the immediate situation.
- Know your accommodations needs, and be prepared to offer suggestions regarding such things as costs, suppliersof needed devices, and knowledge of maintaining a piece of assistive equipment.
- Be prepared to provide appropriate documentation of the disability.

Who to Tell?

Not every person that students or employees with disabilities encounter throughout the day needs to know about the disability. Generally, those who might need to know about the disability are:

- Anyone directly involved in providing accommodations.
- Anyone who is positioned to support the request for accommodations.
- Anyone who is responsible for evaluating the student or employee's performance.
- Anyone responsible for the health and safety of other students or employees.

How to Disclose?

How, or in what form, information about a disability is best shared depends, in part, on when the individual chooses to disclose , and how much information they intend to share. Generally, the disclosure may be:

- Verbal: e.g., a perspective job applicant requests an accommodation in order to complete the application and interview process.
- Written: e.g., in response to an acceptance letter, a student notifies a college about the disability and need for accommodations.
- Third party: e.g., an advocate, such as a job coach, requests assistance on behalf of an employee with a disability.

Where to Disclose?

Students , employees, and advocates should take great care in choosing a setting in which to disclose. Without question, any information of a personal nature should be provided:

- In a private setting.
- In a place where only the intended recipient of the information will be informed.

Instructive advocacy leads to effective self-advocacy. Openly discuss prospective students' and employees' questions and concerns about disclosure. Actively engaging their input in the process will prepare them to handle similar future challenges independently . Taking the time to sort through these questions will also convey a sense of empowerment, and an understanding that, like any other students or employees, they too are entitled to privacy and dignity.

Disclosure Do's and Don'ts for Advocates

The following is a list of Disclosure Do's and Don'ts for Advocates:

DO:

- Link discussion of disclosure to self-determination and self-advocacy.
- Engage the youth/young adult in a discussion regarding thoughts and feelings on disclosing personal information.
- Determine the reason for needing to disclose.
- Weigh benefits and risks of disclosure or not disclosing.

- Plan and, if necessary, practice with the youth how to disclose personal information.
- Determine who needs to have this personal information and why; limit information sharing to essential persons.
- Assure the youth that both written and verbal information will be maintained in a confidential manner.
- Get the permission of the youth and parents/ guardians to share personal information.
- Relate disclosure comments to current situation.
- Be aware of accommodation needs; be prepared to provide appropriate documentation.
- Discuss private information in a private setting.

DON'T:

- Share personal information about the youth/ young adult without his/her consent and involvement, or the consent of parents/guardians.
- Discuss personal information regarding the youth/young adults with persons who are not involved in their service delivery.
- Ask personal or specific questions in a group or public settings.
- Leave written information in an area that may be read by others not involved in the delivery of services to the youth.
- Use confidential information for any reason(s) other than the purpose for which it was collected, disclosed and indicated to youth and parents/ guardians.

LaVerne A. Buchanan is a senior consultant with TransCen Inc., where she consults and provides training to state and local school systems, adult service providers, employers, youth/young adults and their families regarding best practices for school-to-work and transition activities and services.

References

Deschamps, A. (1999, Spring) *The disclosure and dilemma.* (Available from the ADA Information Center for the Mid-Atlantic Region, 451 Hungerford Drive, Suite 607, Rockville, MD. 20850).

Disclosure of your disability in your application (1997). Employability: A Guide for Students with Disabilities. Retrieved May 28, 2002 from Flinders University of South Australia, The University of Adelaide and The University of South Australia Web Site: http://flinders.edu.au/careers/empdisc.html

Career Opportunities Student with Disabilities. Disclosure: What should I do? Retrieved May 22, 2002, from he University of Tennessee, Career Services and Disability Careers Office Web Site: www.cosdonline.org/training/disclosure.shtml

The National Center on Workforce and Disability/ Adult. *Asking about disability and respecting confidentiality in one-stop service delivery.* Retrieved April 22, 2003, from University of Massachusetts Boston, Institute for Community Inclusion Web site: www.onestops.info/print/php?article id=84

The National Center on Workforce and Disability/ Adult. *Disclosure of a Non-Apparent or Hidden Disability.* Retrieved April 22, 2003, from University of Massachusetts Boston, Institute for Community Inclusion. Website: www.onestops.info/print.php?article id=107

Lynch, **R.T.**, & Gussel , **L.** (1996). *Disclosure and self-advocacy regarding disability related needs: Strategies to maximi ze integration in postsecondary education.* Journal of Counseling and Development, 74(4), 352-362.

SJSU Workability IV Program. *Disclosure.* Retrieved May 28, 2002 from: http://www.work4.s jsu .ed u/Stud ents/ jo b search/stud-jo b-disclosure.html

SJSU Workabilit y IV Progra m. Di sabilit y disclosure information. Retrieved May 28, 2002, from Washington Sta te Department of Social & Health Services Web site: http://wwwl.dshs.wa.gov/dv r/jo bseekers/disabilitin fo rmation/htm

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U.S. Office of Special
Education Program

Comparison of Medicaid Programs that Serve Adults with Autism Spectrum Disorders **(ASD)**

	Adult Autism Waiver	**Adult Community Autism Program (ACAP)**	**Consolidated and PFDS Waivers**	**OBRA Waiver**
Eligibility - Diagnosis	Autism Spectrum Disorder (ASD}[1]	Autism Spectrum Disorder (ASD)[1]	Intellectual disability (also known as mental retardation)	The OBRA Waiver is currently closed. For questions about individuals who are currently receiving services through the OBRA waiver, please contact Sharon Tomforde at (717) 783-8391 or stomforde@state.Qa.us
Eligibility - Level of Care	Either Intermediate Care Facility for people with Other Related Conditions (ICF/ORC) or Intermediate Care Facility for people with Mental Retardation (ICF/MR), IQ score is not considered.	Either Intermediate Care Facility for people with Other Related Conditions (ICF/ORC) or Intermediate Care Facility for people with Mental Retardation (ICF/MR), IQ score is not considered.	ICF/MR	If providers have questions about the waiting list and the impact that may have on individuals, please send questions to the following email account with the words "OBRA Waiver Waiting List" in the subject line: ra-act150review@state.Oa.us
Eligibility - Financial	Medical Assistance Financial Eligibility requirements for long-term care participants	Medical Assistance Financial Eligibility as determined by the County Assistance Office (CAO) (Long Term Care requirements do not apply)	Medical Assistance Financial Eligibility requirements for long-term care participants	
Eligibility - Age	21 and older	21 and older	3 and older	
Geographic Area	Statewide	Cumberland, Dauphin, Lancaster and Chester counties	Statewide	
Type of Program	1915(c) Medicaid Home and Community-Based Services Waiver	**ACAP** is a Home and Community-Based Services program that provides physician, behavioral, and community services through an integrated approach to create a coordinated system of supports	1915(c) Medicaid Home and Community-Based Services Waivers	
		Chart continued on page 2		

	Adult Autism Waiver	Adult Community Autism Program (ACAP)	Consolidated and PFDS Waivers	OBRAWaiver
Medical and Behavioral Health Services	Services are offered through HealthChoices and Behavioral HealthChoices managed care organizations or Medical Assistance fee for service. **Providers must receive training specific to supporting adults with an ASD.**	The ACAP provider and their network of providers provide medical, dental, behavioral health and home and community-based services. Several services, such as pharmacy, will continue to be provided through Medical Assistance. **Providers must receive training specific to supporting adults with an ASD.**	Services are offered through HealthChoices and Behavioral HealthChoices managed care organizations or Medical Assistance fee for service.	
Covered Home and Community-Based Services	• Assistive Technology • Behavior Specialist Services • Community Inclusion (similar to community integration and habilitation) • Community Transition Services • Day Habilitation • Environmental Modifications • Family Counseling • Family Training • Job Assessment and Finding • Nutritional Consultation • Residential Habilitation • Respite • Supported Employment • Supports Coordination • Therapies (Speech, Occupational, Counseling) • Temporary Crisis Services • Transitional Work Services The AAW does not include an individual cost limit, or cap. However, there are service limitations for some specific waiver services as outlined within the Participant Handbook.	• All physician services (including emergency services provided by a physician, psychiatric services, and direct access to a woman's health specialist to provide women's routine and preventive health care services) • Certified Registered Nurse Services • Intermediate Care Facility (ICF services) • Nursing Facility Services • Non-emergency medical transportation to services covered under the Medical Assistance Program • Optometrists' services • Chiropractors' services • Audiologist services • Dentist services • Health Promotion and Disease Prevention services • Medical supplies and durable medical equipment • Prosthetic eyes and other eye appliances • Hospice services • Mental health crisis intervention services • Outpatient psychiatric clinic	• Assistive Technology • Behavior Support Services • Education Support Services • Home Accessibility Adaptations • Vehicle Accessibility Adaptations • Unlicensed Home and Community Habilitation • Home Finding • Homemaker/Chore • Licensed Day Habilitation • Licensed Residential Habilitation (Consolidated only) • Unlicensed Residential Habilitation • Nursing Services • Prevocational Services • Respite • Companion • Specialized Supplies • Supported Employment • Supports Broker Services • Supports Coordination	

		services • Respiratory services • Targeted Case Management • Assistive Technology • Behavioral Support (similar to Behavioral Specialist Services in waiver) • Community Transition Services • Crisis Intervention Services • Adult Day Habilitation • Environmental Modifications • Family Counseling • Habilitation • Homemaker/Chore services • Non-Medical Transportation • Personal Assistance Services • Pre-vocational Services • Residential Support (similar to Residential Habilitation) • Respite • Supported Employment • Supports Coordination • Visiting Nurse • Additional services determined necessary • Physical, Occupational, vision and mobility, and speech therapies (group and individual) • Certified nurse Practitioner • Podiatrist There is no individual cost limit, or cap. However, all services must be determined medically necessary and listed in the ISP.	• Therapies (Behavior, Occupational, Physical, Speech, Visual/Mobility) • Transitional Work Services • Transportation The PFDS Waiver includes an individual cost limit, or cap. All services funded through the PFDS Waiver, with the exception of Supports Coordination, may not exceed this limit for any participant during a fiscal year. The individual cost limit is currently $26,000 per participant per fiscal year. There are also service limitations for some specific waiver services.	

AUTISM & WANDERING

In 2008, Danish researchers found that the mortality rate among the autism spectrum disorder (ASD) population is twiceashighas the general population.In 2001,a California research team found that elevated death rates among those with ASD were in large partattributed 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 theautismpopulation, 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 onFacebook

CAREGIVER RESOURCES

AWAARECOLLABORATION
awaare.org

NAA/UA AUTISM SAFETYTOOLIOT
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 Childis Missing:**achildismissing.org**

FORFIRST RESPONDERS & CAREGIVERS
NationalCenter for MissingandExploited Children:
missingkids.com | 1-800-THE-LOST
Autism RiskManagement:
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: Ageof Autism | Autism One | Autism Research Institute | Autism Speaks |DougFlutie 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 findit isnecessary to prevent your loved one from slipping away unnoticed by:**

0 *Installing securedead bolt locks that require keys on both sides.*
0 *Installing a homesecurity 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 eyelocks on all doors, aboveyour child's reach.*
0 *Fencing youryard.*
0 *Adhering printableSTOPSIGNS to doors, windows and other exits,suchas 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 NOTmeanyour child issafe in water.*
0 *If you own a pool,fenceyour pool.Use gates that self-closeand self-latch higher thanyour children's reach.*
0 *Removeall toys or items of interest from the pool when not in use.*
0 *Neighbors withpoolsshould bemade aware of thesesafety precautions and your child's tendency to wander.*

The American Academy of Pediatrics does not recommend swimmingclasses as the primary means of drowning prevention.Constant,careful supervis,on 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 *Giveyour neighbor a simple handout with your namaddress,and phone number.*
0 *Askthem to callyou immediately if they seeyour child outside the home.*
0 *Decidewhat other information to present to neighbors.*
0 *Does your child havea fear of cars and animals or is he/shedrawn 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 thinkthey are deaf?*
0 *Are theresensory 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 *Nameof child oradult,current photographand physical description including any scars or other identifying marks*
0 *Identify your child's favoritesong,toy or character*
0 *Names,home,celland pager phone numbers and addresses of parents, other caregivers and emergency contact persons*
0 *Sensory,medical or dietary issues and requirements*
0 *Favoriteattractions and locations wherethe person may be found*
0 *Likes,dislikes,fears,triggers,and de-escalation techniques*
0 *Method of communication:noteif nonverbal uses sign languag picture boards,or written words*
0 *ID wear, jewelry, tags on clothes*
0 *Map and address guide to nearby properties withwater 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:	

Developing Risk and Safety Life Skills for Persons with Autism

by Dennis Debbaudt 2009

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. Make building safety skills a part of the daily routine. 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 and safer 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. 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.

Skills to build:

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 person with 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 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.

Expect public or private sector scrutiny at:

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

In these days of heightened security? Anywhere!

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

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

Disclosure tools and options

What's the best tool to use when you make the decision to disclose your autism or Asperger syndrome to a police officer? A handout card.
1) Develop a handout card that can be easily copied and laminated
2) The handout is replaceable. You can give it away to the officer on the scene
3) Carry several at all times
4) The handout card can be generic or specific to you
5) Work with an AS support organization to develop a generic handout
6) Work with persons whose opinions you trust and value to develop a person specific handout

How to present a handout to a police officer

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

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

Disclosure to a police officer

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

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

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 street crime

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

Author, Dennis Debbaudt, is the parent of a young man who has autism, an author, law enforcement trainer and producer of autism-related videos and curriculum for law enforcement and first response agencies. His materials are in use by NYPD, Chicago Police Department, and the Palm Beach County Sheriff's Office among hundreds of agencies in the U.S., Canada and United Kingdom.

Dennis can be reached via his web site: http://www.autismriskmanagement.com/
email ddpi@flash.net or call 772-398-9756.

References:

Debbaudt, D. (2002) Autism, Advocates and Law Enforcement Professionals: Recognizing and Reducing Risk Situations for People with Autism Spectrum Disorders, London-Philadelphia, Jessica Kingsley Publishers

Debbaudt, D. and Coles, W. (2004) The Role of the Family-School Liaison Counselor: Safety & Risk Support for Students with ASD. Autism Spectrum Quarterly

Debbaudt, D. (2007) Plan Your Response to an Autism Emergency. Autism Risk & Safety Newsletter. Port St. Lucie, Florida

Debbaudt, D. (2002) Protect Students with Autism from Bullies Taunts. Maintaining Safe Schools LRP Publications, 9, 1, 7

Debbaudt, D. (2003) Safety Issues for Adolescents with Asperger Syndrome. In Liane Holliday Willey (ed) Asperger Syndrome In Adolesence: Living With the Ups, the Downs and Things In Between London: Jessica Kingsley Publishers

Debbaudt, D. and Rothman, D. (2001) Contact With Individuals With Autism: Effective Resolutions. FBI Law Enforcement Bulletin, 7, 4, 20-24

Additional Reading & Viewing

Debbaudt, D. (2006) 'Disclosing to the Authorities' In Dinah Murray (ed) Coming Out Asperger: Diagnosis, Disclosure and Self-Confidence London-Philadelphia: Jessica Kingsley Publishers.

Debbaudt, D. and Legacy, D. (2004) Autism & Law Enforcement Roll Call Briefing Video. Debbaudt Legacy Productions, Port St. Lucie, Florida. (video and booklet)