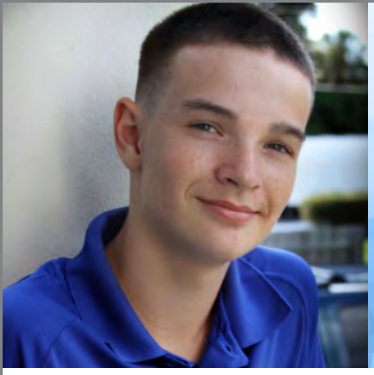
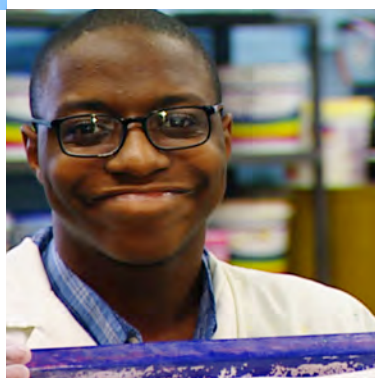


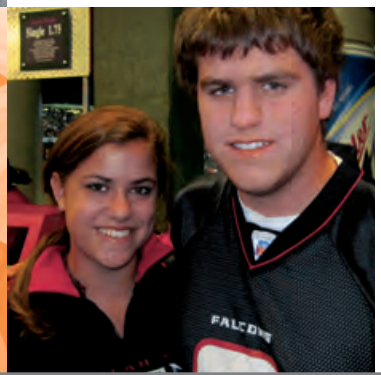


Autism Speaks™

FAMILY SERVICES

Transition Tool Kit





AUTISM SPEAKS™

Transition Tool Kit

A guide to assist families on the journey from adolescence to adulthood

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Autism Speaks Transition Tool Kit

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INTRODUCTION

A Little about this Kit

We recognize that all adolescents living with autism have their own unique strengths, as well as their own unique challenges. In addition, as with all people, adolescents with autism have their own specific likes and dislikes. So what may be an appropriate or desired employment, housing, or community involvement option for one individual may not be the right fit for someone else. As parents and caregivers, we all want our children (those living with or without autism) to be happy and healthy, and to live fulfilling lives. It is important to remember that what constitutes happiness or fulfillment for a person is specific to that individual.

We hope that this kit will serve as a guide that can provide you with options to think about and explore as you and your adolescent with autism begin to plan for adulthood. The guiding principle that we used in developing this kit is that all individuals with autism, regardless of the level of support needed, should be able to live lives filled with purpose, dignity, choices, and happiness. With this in mind, the development of self-help and self-advocacy skills is highlighted throughout this kit.

We have broken the kit down into different sections. You may want to read the kit in its entirety or work on a section at a time. At the end of each section, we have provided resources specific to that section, as well as forms to help you keep track of the many pieces that constitute a transition plan. Since the transition process is different in each state, we have also developed timelines for each state, with state agency information that may be helpful to you throughout this process.

Please visit the Autism Speaks Resource Guide to find resources in your area, as well as information specific to your state at www.autismspeaks.org/community/resources.

Introduction

Transition is the movement from one stage or place to another. As your child reaches adolescence, you will begin to work with him or her, your school district, and others to develop a plan for the transition to adulthood. This kit will provide you with suggestions and options for you to consider as you set out on this journey. Remember that all roads do not lead to the same place. The path will be different for each family, but the goal remains the same: for your adolescent with autism to lead a fulfilling, healthy, and happy adult life.

We know that the future can seem uncertain for an adolescent with autism. After years of intervention, you are not alone in hoping that the autism diagnosis may have been altered by now. As a parent or guardian, it may be hard for you to imagine your child out in the world, or what he or she will do once the school bus is no longer arriving each morning. Some parents find the thought of the transition process overwhelming. Like many parents or caregivers, you have worked hard to obtain services and supports for your child with autism. Many families have spent years researching, negotiating, and advocating for these services and supports in order to maximize their child's potential. The thought of doing this again with a whole new system can seem daunting. It is at times such as this that you may want to take stock, look back, and calculate all of the strides that your child has made. It is also important to take the time to reflect on how

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much you have learned and how vital it is to be proactive. It is with this energy that you will move forward in the transition to adulthood.

Before you begin the journey into the transition process, it may be helpful to recognize that others have traveled this road. A significant amount of information has been collected, and while the process may have been trial and error for some families, valuable information has been gleaned. Additionally, experts in the field have researched and investigated the process. We have compiled a great deal of this information and many of these resources into this kit. The best news is that autism awareness is continuing to generate more opportunities for growth in the transition process, which can lead to more opportunities for young adults with autism to live independent and fulfilling lives.

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SELF-ADVOCACY

Where Do I Start?

The most important place to start the transition process is with your child, who is now an adolescent with autism. His or her hopes, dreams, and desires should drive the transition process.

Some individuals with autism can verbally communicate their goals and ideas for their adult lives. These conversations should serve as starting points to develop their transition plans. Transition planning is not a single conversation, but rather a process that will evolve over time.

Some adolescents may not be developmentally ready to tackle the transition process. Others may be unable to express their wants and needs for the coming years due to limited communication skills. This is particularly challenging for families, as many want to provide their adolescent with the life that he or she wants.

The transition process will take time. It is important that you work with your adolescent to provide the communication, self-help, and self-advocacy skills that he or she needs in order to be an active participant in the process.

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What is Self-Advocacy?

For most of your child's life, you have probably been advocating for your child– making decisions for him or her. However, as individuals with autism age, they will need to advocate for themselves to the best of their ability. Helping adolescents with autism to develop a sense of self will aid in the transition process and will develop a skill that will benefit them throughout their lives.

> "*Self-advocacy is a life-long endeavor, and the teen years offer a particularly fruitful moment for cultivating self-awareness, self-monitoring, and deeper exploration of what it means to be autistic, by way of peer discussion groups. Self-advocacy differs from advocacy in that the individual with the disability self-assesses a situation or problem, then speaks for his or her own needs. Learning how to do this takes practice and direct instruction. Too often, we raise our kids, treat our patients, and educate our students without ever speaking to them directly about autism. Perhaps we've made assumptions or even harbor fears that they aren't capable of self-reflection. Yet if we deny kids this very important aspect of identity, we limit their ability to become the successful adults we want them to be. As with any academic subject, teaching self-advocacy takes training as well as knowledge of and respect for the disability movement. Parents can model self-advocacy at home, teachers can offer curricula in school, and most importantly, peers on the autism spectrum can offer strategies for good living and share mutual experiences*."
>
> *Valerie Paradiz, PhD – Developing Self Advocacy Skills: An Integral Aspect of Transition Planning*

Self-Advocacy is:

- speaking up for yourself,
- asking for what you need,
- negotiating for yourself (working with others to reach an agreement that will meet your needs),
- knowing your rights and responsibilities,
- using the resources that are available to you,
- being able to explain your disability either by the use of written words, pictures or gestures.

It is never too early to begin to teach self-advocacy skills.

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Introducing Self-Advocacy

Self-advocacy should be taught throughout a person's lifetime. It can start in small ways by teaching an individual to make choices. Gradually, more advanced skills such as those involving negotiations and disclosure should be added to the curriculum if appropriate.

Learning to ask for help is another step in developing self-advocacy skills. In order to do this, the individual must be able to identify that there is an obstacle or difficulty, and then seek out assistance to have the issue resolved.

Matthew is a 15-year-old boy with autism and limited verbal skills. Matthew and his family frequently go to the local ice cream shop. Matthew's dad worked with him to teach him to order his own ice cream. Matthew was fairly competent at doing this, and so his dad suggested that he go into the shop by himself and order. Matthew's dad would watch through the store front window. Matthew went in with his money and ordered his ice cream. When Matthew came out of the store, he was unhappy because he didn't get the mint chocolate chip ice cream that he had asked for. Matthew's dad guided him through his options. They identified three options: Matthew could get very upset because he didn't get the ice cream flavor that he wanted and have no ice cream; he could eat the ice cream that he got; or he could go back into the store and let the server know that he had asked for mint chocolate chip. Matthew decided to go back into the store. Before Matthew went in, his dad helped him practice what he needed to say. Matthew was very nervous, but he went back into the shop. He showed the server the ice cream he got and he told him that he wanted mint chocolate chip. The server apologized for the error and gave Matthew the mint chocolate chip that he had wanted. Matthew was so happy to have his mint chocolate chip ice cream, and his dad was very pleased with Matthew's new found self-advocacy skills.

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Disclosure

It is important to note that part of self-advocacy may involve disclosure. Therefore, it is important that an adolescent with autism be told that he or she has autism. Many families have shared with their child or adolescent that autism has provided him or her with strengths such as a very good memory, tremendous knowledge about a specific topic, or strong skills in a particular subject at school. It is also important to let the individual know that autism also makes some things more challenging as well, and then list some of the things that may be difficult for the individual.

Many individuals with autism have shared that they were relieved to know that there is a label for what may make things more difficult. Others have said that they felt as if there were rules that they just didn't understand. These individuals realized that their inability to understand certain rules is not by any fault of their own, but only because their brains work differently.

Each individual will react differently to learning that he or she has autism. It may be helpful to come back to the subject from time to time so that the adolescent can process the information. It may also be helpful for the individual to join a support group or a social skills group for those with similar abilities. You may be able to find groups in your area in the Autism Speaks Resource Guide (www.autismspeaks.org/community/resources).

It is never too early to start developing appropriate self-advocacy skills. And if you haven't started, it is never too late!

How Do We Teach Self-Advocacy Skills?

When helping individuals to learn self-advocacy skills, both parents and educators can still assist them in decision making, help to explain things, and guide them. Teaching self-advocacy skills will be a process, and it will take time to acquire these skills.

There are many opportunities for teaching self-advocacy skills throughout the day. It starts with making choices – choices for meals, choices for leisure activities, even choices for which chores to do around the house. You may want to consider the following ways to further promote an individual's preferences as well as his or her ability to be more independent:

Timing of events – choosing when to get up, when to go to bed at night, when to get a haircut or when to eat dinner.

Personal choices – choosing what clothes to wear, what shampoo to buy or which cereal to eat.

Methods of training – choosing where learning will occur or who will provide the support. ex: do you want to work at home or at the library?

Staff evaluations – through interviews with individuals who are supported by staff or through observations of staff relationships with individuals

Hiring of staff – asking individuals to serve on hiring committees.

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*As described in "*It's My Choice*" from the Minnesota Governor's Council on Developmental Disabilities (page 83)*

When teaching your adolescent about self-advocacy you may want to consider the following five decision making steps:

- What is the decision you need to make?
- What decisions could you make?
- Evaluate each choice. What are the pluses and minuses of each choice?
- Pick the best choice. Describe which choice you think is best for you.
- Evaluate. Did you make the best choice for you?

As adapted from The Wisconsin Department of Public Instructions handbook, Opening Doors, (www.dpi.state.wi.us/sped/transition.html)

Self-Advocacy and the Transition Process

No matter what type of housing, employment or community life option that your adolescent with autism chooses, self-advocacy will play an important role in getting there. There are several tools that are available to help adolescents and their families think about what they want and to build the skills necessary for them to communicate their desires for the future.

"Self-advocacy plays a vital role in nearly every aspect of life…The more self-aware people on the spectrum become, the more they can be players in advocating for their own comfort, happiness, and well-being."

The Integrated Self-Advocacy Curriculum by: Valerie Paradiz, PhD

Well in advance of the first transition meeting with your school district (*please see TRANSITION AND THE IEP PROCESS for more information*), you and your adolescent with autism may want to think about his or her future. This is an ongoing process and is best done in small segments to start. There are several good tools that may be helpful to families as they work with their adolescent with autism to think about the future that what he or she wants. The Minnesota Governor's Council on Developmental Disabilities has developed a workbook titled "*It's My Choice*" that may be helpful: www.mnddc.org/extra/publications/choice/Its_My_Choice.pdf. In the online appendix of this kit, you will find some of the questions from "*It's My Choice*" that will be helpful for your adolescent with autism to prepare for the Transition IEP.

Another tool that families may consider is "*Keeping it Real*" which can be found on the The Elizabeth Boggs Developmental Disabilities website:
http://rwjms.umdnj.edu/boggscenter/projects/keep_real_more.html
This site provides a 12 chapter curriculum on the transition process for individuals with developmental disabilities. It also provides a parent's module, a teacher's guide and budget module. The student curriculum and parent's module are also available in Spanish.

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Person Centered Planning



Person centered planning is an ongoing problem-solving process used to help people with disabilities plan for their future. An initial meeting is usually set up. The individual (the focus person) can invite those that he or she would like at the meeting; this may include family members, friends, professionals, and community leaders as well as others. The group should be a balanced team that can help the focus person to realize his or her goals and dreams. There is usually a facilitator to lead the group and keep everyone focused. The goal of the meeting is to identify opportunities for the focus person to participate in the community, to get a job or go on to post-secondary education, and to live as independently as possible. The team members will implement the strategies discussed in planning meetings.

The person centered planning process will provide you and your adolescent with a vision for his or her future and some specific steps to get there. This is an important step that you may want to consider before developing your transition plan with your school district. For families that already have a transition plan in place, this is still a valuable tool to further identify and crystallize the hopes and dreams that your adolescent may have.

The self-advocacy skills that you are working on with your adolescent should be utilized during the person centered planning sessions. You may want to prepare your adolescent ahead of time. The tools such as *It's My Choice* and *Keeping it Real* may be a good place to start. It may be helpful to speak with the facilitator and get an outline of the meeting, and then use the outline to review with your adolescent in advance of the meeting. A social story of the meeting may also be helpful. If communication can be a challenge for your adolescent, you may want to provide picture choices that he or she may be able to use to communicate their ideas.

There are several different person centered planning tools that are available to families. We have provided information about two person centered planning tools that families have found to be helpful. These are not the only tools available, but they do provide a framework for what families may want to include in the person centered planning process.

PATH: Planning Alternative Tomorrows with Hope

PATH is a person centered planning and goal setting tool that uses graphic facilitation to map out a vision of a desirable future for an individual or a group of people. PATH was developed by Jack Pearpoint, John O'Brien, and Marsha Forest. PATH helps a group that has come together to work with a young adult to "think backwards" and develop a plan for the young adult's future. Steps include:

- The ***North Star***, the Dream, the Vision - create a portrait of the future - many generations ahead.

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- ***Goals*** - "remember the future" - possible and positive future goals - one or two years "ahead."
- ***Now*** - ground the PATH by "noticing what it is like now."
- ***Enrollment*** - who do we need to enroll if we are really going to get anywhere?
- ***Getting Stronger*** - what do we need to actually do to stay strong enough for the journey?
- ***Six Months*** - from the future - remember backwards what has happened in six months.
- ***One Month*** - remember what has happened - one month from now.
- ***First Steps*** - list *immediate* beginning steps on this journey - and appoint a coach to keep you on your PATH.

PATH Information: www.ont-autism.uoguelph.ca/PATH-jan05.pdf

You can find more PATH related resources at www.inclusion.com/path.html

MAPs: Making Action Plans

MAPs is a tool used to help an individual create and plan his or her own life. The MAP serves as the compass that points in the direction of a positive future. MAPs begins with a story- the history of the person's life. The history will surface important milestones and identify future hopes that will serve as the foundation upon which the rest of the process unfolds and action is charted.

1. **What is a map?**
   Allows the facilitator to welcome the group, to review the purpose of the gathering, and to give people a general description of what they can expect.
2. **What is the person's history or story?**
   Provides everyone in the room an opportunity to contribute along the way as the story unfolds.
3. **What are your dreams?**
   Critical question so that everyone involved knows where he or she is headed when it comes time to do the hard work of developing a plan of action.
4. **What are your nightmares?**
   Serves as the guideposts for the journey so that planning can incorporate strategies to avoid creating, or recreating, the nightmare in someone's life while heading toward the desired future.
5. **Who is the person?**
   Brainstorming, group participants are asked to use words that come into their mind that describes the person with whom the planning is being conducted.
   The focus person, this time, is asked to listen.
6. **What are the person's talents, gifts, and strengths?**
   Provides the opportunity to present a multi-faceted picture of the person that is based on capacity and contribution.
7. **What does the person need?**
   Participants are drawn to consider what it will take in terms of people and resources to make the dream become a reality.

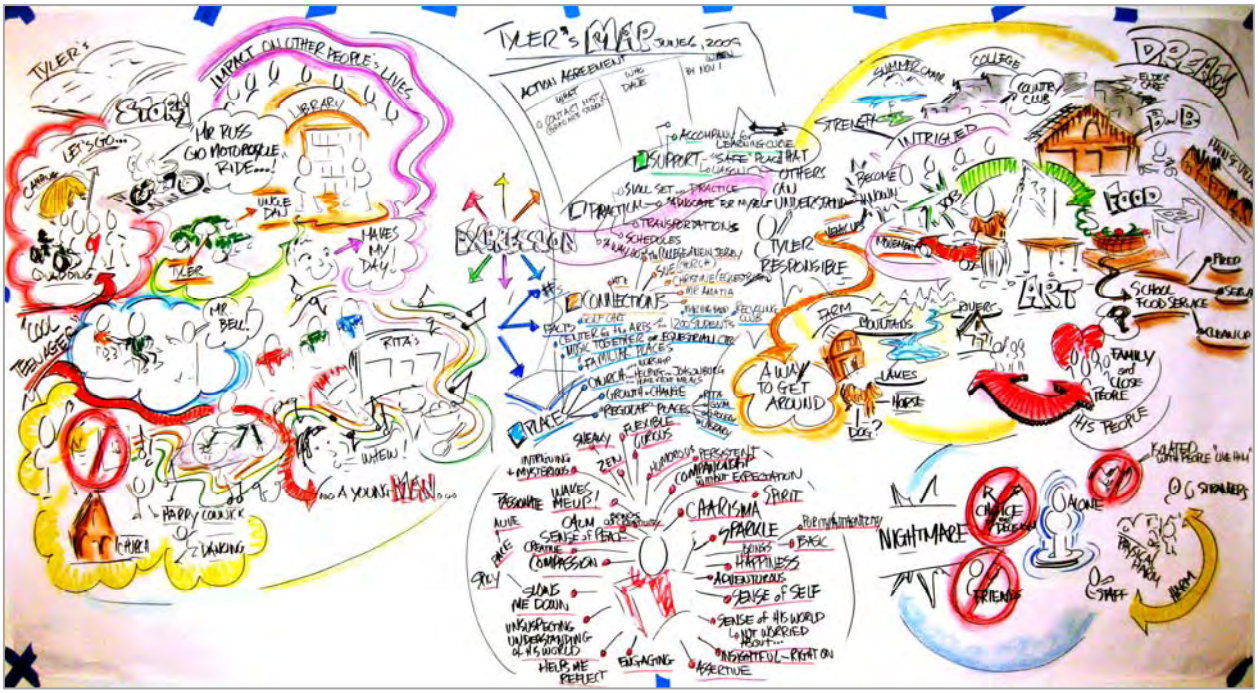
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8. What is the plan of action?

Participants use this step to identify the specific steps, actions, and chart responsibility for actions that are needed to mobilize the plan toward the person's desired dream.

Cornell University ILR School Employment & Disability Institute: The Person Centered Planning Education Site

For more information please visit:
www.ilr.cornell.edu/edi/pcp



This is an example of MAP planning.

The goal of self-advocacy training is to make sure that young adults with autism have as much input as they are capable of providing regarding their thoughts and dreams for the future.

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Self-Advocacy Resources

Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum
edited by Stephen M. Shore

The Everyday Advocate: How to Stand Up for Your Autistic Child
by Areva Martin, Esq.

Developing Self-Advocacy Skills: An Integral Aspect of Transition Planning
Asperger's Association of New England
www.aane.org/asperger_resources/articles/teens/developing_self_advocacy_skills.html

Helping Your Child to Help Him/Herself: Beginning Self-Advocacy
by Stephen Shore
autismasperger.net/writings_self_advocacy.htm

The Integrated Self-Advocacy ISA® Curriculum
by Valerie Paradiz, published by Autism Asperger Publishing Company
www.asperger.net/bookstore_9028.htm

Learning the Skills of Self-Advocacy and Disclosure
www.autism.com/ind_learning_self_advocacy.asp

It's My Choice
by William T. Allen, Ph.D.
Minnesota Governor's Council on Developmental Disabilities
www.mnddc.org/extra/publications/choice/Its_My_Choice.pdf

Youths4Advocates (Y4A)
www.self-advocate.org

Opening Doors to Self-Determination Skills: Planning for Life After High School – A Handbook for Students, School Counselors, Teachers & Parents
Wisconsin Department of Public Instruction
www.dpi.state.wi.us/sped/transition.html

Cornell University ILR School Employment & Disability Institute: The Person Centered Planning Education Site
www.ilr.cornell.edu/edi/pcp

Planning Alternative Tomorrows with Hope (PATH) Information
www.ont-autism.uoguelph.ca/PATH-jan05.pdf
More PATH-related resources: www.inclusion.com/path.html

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More General Resources

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

Autism & the Transition to Adulthood: Success Beyond the Classroom
by Paul Wehman, Marcia Datlow Smith and Carol Schall

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

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WHY DO WE NEED A TRANSITION PLAN?



The Individuals with Disabilities Education Act (IDEA) mandates a public education for all eligible children ages 3 through 21 (in most states), and makes the schools responsible for providing the supports and services that will allow this to happen. It is important to recognize that one of the goals of IDEA is for students to be prepared for employment and independent living. As you may know, IDEA requirements are facilitated through the Individualized Education Program (IEP) process. The IEP process must include transition planning services for all special education students at age 16. Ideally, this process should begin at age 14.The funding and the services available through IDEA are not available once the student has received a high school diploma, or aged out of the school system.

Transition Planning and the Individual Education Program

Transition services as outlined in **§300.43 of IDEA**

(a) Transition services means a coordinated set of activities for a child with a disability that…

(1) Is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;

(2) Is based on the individual child's needs, taking into account the child's strengths, preferences, and interests; and includes:

i. Instruction
ii. Related services
iii. Community experiences
iv. The development of employment and other post-school adult living objectives
v. If appropriate, acquisition of daily living skills and provision of a functional vocational evaluation.

(b) Transition services for children with disabilities may be special education, if provided as specially designed instruction, or a related service, if required to assist a child with a disability to benefit from special education

http://idea.ed.gov/explore/view/p/%2Croot%2Cdynamic%2CTopicalBrief%2C17%2C

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It is important be mindful that the transition process must include goals that are:

- Outcome-oriented
- Based upon the student's strengths and areas of need
- Focused on instruction and services for education, employment, and other living skills.

This is a process that will continue to evolve. The transition plan is **a work in progress** that should be monitored several times per year. You and your adolescent with autism will continue to learn and grow during this process, and you will need to adjust your plan accordingly. By beginning early and working collaboratively with your school district, outside agencies and others in your community, you will be able to make the best possible use of educational entitlements afforded to your child with autism before he or she enters adulthood.

What Are My Child's Rights and How Do They Change When He Leaves the Educational System?

As mentioned previously, IDEA provides federal funding to state and local school districts to provide special education services to eligible students with disabilities. Under IDEA, your child is eligible for special education services from ages 3 through 21 (in most states). This act ensures that schools seek out students with disabilities, and that services are provided based upon the student's strengths, challenges, and interests. An IEP facilitates this process.

Under IDEA, there must be a transition plan in place for all students by the age of 16 (ages vary by state). Just as with other educational services in a student's IEP, the school district must provide the transition services necessary for the student to achieve the transition goals stated in the IEP.

Once the child leaves the school system, the educational entitlements of IDEA are no longer in place. There are some laws listed below that will provide some services after your young adult leaves the educational system:

> **The Rehabilitation Act** is the federal legislation that authorizes the formula grant programs of vocational rehabilitation, supported employment, independent living, and client assistance. It also authorizes a variety of training and service discretionary grants administered by the Rehabilitation Services Administration.
>
> The Rehabilitation Act authorizes research activities that are administered by the National Institute on Disability and Rehabilitation Research, and the work of the National Council on Disability. The Act also includes a variety of provisions focused on rights, advocacy and protections for individuals with disabilities.
>
> More specifically, Section 504 of this act is a civil rights law that protects people with disabilities from discrimination concerning services, employment, and public

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accommodations. Section 504 applies to any institution that receives federal funds such as schools, public colleges, hospitals, non-profit agencies, and public housing. www2.ed.gov/policy/speced/reg/narrative.html

The Americans with Disabilities Act (ADA) is a federal law that prohibits discrimination against people with disabilities in employment, and mandates that these individuals have the right to public accommodations, as well as access to programs of public agencies. The ADA protects against discrimination only if the person with a disability could participate in the program or perform the job with "reasonable accommodations". Without the accommodations, the individual must be "otherwise qualified".

It is important to note that after high school, the accommodations accessed through ADA or Section 504 are not provided automatically, but they must be requested by you or your young adult with autism. www.ada.gov/pubs/ada.htm

Different Types of Diplomas

It is very important to understand the different types of diplomas available to individuals with disabilities in the public school system. Some learners with autism will be able to receive a general high school diploma, while others may work toward an IEP or Occupational Diploma. The following list outlines some of the different types of diplomas, and what opportunities they may provide for post-secondary education. Each state has different options and guidelines for diplomas. For the diploma options in your state, please refer to the Autism Speaks Resource Guide.

High School Diploma – This diploma is awarded to students who have passed required courses and exams in a number of subjects. The diploma is generally accepted for admission everywhere: 2 and 4 year colleges as well as military and trade schools.

General Education Development (GED) Diplomas – This diploma is awarded to students who have passed the GED exam. The GED is generally accepted by military, trade schools, and some junior/community colleges (which sometimes require additional qualifications).

IEP/ Local Diplomas or Certificates of Completion – This diploma is awarded to students who have reached the goals on their Individualized Education Programs. The IEP qualification is not recognized as a diploma by 2 and 4 year colleges, the majority of companies, or the military. It is not accepted for admission to any post-secondary degree program without other testing or certification.

You may also want to confirm the date of your child's graduation. Federal law states that your child's eligibility for special education ends when he graduates from high school with a diploma, or until the child ages out of educational entitlements (this varies by state – see your state's timeline in the Autism Speaks Resource Guide: AutismSpeaks.org/community/fsdb/search.php).

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Getting Started

In preparation for the Transition IEP Meeting

As far in advance of the first meeting as possible, you should talk with your adolescent with autism about what he or she may want to do in the future. While out in the community, you can identify different jobs that may be of interest to him or her. You may also want to point out older siblings or other young adults in your family or neighborhood that are going off to college, getting a job, or living on their own. It is important to remember that this may seem like a scary topic for adolescents with autism to discuss, and they may not be ready. Some families have shared that they have scheduled a specific day of the week and a specific time to discuss future plans with their young adult. Along with their adolescent, one family scheduled Sundays from 3:00 to 3:30 as their time to discuss employment, living arrangements, or community life. This helped provide structure and a time limit on a sensitive subject. It also provided some time for the young adult to prepare for what he or she was going to share during these sessions.

If you have completed a person centered plan, or if you would like to implement a person centered approach, the best time to do this is before the Transition IEP meeting. The information generated from the person centered planning should be shared with the Transition IEP team in advance of the meeting.

There are also several tools available that can help you and your adolescent to prepare for the transition IEP meeting. Two such tools are listed below and are available online:

1. *It's My Choice,* The Minnesota Governor's Council on Developmental Disabilities Transition workbook, has some specific tools that may help your young adult with autism to prepare for a transition IEP meeting. The list is included in the online appendix of this kit. www.mnddc.org/extra/publications/choice/Its_My_Choice.pdf

2. Another tool that may be helpful to you and your young adult is Chapter 3 of *Keeping it Real* on The Elizabeth M. Boggs Center on Developmental Disabilities website. This chapter specifically outlines information about the transition process, supports, and IEP meetings. Also included are activities to help your young adult focus on these topics. rwjms.umdnj.edu/boggscenter/projects/keep_real_more.html

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Assessments

In preparation for the transition meeting, your school district may also conduct several assessments that should be shared with you and your adolescent in advance of the meeting. Some of the assessments are outlined below:

Level I Assessment

- The parents, student and teachers all complete a questionnaire to help them focus on the student's long term career goals.
- This assessment helps to explore possible areas of interest that can be used in the transition plan.
- Level I assessments should be updated yearly.

Level II Assessments

- Provide feedback as to a student's skills and aptitudes when compared to his or her peers.
- The Level II Assessments can often help pinpoint areas where further skills can be developed.

Level III Assessments

- This assessment is for students who do not perform well on tests or thrive in testing environments.
- This is a situational assessment. The student tries out different areas of work in different settings with the proper supports in place.
- Level III assessments allow for the student to get some hands on work experience and to see what they enjoy and in what fields they excel.
- The staff on hand will assess the student's response to each environment.

Preparing Your Adolescent for the Transition Meeting

An excellent way to develop self-advocacy skills is to make sure that your adolescent with autism is involved in the IEP process.

"The beauty of using the IEP as a tool for building skills in self-advocacy and disclosure is that it already exists. Presently, the IEP involves different professionals and parents meeting to create a customized education for the child."

- Stephen Shore

Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum, p. 76.

It is important that your adolescent with autism knows about his or her disability, and can communicate to others the nature of the disability and the accommodations that he or she may need as a result. Once young adults with autism leave the educational system, they will need to be able to do this on their own to the best of their ability. Parents know that advocacy skills can take years to develop. It is therefore very important that the student can begin to develop these skills as soon as possible.

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Below is a list of questions and topics that you might review with your adolescent with autism prior to the transition meeting:

1. What is a disability?
2. Do you have a disability?
3. What is the name of the law that allows you to receive special services from the school?
4. What is an accommodation?
5. Do you have any accommodations in your classes?
6. What's an IEP?
7. Do you have an IEP?

For those adolescents with limited verbal ability, pictures or written statements may be helpful. See the online appendix of this kit for examples.

Options for Student Participation during the IEP Process

From *Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum* by Stephen Shore (p. 84 – 86)

"Just as when transitioning to any other new activity, prepare the student in advance of the IEP meeting and describe its purpose. Student involvement can take place on a sliding scale of responsibility. Initially, and/or for students at a lower cognitive or developmental stage, having students just be familiar with the purpose of an IEP can be sufficient and all that can reasonably be expected. The range of involvement might include the following:

- The teacher brings the student to the IEP meeting for a brief period of time, encouraging interactions with some or all the team members. This introduction may be as short as a few minutes where the student just says "hi" to one or two IEP team members, or helps pass out materials.
- The student prepares a short statement that he or she distributes or reads aloud to the IEP team indicating strengths and difficulties in school.
- After obtaining data from IEP team members prior to the meeting, the student writes sections of the IEP for modification and approval at the IEP meeting.
- The student co-presents as an equal member of the IEP team.
- The student leads the IEP meeting with support from his or her primary teacher."

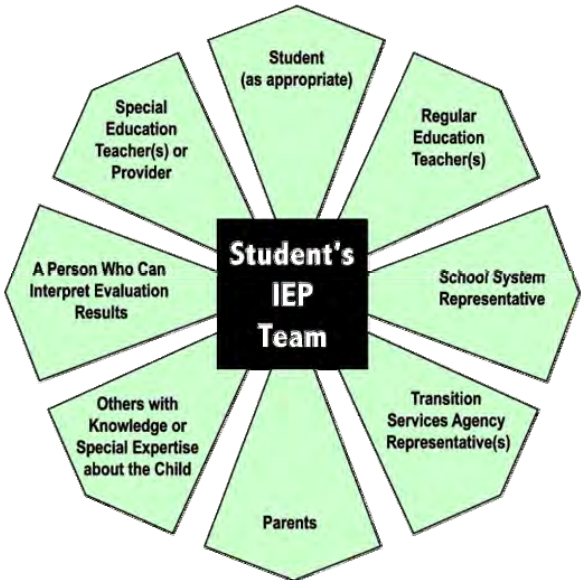
Just as with every other subject, it is important to develop a lesson plan and anticipate questions and concerns that students may have as they work on applying their strengths and challenges to create their own customized education.

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Nicholas was worried about his transition team meeting. He asked Mr. Newberg, his special education teacher, repeated questions about the meeting. He was so afraid of making a mistake or saying the wrong thing. Mr. Newberg suggested that they spend some time talking about the transition team meeting. Mr. Newberg spoke with Nicholas and provided a visual schedule of what would happen during the transition meeting. In addition Mr. Newberg and Nicholas then decided to develop a video of Nicholas talking about what he would like to include in his transition plan. Mr. Newberg let the transition team know that a video clip from Nicholas would be played during the meeting.

Nicholas's IEP meeting was a great success, because he felt represented by the video tape that he had made. Once the video was played, Nicholas was able to relax at the meeting and even answer questions about his disability.

Who is involved in the Transition Planning Process?



- The student (as appropriate)
- The student's parents or guardians
- Teachers (Special and General Education)
- School Administrators
- Related service providers such as speech therapists, behavioral consultants, etc.
- Representatives of outside agencies that may provide support to reach post-transition goals, such as the state Division of Vocational Rehabilitation
- Other individuals that can support the student

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From: A Guide to the Individualized Education Program Office of Special Education and Rehabilitative Services U.S. Department of Education.
http://www2.ed.gov/parents/needs/speced/iepguide/iepguide.pdf

Since your school district is responsible for coordinating transition services for your adolescent with autism, you may want to partner with the school district in advance of the transition planning meeting to make sure that any outside agencies or individuals that can offer resources have been invited to the meeting. As you can imagine, it takes a fair amount of time to coordinate with all of those that may need to attend the transition meeting. The outside agencies may serve many schools in your area, so you may want to work with your school advisors to start the process as early as possible.

How Do You Create and Implement a Transition Plan?

The Transition Meeting

You may feel overwhelmed sitting at a table with educators and professionals who are making recommendations about your adolescent's future. Your adolescent may feel the same apprehension. Remember, nothing is "written in stone", and the plan continues to be a work in progress. However, goals are set in order to move forward, and with a proper plan, your child will reach new vistas.

It is important to respect your adolescent's wishes and needs, and encourage others to do so as well. You should try to model appropriate behavior during the meeting by addressing questions about your child, to your child. Look at your child for a response, and encourage others to do the same. If your child is having trouble answering a question, provide visual supports or choices to further encourage the adolescent to be an active participant in the meeting.

Many parents want to highlight their child's successes, while downplaying struggles. It is important that skills be developed so that they can be completed independently. There are times when parents will believe that their adolescent has mastered a skill even though the skills may not be done completely independently. In doing so, you are doing a disservice to your adolescent. A mastered skill needs to be done correctly from beginning to end, without prompts or support. This is an important point to keep in mind as you develop IEP goals.

During the transition meeting the transition team should consider the following areas as they relate to the adolescent with autism:

- community participation
- adult services
- integrated employment (including supported employment),
- post-secondary education
- vocational education
- integrated employment (including supported employment)
- continuing and adult education
- independent living

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Helpful Guidance

The National Dissemination Center for Children with Disabilities (NICHCY) provides excellent resources for families going through the transition process. They provide the following guidance:

Remember that IDEA's definition of transition services states that these are a "coordinated set of activities" designed within a results-oriented process. Specific activities are also mentioned, which gives the IEP team insight into the range of activities to be considered in each of the domains above:

- Instruction
- Related services
- Community experiences
- The development of employment and other post-school adult living objectives
- If appropriate, acquisition of daily living skills and provision of a functional vocational evaluation.

Confused by all these lists? Putting them together, what we have is this: The IEP team must discuss and decide whether the student needs transition services and activities (e.g., instruction, related services, community experiences, etc.) to prepare for the different domains of adulthood (post-secondary education, vocational education, employment, adult services, independent living, etc.) That's a lot of ground to cover!

But it's essential ground, if the student's transition to the adult world is to be facilitated and successful. A spectrum of adult activities is evident here, from community to employment, from taking care of oneself (e.g., daily living skills) to considering other adult objectives and undertakings.

From: www.nichcy.org/EducateChildren/transition_adulthood

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Adolescents with autism and their transition team members may keep the following in mind:

- People learn things best in the places where they happen – like buying things at a store or shaving in the bathroom.
- People learn things best when they use the real item- like using real money when learning to count.
- People learn things best when they do them at the time they are usually done – like brushing teeth after a meal or before going to bed.
- People learn best from other people- like learning how to work in places where other people work.
- People learn best when the things that they learn are useful – like using the telephone or taking the bus or writing a check.
- It is important to think about things to learn that will help you become more independent where you live and work right now and where you will live and work in the future.

It's My Choice by the Minnesota Governor's Council on Developmental Disabilities, p. 40
www.mnddc.org/extra/publications/choice/Its_My_Choice.pdf

General Steps for Creating a Transition Plan

Several steps have been outlined that will be important in developing a transition plan for your adolescent with autism. These should be a part of the transition plan:

- Describe the student's strengths and present levels of academic achievement and functional performance.
    - Descriptions of the student's strengths and present levels of academic achievement and functional performance are frequently given at IEP meetings only by school personnel, such as general and special educators, speech and language therapists, and school psychologists. It is critical that students and parents be provided opportunities to participate in this step of the process, as well.
- Develop measurable postsecondary goals.
    - The development of measurable annual goals should support the student's expressed post-school goals and should be based upon the student's present levels of academic achievement and functional performance and age-appropriate transition assessments.
- Develop corresponding IEP goals that will enable the student to meet their postsecondary goals.
- Describe the transition services needed.
    - This portion of the IEP planning process identifies the transition instruction and services, activities, personnel, or resources that can be used to help the student achieve his or her desired post-school goals.

In addition to stating the goals for your adolescent, the transition plan should include logistical information on how the plan will be implemented and monitored, such as:

- A timeline for achieving goals
- Identified responsible people or agencies to help with these goals
- Clarification of how roles will be coordinated
- A plan for identifying post-graduation services and supports, and obtaining the necessary funding to access these services and supports

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Examples of specific of Transition IEP goals in the areas of education/training, employment, and independent living can be found on the National Dissemination Center for Children with Disabilities (NICHCY) website: www.nichcy.org/EducateChildren/transition_adulthood/pages/iep.aspx

"Once we started the transition process, I looked at Stacey's education with a different focus. Although academics are important, I needed to work with her to make choices as to the best possible use of her high school time. Was it more important for her to identify the predicate of the sentence, or to respond when a peer spoke to her? My husband and I started to think about Stacey's education by asking the question 'is this a skill or information that she will use when she leaves school?'"

—Jeannette, Mom of Stacey, age 14

If a parent or caregiver is not in agreement with the transition services proposed, then he or she can try to reach an acceptable agreement with the school district. If this is not possible, then the family has the right to go to mediation or an impartial hearing.

Long-term transition planning is an ongoing process that reflects the continuing development and changing needs of your adolescent. Given that the process starts in the early to mid-teen years, there needs to be a great deal of flexibility in the plan. Your adolescent with autism will continue to grow and learn throughout his or her remaining school years and beyond, so the plan needs to be flexible and at times altered to meet his or her changing needs and goals.

"Once the actual plan is completed by the team, it is a living, evolving document that should be reviewed and updated several times a year to ensure it reflects and meets all of your young adult's needs, and adequate progress is being made to that end. By creating a document with outcome-oriented goals that can be measured, you can more efficiently and effectively monitor your young adult's progress."

-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.

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Transition and the IEP Process Resources

Transition Goals in the IEP
National Dissemination Center for Children with Disabilities (NICHCY)
www.nichcy.org/EducateChildren/transition_adulthood/pages/iep.aspx

Keeping It Real: How to Get the Support You Need for the Life You Want, Keeping It Real Teacher's Module, and *Keeping It Real Parent's Module*
K. Roberson, R. Blumberg, D.Baker.
The Elizabeth M. Boggs Center on Developmental Disabilities
rwjms.umdnj.edu/boggscenter/projects/keep_real_more.html

Training Modules for the Transition to Adult Living: An Information and Resource Guide
CalSTAT: Technical Assistance & Training
www.calstat.org/transitionGuide.html

Living with Autism: Preparing for a Lifetime
Autism Society
www.autism-society.org/site/DocServer/Transition-Preparing_for_a_Lifetime.pdf?docID=10622

It's My Choice
by William T. Allen, Ph.D.
Minnesota Governor's Council on Developmental Disabilities
www.mnddc.org/extra/publications/choice/Its_My_Choice.pdf

The Rehabilitation Act
www2.ed.gov/policy/speced/reg/narrative.html

The Individuals with Disabilities Education Act
idea.ed.gov

Americans with Disabilities Act
www.ada.gov

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More General Resources

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

Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum
edited by Stephen M. Shore

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Transition and the IEP Process

Agency and Contact	*Phone Number*	*Date Called*	*Service Requested*	*Appointment Date*	*Documents Needed*	*Status*	*Follow – Up*

COMMUNITY LIVING

All roads lead to community living. You may want to think early on about introducing your child to members of the community. Families may feel that as children enter adolescence, social differences become more apparent, and opportunities for leisure and socialization in the community become more difficult. As your child grows older, you and his or her educators may need to become creative in your efforts to create opportunities for social interactions. It is important to remember that integration into the community is a key component of happiness and independence in the lives of adults with autism. Interacting with others by participating in sporting events, joining a local club, or being a part of a religious community will improve self-esteem and confidence, and provide great enjoyment and pleasure.

Whether an individual has contact with the bagger at the grocery store, or the crossing guard outside his or her school, these regular interactions are the foundation for being part of the community. This is just the beginning. Community ties can be developed at different times on different levels. Adults with autism can be active participants in all areas of community life including social and recreational activities, just like their peers.

There is truly something for everyone. It may just take a bit more effort to find what your young adult with autism is looking for, and what social opportunities will provide him or her with the greatest amount of happiness.

Picking the Right Activities

"As part of the transition planning process, consider how individual interests might be used to help your son or daughter develop contacts outside of the classroom. Some interests (i.e. hobbies) have related organizations that meet socially: Yu-Gi-Oh!™ or Magic: the Gathering® clubs, science fiction clubs, computer/technology clubs, chess clubs, military history clubs, and so on. Introduce your young adult to these groups and encourage his participation. The ability to meet new people based upon a similar interest and expand his potential support system can be extremely helpful as your young adult gets older."

- 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.

There are a number of programs available that vary from athletic to creative, one-on-one instruction to full inclusion, and recreational to competitive.

Some things families and adolescents with autism may want to think about:
- What are your child's likes and dislikes?
- What makes your child tick or motivates him or her?

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- What are your goals for your child with this activity? (ex: to socialize, learn how to play, develop a hobby, strengthen an existing skill, etc.)
- What are your child's challenges?
- Does your child have behavior problems that may prevent him or her from participating in certain activities?
- What kind of sensory integration or processing issues does your child have?
- Does your child need a one-on-one aide to participate?

School Activities

Autism Speaks student clubs are a great way to have students with and without autism to make a difference. The goal of the Autism Speaks student club is to create a community that is educated about autism by empowering students to pave the way for acceptance and understanding. For more information see the Autism Speaks Student Initiatives website: http://youthprograms.autismspeaks.org

Best Buddies is an international organization dedicated to establishing a global volunteer movement that creates opportunities for one-to-one friendships, integrated employment, and leadership development for people with intellectual and developmental disabilities. For more information about the Best Buddies program, visit www.bestbuddies.org.

School clubs, sports teams, after school programs, and school- sponsored recreational activities are all possibilities for community involvement. You may want to keep in mind that some teams or programs may not be possible or fitting for your adolescent with autism. Think about if there are any possible activities that may work if the proper supports are in place.

Community Activities

There are many opportunities for activities for individuals with autism in most communities. Activities in the community may include:

- Public/private facilities: pools, parks, YMCAs, fitness clubs, programs at local universities. Search these to find inclusive activities, or those specifically for students with developmental disabilities.
- Trips and outings
- Exercise and sports
- Hobbies, games, arts and crafts
- Social events
- Youth groups or religious community activities
- Special Olympics





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Title II of the Americans with Disabilities Act (ADA) prohibits discrimination against individuals with disabilities by any state or local government agency. An additional source of activities can be found by contacting local government agencies, such as the parks and recreation department in your city.

For a list of recreational opportunities, check the Autism Speaks Resource Guide under Recreation and Community Activities for children, or Recreation and Leisure Activities for adults at AutismSpeaks.org/community/resources.

Autism Speaks also funds recreational programs through the Family Services Community Grants program. Most of the programs funded have the ability to be replicated. For more information on grants we have funded in the field of recreation, visit: www.autismspeaks.org/community/family_services/community_grants.php#funded.



Prepare your adolescent for participation in these activities with social stories, schedules of what is going to happen, behaviors to expect, etc. Use the same strategies you use when helping him or her in other areas. In some cases, it may be helpful to have an aide who knows the adolescent to go with him or her to the sessions in order to ensure that participation in the activity is a success.

Before you register your adolescent with autism for an activity, it is important that you speak with the activity leader. Talk about the positive attributes of your adolescent, as well as some of the challenges he or she may have specific to the activity. If your adolescent will be bringing an aide to the activity, it will be important to explain the aide's role as well. Ask if you can bring your adolescent on a trial basis, and arrange the most practical time. It would be most helpful if you bring the aide as well so that you can all meet the leaders of the activity, and ensure that all are comfortable before your adolescent begins to participate in this activity.

Autism and the Transition to Adulthood by Paul Wehman, Marcia Datlow Smith, Carol Schall provides a list of social skills that can be helpful our in the community as well as in the workplace. If your adolescent does not have these skills they may be worth considering as you work with your team to develop his or her IEP goals.

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Social Skills in the Community and the Workplace

Autism and the Transition to Adulthood by Paul Wehman, Marcia Datlow Smith, Carol Schall

Using Social Amenities – Students with autism sometimes do not use social amenities. Phrases such as *please, thank you*, and *you're welcome* are simple, short and easily taught. Although students might know to use these phrases with family members, it might be necessary to teach them to use them at school, at work, in stores, in banks and in restaurants.

Using Appropriate Greetings – A common complaint about individuals with autism concerns their greeting of other students and co-workers. Some students with autism fail to greet or acknowledge others; others greet the same people over and over again. Teaching the appropriate use of greetings can be helpful, especially as the student in transition strives to fit in at the workplace.

Terminating Conversations – Some individuals with autism, even if they are intelligent and have good verbal skills, need to learn how to end conversations. A common complaint of peers, supervisors, and co-workers, is that the worker with autism walks away while being spoken to.

Sharing Workspace – Workplaces can sometimes require workers to rearrange their space or share space that was previously their own. This can be irksome to anyone, but it is especially upsetting to a worker with autism who has come to rely on the consistency of his or her area. Social skills training can target learning to share space.

Accepting Correction – Difficulty accepting correction is not limited to individuals with autism. Many people do not like to receive correction or criticism. People with autism, however, often react more strongly. Social skills training may need to focus on teaching the student exactly what to say and do when given correction.

Responding Assertively – People with autism can sometimes be easily taken advantage of. One young woman with Asperger Syndrome was arriving at work each morning quite distraught. The problem was that a strange man had been sitting next to her on the bus and putting his arm around her, and she did not know how to respond. Social skills training was needed to teach her to say "Leave me alone." Another student attended many general education classes throughout his school day and was often approached by his peers. His gym teacher eventually found out that these students were asking for his money and that he had given away hundreds of dollars over the course of the school year.

Accepting Suggestions – Some students with autism have trouble accepting suggestions. They can be rigid in their outlook. If a teacher or parent provides a suggestion, this can result in refusal to take the suggestion, and can even serve as a trigger to acting out behavior. Providing the student with general instructions on the need to accept suggestions, followed by regularly scheduled role playing and the opportunity to practice accepting suggestions can be effective. When a suggestion is provided, the student can be reminded to accept suggestions just as he or she practiced in the role plays.

Asking for Help and Revealing a Problem – One of the most important social skills at work is to ask for help when it is needed. Individuals with autism faced with difficulty at work might become upset, stop working, and even leave. Students with autism might also be reluctant to reveal that they have a problem for which they may need help. In either the work or school setting, social skills training can be used to teach individuals how to ask for help and how to talk to others about a problem.

Waiting in Line and Taking Turns – Waiting in line and taking turns can be challenging for anyone. For some people with autism, waiting in line can trigger behavior that is unacceptable in the community, such as cutting in line, pushing, or walking directly up to the counter. Some students with autism may need to be taught how to behave in crowded situations and when waiting in lines.

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Please see below for an example of a community life experience from "In Their Own Words" by Robyn Schneider, mother of Alex and Jamie, two young men with autism.

He's 16 years old, tall, slim and handsome. A year ago he started running, and now he runs a mile in 6 minutes and 30 seconds, competes in races all over Long Island, has won trophies and awards, and in a recent race finished 90th out of 1183 runners. He's my son Alex and he has autism.

Alex and his twin brother Jamie, who also has autism and runs an 8:30 mile, run in competitive mainstream races throughout Long Island. They are able to do this with the help and dedication of the Rolling Thunder Running Club, where experienced runners volunteer their time providing one-to-one support to special needs kids in races all over the country.

When they first started, their coaches held their hands while running with them, not sure what to expect as both Alex and Jamie have limited language and self-injurious behavior that can oftentimes be unpredictable. Soon the coaches were able to let go and run with them side by side. Now, in just a little over one year, Alex and Jamie have run in 15 races all over Long Island. Their first race was a 5K (3.1 miles) and Alex finished in 27:45, Jamie in 31:24. Now, for the same 5K race, Alex finishes in 20:53 and Jamie in 25:35. They have also begun to increase their distance running in 10K races (6.2 miles). In the last 10K, Alex finished in 43:28 and Jamie in 55:35. They have both placed in several races, including first and second place! Their trophies and race photos have begun to clutter our home and it's wonderful. They have even been featured in the New York Times and the Greater LI Running Club Magazine!

Kids with autism have many skills that we often never know exist. The best part of our new discovery is that Alex and Jamie are running with typically developing kids and adults, together. As we watch and cheer and wait with nervous anticipation until they cross the finish line each time, we are so excited and proud to see them with all the other runners and realize their abilities to succeed in this wonderful outdoor sport. Best of all are the ear to ear smiles on both of their faces; they really love to run! Now we are planning our own race to increase awareness of autism and to benefit Eden II's Genesis School, a program exclusively for individuals with autism, where Alex and Jamie have attended since its inception in 1995.

We have lived through many tough times through the years, but there's one thing that we've learned and that's to keep exploring the inner talents and skills that our kids possess. A year ago we had no idea that Alex and Jamie could run so fast. Now, come this September, the boys will be included in their high school cross country team. Inclusion in their own district high school was so far beyond our expectations. We never dreamed of this happening!

The greatest joy I have as a parent is to see how happy our boys are. As parents of boys who are predominantly non-verbal, it has always been a challenge to assess their likes and dislikes. But happily, we accept their beautiful smiles that warm our hearts. For us, these are better than any words could describe.

If you have a child with autism or you know someone who does, keep on exploring and never stop dreaming! You never know what they can do; if only they're given the chance they deserve!

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A Success Story While Learning to Travel

Rachel is a 20-year-old young woman with autism and she requires a substantial level of support. She lives at home with her parents, but participates in a day program in her community. One of her favorite activities is doing map puzzles. Rachel's receptive language is good, but she does not speak. Her parents have protected her from the outside world for years, and they now worry that their daughter might need to be taught more skills to become independent.

Rachel's parents were not aware that travel training was offered in their community and were quite interested in pursuing the opportunity, since transportation and travel would allow her to become more independent. They enlisted the help of a travel training counselor named Bob Daly. Bob spent a few hours getting to know Rachel. He learned about Rachel's remarkable knowledge of geography and maps. Bob used picture cards of each train station in their local area.

The following week he began to take Rachel to the train station and take the local train one stop, then two and finally they traveled several stations away from Rachel's home. One day, Bob said to Rachel. "Would you like to try to get home yourself?" Rachel smiled and nodded.

Travel Training

An important part of community integration is the issue of transportation. In order to be able to gain more independence and greater access to the community, travel training is very important. Travel training is available to individuals with disabilities and can be part of the transition IEP.

National Dissemination Center for Children with Disabilities' (NICHCY) Transition Summary has a section devoted to *Travel Training for Youth with Disabilities:* www.nichcy.org/InformationResources/Documents/NICHCY%20PUBS/ts9.pdf

Many families are not aware that their son or daughter is entitled to travel training. It is a proactive tool that will play a big role in establishing more independence for your adolescent. Some individuals with autism may be quite savvy about reading maps, but they may have no idea how to ask how much a ticket costs. A travel coach will help your adolescent by addressing his or her needs at whatever pace is required. In many states, the travel training will be offered to your son or daughter until he or she is comfortable.

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Several states have implemented travel training programs. Please check the Autism Speaks resource guide for the contact information of state agencies. See if there is a specific travel training program in your state. AutismSpeaks.org/community/resources

You may also want to view the information provided by Dennis Debbaudt, *Autism and Airport Safety Travel Tips* at www.sath.org/index.php?sec=768&id=2371.

Safety

Safety is a very real concern for all parents, but especially parents of children and adolescent with autism. Your adolescent may be seeking more independence and as a parent, you would like to foster this growth. But you may also be concerned about the many risks associated with your adolescent being out in the world. It is important that safety is taught to adolescents with autism as part of the skills that they will need to enhance their independence. Some skills to consider:

- Identifying strangers.
- Identifying community members that can offer assistance.
- Knowing what to do when he or she gets lost.
- The ability to communicate name, address, phone number and emergency contact person. This should be either verbal or the adolescent should be taught to provide a card with this information to community helpers.
- The ability to use a cell phone. In the resource section of this kit if information on teaching this skill. For those with limited verbal skills text messaging may be an alternative means of communication in an emergency:
- Ability to identify public versus private spaces.

You may also want to consider the suggestions of autism safety expert Dennis Debbaudt:

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. Individuals with autism may only be able to learn these lessons if we teach these safety skills at home, reinforce them at school, and practice them in the community. You may want to make building safety skills a part of your daily routine. Safety skills are learned best when they are delivered early and often, and are suited to a child or adult's age and ability levels.

You may also want to plan cross-educational opportunities for students with autism and law enforcement professionals. Be sure to provide them in a safe, non-threatening environment.

As outlined in Developing Risk and Safety Life Skills for Persons with Autism at: www.autismriskmanagement.com/documents/Life_Skills.pdf

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Building Skills for Children and Less Independent Adults

You may want to form partnerships with teachers and law enforcement professionals to develop a simple curriculum that helps expand the skills that will enhance the safety of young adults with autism in the community, and help them build personal resilience to risk.

Formally or informally, invite a variety of law enforcement officers and other safety professionals 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 safety skills 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 speak in their own words about the life skill that is being taught at the time.

Additional Skills to Build:

1. Recognize and respond to law enforcement officers, their uniforms, badges and vehicles.
2. Stay with—do not run from— safe "go to" police officers or other uniformed first responders.
3. Keep an appropriate distance when interacting with a law enforcement officer—or anyone else.
4. Avoid making sudden movements, i.e. putting hands into pockets.
5. Carry and safely show an ID card.
6. Disclose your autism, carry and safely show 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 you need help, or use the phone to request it.

Source: *Debbaudt and Coles, 2004*: www.autismriskmanagement.com

In addition, officers can participate in mock interviews, for example, by asking the student what his or her name is, and if he or she has an ID card. With permission from all involved, consider videotaping the visits, and using the videotape later on as a learning tool whenever possible.

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

For more information about safety, visit Autism Speaks' Autism Safety Project web site at AutismSafetyProject.org.

For additional tips, as well as examples of disclosure letters and cards, please see the online appendix of this kit.

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Community Life Resources

Recreation & Leisure:

What Leisure Activities Are Good Options for Adults with Autism, and Is It Important to Exercise Regularly?
by Toni Thomas, Family Program Manager, Emory Autism Center, Emory University School of Medicine
ABC News, October 23, 2008
www.abcnews.go.com/Health/AutismLiving/story?id=5930840

Safety:

Autism Risk & Safety Management
By Dennis Debbaudt
www.autismriskmanagement.com

Autism Speaks: The Autism Safety Project
www.AutismSafetyProject.org

Travel:

Travel Training for Youth with Disabilities
National Dissemination Center for Children with Disabilities' (NICHCY) Transition Summary
www.nichcy.org/InformationResources/Documents/NICHCY%20PUBS/ts9.pdf

General Community Life Information:

Autism Spectrum Disorders: The Complete Guide to Understanding Autism, Asperger's Syndrome, Pervasive Developmental Disorder and Other ASDs
by Chantal Sicile-Kira

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

Autism & the Transition to Adulthood: Success Beyond the Classroom
by Paul Wehman, Marcia Datlow Smith and Carol Schall

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

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Americans with Disabilities Act
www.ada.gov

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

Alpine Leaning Group: Teaching Teenagers to Answer Cellphones
www.alpinelearninggroup.org/resources/documents/teaching_teenagers_answer_cellphones.pdf

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Community Life –
Social Activities and Resources

Agency and Contact	*Phone Number*	*Date Called*	*Service Requested*	*Appointment Date*	*Documents Needed*	*Status*	*Follow – Up*

EMPLOYMENT AND OTHER OPTIONS

What will the day look like when high school ends? There are several different options for individuals with autism when it comes to what they will do when they leave the education system. Some individuals may want a structured vocational or day program, others may choose to focus on community experiences or some type of employment. These options may include sheltered employment, supported employment, or competitive employment. Other young adults with autism may want to attend college or another type of post-secondary education institution before they enter the world of employment.



Employment is an important part of adult life. For many of us, our job defines a big piece of who we are. As outlined in IDEA, one of the most important objectives of transition planning is to develop and implement a plan to secure employment. In order to do this, you and your young adult may want to consider activities that utilize his or her strengths as well as activities that he or she likes to do. Information gathering, assessments, volunteer opportunities, internships, job sampling, and job matching all play important roles in preparing a young adult for employment.

Preparation

IDEA federal special education law requires that school districts help students with disabilities make the transition from school to work and life as an adult. While young adults with autism are still in high school, they may want to begin the process of learning and educating themselves about possible future careers.

Life Journey through Autism: A Guide for Transition to Adulthood, by Organization for Autism Research, Southwest Autism Research and Resource Center and Danya International, Inc., recommends the following for students in high school and middle school:

- Learn more about the wide variety of careers that exist.
- Take part in vocational assessment activities in the community through “job sampling” at the actual places of employment.
- Have the opportunity to learn, by practice and exposure, what his or her work preferences might be.
- Identify training needs and effective strategies to address deficits.
- Be provided with sufficient opportunity to develop basic competencies in independence, self-monitoring, travel training, and life outside the classroom.
- Develop effective disclosure strategies relative to your son or daughter’s abilities and needs.
- Identify critical skill deficits that may impede the transition to post-21 life and provide individualized instruction to minimize the deficits.
- Learn more about school-to-work programs in the community, which offer opportunities for training and employment through job sampling, youth apprenticeships, cooperative education, tech-prep, mentorships, independent study, and internships.

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Sometimes working with a career center or Office of Vocational Rehabilitation can be helpful. These agencies can help assess the individual's strengths, as well as his or her likes and dislikes. You may want to discuss the possibility of inviting a representative from your state or local vocational rehabilitation office to be a part of the Transition IEP meeting.

"On Thursdays when Danny was scheduled to work at the distribution center, he was always waiting at the door with his coat on. This was so different than Wednesdays when Danny was scheduled to work at the movie theater. Danny would procrastinate and need several reminders that it was time to go. Without any words Danny told us very clearly that he preferred his job at the distribution center. We are constantly reminded that behavior is a form of communication."
— Sarah, Danny's job coach

Career Exploration

Volunteer Opportunities, Internships & Job Sampling



Even before adolescents with autism are ready to sample different work experiences in the community, there are opportunities for them to get some work experience right in their own school buildings. This is an important first step in understanding your adolescent's strengths and challenges within different types of work. Strengths can be built upon and challenges minimized before work experiences in the community begin. Some examples of possible work experience in the school building include:

- Working in the school store – filling orders, stocking shelves, completing transactions.
- General office tasks – sorting mail, shredding documents, greeting visitors.
- Volunteer opportunities for community service.
- Maintaining a portion of grounds or garden.
- Participating in a recycling program.
- Collecting canned goods for a food bank.
- Working in the cafeteria.

Internships

During school, or even after graduation, finding a paid or unpaid internship can help individuals with autism gain valuable work experience. Internships can often help with skill building, job training programs, and eventually the job application process. Some students can be connected to a peer or mentor at the internship or volunteer site who can lend a hand if needed.

For young adults with autism with more significant challenges, job coaches can help them reach their full potential. A job coach will assist the adolescent or young adult with

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autism in obtaining a job and provide onsite support and assistance. A job coach may spend time at a job site before the individual begins the job in order to understand the requirements of the job and then will provide assistance to the individual with autism to successfully complete the job. Your school district may be able to help you find an agency that can supply a job coach.

"Typical vocational assessment may suggest that people with ASD are not adequately prepared for employment. We need to fight this notion and acknowledge that most jobs are going to require some degree of accommodation and support. The best ways to assess strength, interests, and support needs in a particular environment is to conduct the assessment in the environment in which one is expected to perform. Therefore, by conducting situational assessments across a variety of community jobs, an employment specialist can accurately assess such aspects as a person's work styles, time management and problem solving skills, and preferences in terms of environments, socialization, communication, and routines."

– As outlined in *Employment Planning for People with Autism Spectrum Disorders* by Speaker's Journal, The Pennsylvania House of Representatives, Fall 2008

Families may also need to keep in mind that individuals with autism may need to build up the endurance and stamina needed to complete their work day. This needs to be taken into consideration when exploring internships and job sampling options. Adequate time needs to be provided to make sure that the appropriate level of endurance and stamina is achieved. This way, the young adult can meet the requirements of the job.

Types of Employment

There are several different employment options for individuals on the autism spectrum. It should be noted that a young adult with autism can go from one type of employment option to another.

Life Journey Through Autism: A Guide for Transition to Adulthood, by Organization for Autism Research, Southwest Autism Research and Resource Center, and Danya International, Inc. lists several possible types of employment:

Competitive Employment – A full-time or part-time job with market wages and responsibilities is considered competitive. Usually, no long-term support is provided to the employee to help him learn the job or continue to perform the job.

Supported Employment **–** In supported employment, individuals with autism work in competitive jobs but receive ongoing support services while on the job. The support is provided as long as the person holds the job, although the amount of supervision may be reduced over time as the person learns to do the job more independently. Supported employment, in whatever form it takes, can be funded through state developmental disabilities or vocational rehabilitation agencies, but families will have to advocate strongly that: (1) supported employment, by definition and statute, is intended for people with severe disabilities; and (2)

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individuals with autism can, in fact, work if given the proper support, training, and attention to job match characteristics.

Customized Employment – Customized employment involves finding creative ways to identify and using the strengths and abilities of individuals with significant disabilities by actively negotiating job tasks or duties with businesses (*Autism and the Transition to Adulthood,* Wehman Smith, Schall). This avenue of customized employment establishes a unique relationship between employer and employee, in that it enables both parties to get as much from the relationship as possible. Customized employment is similar to supported employment in that it requires learning about the individual and understanding his or her strengths and support needs. In a customized employment situation, however, the job and job description are uniquely created for the individual at hand.

Self Employment – involves matching an individual's interest and strengths to a product or service that could provide an income. For some this can increase the opportunity to tailor the work environment to the needs of the individual, and to tailor the job, or a portion of the job to the strengths of an individual.

Secured or Segregated Employment – In secured or segregated employment, individuals with disabilities (not necessarily autism specifically) work in a self-contained units and are not integrated with workers without disabilities. This type of employment is generally supported by a combination of federal and/or state funds. Some typical tasks include collating, assembling, or packaging. While such programs remain available, critics argue that the sheltered workshop system is more often geared toward the fostering of dependence within a tightly supervised, non-therapeutic environment than toward encouraging independence in the community at large.

Sheltered Employment – Sheltered employment involves programs in a protected environment that provide training and services that will assist adults with autism in developing life skills as well as educational and pre-vocational skills.

Autism Speaks celebrates the success of individuals who are working on the *Autism in the Workplace* page *on the* Autism Speaks website. For video clips of different individuals with autism who are working, as well as information from their employers and the steps that were put in place to make the job match successful, visit AutismSpeaks.org/community/family_services/autism_in_the_workplace.php.

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Job Matching & Searching

The below information comes from**:** *Achieving a Good Job Match*: *Considerations for Placement Planning and Assessment* as described in Institute for Community Inclusion – Supporting Individuals with Autism Spectrum Disorders: Quality Employment Practices *by The Institute Brief, Issue No. 25*

"The most important consideration in helping an individual with autism find a job is the job match. When helping a person with autism find a good job match, three broad areas must be considered:

- The interests and skills of the person with autism;
- The individual with autism's learning style; and
- The environmental demands on the worker with autism—including communication, sensory, social, and organizational.

It is imperative to match the job to the unique set of strengths, interests, and passions that the person with autism brings to the situation.

- Jay loves to travel in vehicles and would spend most of his day in a car if he could. His team is trying either to carve out a delivery position for him with an existing company or help him start his own delivery business.
- Alicia is very interested in women's and baby clothes. She works in a department store re-shelving and re-hanging clothes left in the changing rooms. Alicia hangs the clothes according to size using the color codes on the tags.
- Henn and Henn (2005) describe their daughter with autism as being very limited in her communication and as having a history of challenging behavior. However, she also is very meticulous and detailed oriented. She is extremely efficient in her work shelving books in a library.
- As a child, Dr. Temple Grandin became obsessed with cattle handling equipment at her aunt's ranch. She was encouraged to pursue her interests and went on to become one of the world's leading experts on the design of cattle handling facilities."

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Job Match Components

The below information regarding job matching is excerpted from *Life Journey Through Autism: A Guide for Transition to Adulthood*, by Organization for Autism Research, Southwest Autism Research and Resource Center and Danya International, Inc.

Individuals with autism may not be as motivated by money. So, for the majority of individuals with autism, their motivation to work will be directly related to the extent to which they enjoy the work they are being asked to do. A good match is of critical importance in these cases. When considering things that contribute to job match, they can be classified into physical and social components, as shown below:

Components of the Physical Job Match	*Components of the Social Job Match*
▪ Hours of employment ▪ Acceptable noise levels at the job site ▪ Pay, leave, and other benefits ▪ Acceptable activity levels ▪ Physical requirements of the job (e.g., lifting) ▪ Acceptable margin of error (quality control) ▪ Production requirements	▪ Acceptable level of interaction with coworkers and supervisors ▪ Clear job expectations ▪ Grooming and hygiene requirements ▪ Demands on communication skills ▪ Personal space available ▪ Phone/vending machine/cafeteria ▪ Coworker training and support ▪ Community Status

What Skills Do We Need for the Workplace?

There are a variety of skills that you may want to think about for your young adult with autism as he or she enters the workplace. Many of the necessary social skills in the workplace have been outlined by Dr. Paul Wehman in *Autism and the Transition to Adulthood.* For a full description of each bullet point below, see the COMMUNITY LIVING section of this kit.

- Using Social Amenities
- Using Appropriate Greetings.
- Terminating Conversations
- Sharing Workspace
- Accepting Correction
- Responding Assertively
- Accepting Suggestions
- Asking for Help and Revealing a Problem
- Waiting in Line and Taking Turns

In addition, there are some skills that are more specific to the job that an individual with autism will be doing in the workplace. These skills might include:

- Walking in the hallways (Keep to the right)
- What to say and/or do during an interview
- What to do during breaks and lunch
- Appropriate topics to discuss at work
- Travel skills
- Proper dress and grooming
- Maintaining a schedule
- Self Advocacy skills

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Agencies that May Help with the Employment Process

The National Dissemination Center for Children with Disabilities (NICHCY) has provided information about the following agencies:

The Vocational Rehabilitation (VR) Agency

The VR agency has traditionally been a primary player in determining the way transition services are delivered. Typically, VR helps persons with cognitive, sensory, physical, or emotional disabilities to find employment and achieve increased independence. Funded by federal and state money, VR agencies typically operate regional and local offices. VR services usually last for a limited period of time and are based on an individual's rehabilitation plan. If needed, an individual with disabilities can request services at a later time, and a new rehabilitation plan will be developed.

VR has its own eligibility requirements. Therefore, not all students receiving special education services can receive VR services. You will need to check with the VR agency in your own area to learn what eligibility requirements apply. Find that agency by visiting NICHCY's State Resource Sheets (www.nichcy.org/Pages/StateSpecificInfo.aspx) and selecting your state. The VR agency will be listed near the beginning of the list.

Examples of *employment services* that may be available through VR include:

- vocational guidance and counseling
- medical, psychological, vocational, and other types of assessments to determine vocational potential
- job development, placement, and follow-up services
- rehabilitation, technological services, and adaptive devices, tools, equipment and supplies

Examples of *postsecondary education services* that may be available through VR include:

- apprenticeship programs, usually in conjunction with the Department of Labor
- vocational training
- college training towards a vocational goal as part of an eligible student's financial aid package

Examples of *independent living and adult services* that may be available through VR include:

- housing or transportation supports needed to maintain employment
- interpreter services
- orientation and mobility services

To learn more about vocational rehabilitation, see the two resources below:

- *Vocational Rehabilitation Services: Can It Help You*? An online module at the HEATH Resource Center: www.heath.gwu.edu/index.php?option=com_content&task=view&id=1059&Itemid=65
- *Getting the Most from the Public Vocational Rehabilitation System*: www.communityinclusion.org/article.php?article_id=129

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Refer to your state page of the Autism Speaks Resource Guide, AutismSpeaks.org/community/fsdb/search.php, or the specific state page of this tool kit for information about the Vocational Rehabilitation Agencies in your state.

There are also some other websites that may be helpful:

ODEP | Office of Disability Employment Policy.
(866) 487-2365 (Department of Labor, toll-free)
(877) 889-5627 (Department of Labor, TTY)
www.dol.gov/odep

NCWD/Youth | Navigating the Road to Work.
www.ncwd-youth.info

Career One-Stops | Your pathway to career success.
careeronestop.org

Disability.gov | On jobs & self-employment.
www.disability.gov/employment

Options other than employment

Some individuals with autism and their families may feel that employment and/or post secondary educational opportunities are not right for them. There are other options that families and young adults with autism may consider and they include:

Day Programs

Many day programs for individuals with autism are administered through the Department of Developmental Disabilities (state specific). You may need to contact your local office for more information (see the Autism Speaks Resource Guide) on the programs available in your area. It is also important to note that many programs may have waiting lists, so it is important to start the process of getting on a waiting list as soon as possible.

Day Treatment Programs

Day treatment programs are for individuals that may need the most intensive level of supervision and support. Day Treatment Programs combine therapeutic treatment with daily life skills. This type of program is administered at a program site rather than in the community. To find out about day treatment programs in your area you should contact the Department of Developmental Disabilities.

Day Habilitation

Day habilitation programs provide structured activities and specialized supports that will allow individuals with autism to participate in non-employment related activities on site and in the community.

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Brian Merring has never considered himself much of a cook. But there he was, dressed in kitchen whites at the helm of a professional-grade stove and armed with a spoon and a palette of tasty ingredients. Merring, was diagnosed with autism when he was 6, and he has never held a job. He wasn't sure if he would be able to complete the task at hand—turn the raw flavors before him into retail-worthy soups— but he was willing to try. It was the experience that he craved, and that's exactly what the Southwest Autism Research & Resource Center (SARRC) is serving up with this newest addition to its Vocational & Life Skills Academy. Called CulinaryWorks®, this program was recently launched by SARRC through a partnership with notable Arizona chefs, and the program offers adults with autism spectrum disorders hands-on job training through the preparation, packaging, distribution and sale of classic soups. The program is supported through grants from the Virginia G. Piper Charitable Trust and the Noah Family Foundation. Like most programs in the academy, CulinaryWorks provides those with autism vital trade skills that can be translated into employment opportunities in the future that will allow them to live and work independently.

"It's about creating a quality of life and a sense of independence for our adults with autism," says Jeri Kendle, Vocational & Life Skills Academy director. "Our participants are trained in a variety of skills, with opportunities in bookkeeping, sales and cooking. We want to give these individuals valuable skills so they can find jobs, have meaningful experiences and build self-esteem."

Developing skills and working toward employment and independence is crucial for many in this program. Brian's parents, Mildred and Dr. Leroy Merring, want their son to have every advantage possible in the job market. Both worry about what will happen to their son when they are no longer around to take care of him.
"He has never had a job, and we're not going to be here forever," Leroy Mar ring says. "This is the first program out there that does something for the future of people like Brian. And It's a relief that this program is now available."

For more information about the Southwest Autism Research & Resource Center, visit www.autismcenter.org.

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Employment Resources

A Systematic Process for Carving Supported Employment Positions for People with Severe Disabilities
Nietupski, J. A.and Hamre-Nietupski, S.
Journal of Developmental and Physical Disabilities
www.springerlink.com/content/g17288456h568706

Employment Training for People with Autism Spectrum Disorders
Speaker's Journal, The Pennsylvania House of Representatives, Fall 2008
www.house.state.pa.us/SpkrJournal/documents/8/v8_a15.pdf

Working in the Community: A Guide for Employers of Individuals with Disabilities
Supported Employment & Supported Volunteerism Training Manual
Written and produced by the Alpine Learning Group with the support of the Daniel Jordan Fiddle Foundation
www.djfiddlefoundation.org/userdocs/alpine_employment_manual.pdf

Supporting Individuals with Autism Spectrum Disorder: Quality Employment Practices
The Institute for Community Inclusion (ICI) Professional Development Series, December 2008
by Melanie Jordan
www.communityinclusion.org/article.php?article_id=266

Autism Speaks: Autism in the Workplace
www.autismspeaks.org/community/family_services/autism_in_the_workplace.php

Virginia Commonwealth University Rehabilitation Research and Training Center on Workplace Supports and Job Retention
www.worksupport.com

More General Transition Resources

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

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Autism & the Transition to Adulthood: Success Beyond the Classroom
by Paul Wehman, Marcia Datlow Smith and Carol Schall

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

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Adult Services in the Community

Agency and Contact	*Phone Number*	*Date Called*	*Service Requested*	*Appointment Date*	*Documents Needed*	*Status*	*Follow – Up*

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.

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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.

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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 disability who 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 students are 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.

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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.

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Preparing for College While Still in High School

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.

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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.

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- 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.



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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

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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.

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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.

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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

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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

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College Options and Choices

School	*Phone Number*	*Date Called*	*Service Requested*	*Appointment Date*	*Documents Needed*	*Status*	*Follow – Up*

HOUSING

What are the Options for Housing and How Do I Find Them?

Finding the right residential option for a young adult with autism is certainly one of the most difficult parts of the transition process. There are different options to choose from, but several hurdles to get over before the individual is settled in the right place. The most important thing is to build the skills necessary for your young adult to live as independently as possible as an adult.



Start Early!

It is critical to be proactive when it comes to choosing the right residential option.

Think first about what's best for your child as an individual based on his or her needs, abilities, strengths, etc.

- Where would your child thrive?
- Where would he or she be happiest and feel safest?
- What type of setting would best help him or her achieve an independent, successful future?
- What supports does he or she need? What types of options can best provide those supports?
- What setting can help your young adult expand upon his or her strengths and abilities?

A great place to start is your school district. They can help, or they can tell you where you can go to get help. Check in with other families you know who have a family member with autism or other developmental disability. If you don't know any personally, you can most likely find some families through support groups, local autism organizations, etc. To find out about options in your area, contact state and local agencies to speak about residential options. This is hard work and will take time, but it is critical to uncover all possible options in your community and the surrounding area. The hard work will be worth it in the long run.

Once you find some good options, *ASK LOTS OF QUESTIONS*!

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Some Questions to Ask

When reviewing housing options you may want to consider**:**

1. How much experience does the provider have in working with individuals with disabilities? Autism in particular?

2. How does the agency help transition the individual from his own home to the new residential facility? What do they do to smooth the process?

3. What kind of training does the staff receive? How often are they on duty?

4. What is the staff turnover rate? Staff to resident ratio?

5. How does the staff deal with emergencies?

6. How structured is the schedule? What does the schedule look like?

7. What activities take place both in and out of the home? Is there any interaction with the community at large?

8. How will my family be involved in the plan of services?

9. Can I talk to other families with experience in these facilities?

10. What clinical staff do you have?

11. What is the situation with day programs/vocational services/life skills training, etc?

Autism Residential Placement Options: *ARCHWay – State Developmental Disabilities Agencies and Service: A Starting Point*

Types of Housing Options

The issue of housing can be complicated**.** It is important to research all types of options, and continue to narrow down your list until you find the best fit. Each type of residential program is designed to provide a different level of support for the residents in the program. Below, we have provided information about residential program options as well as funding options as outlined in: *Opening Doors: A Discussion of Residential Options* produced by the Urban Land Institute Arizona, Southwest Autism Research & Resource Center and Arizona State University.
www.autismcenter.org/documents/openingdoors_print_042610_001.pdf

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Residential Program Options

Transitional Models

Transitional residential programs offer a relatively short-term (e.g. one month to two years) residential experience with the expressed goal of transitioning the individual back to their previous environment or a new residence upon completion of the program. Transitional programs generally fall into one of three categories: 1) programs providing intensive inpatient behavioral evaluation and intervention for individuals with severe behavior disorders; 2) programs providing an intensive life skills course of instruction for individuals who, upon completion of the program, are expected to live independently; and 3) college support programs.

Supported Living

Supported living programs provide residential services to adults with developmental disabilities who are able to live in self-owned or leased homes in the community. Among the core tenets of supporting living are that 1) everyone, independent of current skills sets, can benefit from supported living; 2) programming and instruction are directed by the consumer and not by the program; 3) to be effective, communities of support must be built around the person and promote their involvement, and; 4) smaller numbers result in greater levels of community integration. Supported living is designed to foster the individual's full membership in the community as they work toward their long-term personal goals.

Supervised Living

Supervised living is a residential model designed to provide services to individuals with ASDs with greater oversight and direction than might be provided in a supported living context, but less than group home living. In supervised living, the homes may be self-owned or leased. Although individual residences may be small (generally no more than one or two adults with autism per residence), there may be a number of such residences scattered throughout the apartment building or housing complex, allowing for greater staff accessibility and oversight.

Groups Homes (Supported and Supervised)

With the onset of de-institutionalization came the movement of individuals with ASDs and other developmental disabilities from large, congregate care facilities to smaller, more typical homes in the community. Group homes exist in every state. They are small, residential facilities (i.e. actual homes) located in the community and designed to serve children and adults with ASDs, intellectual disabilities or other chronic conditions. Typically, group homes have eight or fewer occupants and are staffed 24 hours a day by trained agency staff. Ownership of the house usually lies with the provider agency (as do staffing decisions) and not with the residents of the house. A primary goal of group home living is to promote increasingly greater levels of independence in the residents. As such, instruction in daily living and self help skills including meal preparation, laundry, housecleaning, home maintenance, money management, hygiene, showering, dressing and appropriate social interactions are provided by the agency staff.

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Intermediate Care Facility – Mental Retardation (ICF-MR) (Institutional) (most intensive)

The ICF-MR is a residential program that was established in 1971 by the Federal government as an optional Medicaid service. The funding for this facility-based program, which includes both the facility and the support services, stays with the facility, not the person. Programs range from large congregate settings to those which are community-based and sized much like a group home. The underlying philosophy is that individuals with developmental disabilities can continue to learn and develop skills when supported by adequate programs and services tailored to their individual strengths and needs. Each ICF-MR is responsible for providing active treatment, consistent training and health support allowing individuals to maximize their independence. Currently, all 50 states have at least one ICF-MR facility. The ICF-MR has traditionally served individuals with complex needs and who are medically fragile and multi-challenged. There has been a shift away from the development of new ICF-MR facilities and a transition to more person-centric funding models.

Agricultural Autism Community/Farmstead Programs (Supported and Supervised)

Agricultural autism community, or farmstead programs, are proven hybrid models that generally combine residential living arrangements, typically in several single family homes or individual apartments in multi-unit dwellings located on site or in nearby locations, with stable agricultural science and community-based employment. A few of the communities are residential only. Most offer day programs, job training and employment both on- and off-site for adults with autism who live with their families in nearby areas.

Funding Options

It can be challenging and confusing to navigate the funding streams for housing for your young adult with autism. Each state has varying programs and guidelines, so you will need to research funding options specific to your state. The state page of the Autism Speaks Resource Guide will provide you with some of the contacts necessary to begin this process. The following list outlines some of the national programs that provide funding for services such as housing:

Federal Entitlements

Medicaid – Title 19 – for medical necessity, paid directly to the service provider, not specific to housing. This is not specific to housing services, but is based upon the services delivered. A person must qualify for Developmental Disability Services in their state. States have a required match which can be used for room and board.

Supplemental Security Income (SSI) – paid directly to recipients. This is income to cover everything except medical care. An individual must be disabled and have a limited income.

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Other Funding Options

Large donor/charitable organization (simplest model) – a single donor or multiple donors contribute the construction/acquisition funding through a 501(c)(3) organization that serves the developmentally disabled population.

Private pay (can be families together with other families) – Families with resources pay for all services and the facilities together with other families.

Low income housing (greatest single source of funding) – Federal and state funds are granted to construction housing for low-income and special needs populations.

HUD Section 811- This program provides interest-free capital advances to nonprofit sponsors to develop rental housing for low-income persons with disabilities.

Low Income Housing Tax Credit (LIHTC) – This program allows qualified for-profit and nonprofit developers to apply, on a state-by-state program, for federal tax credits that they can sell to investors and use the proceeds as equity for the development of apartment complexes for persons below 60 percent area median income.

HUD Section 202 – Similar to 811, this program is available only to nonprofit organizations that target both low-income seniors and frail elderly by providing capital advances to finance the construction, rehabilitation or acquisition of structures and also provides rent subsidies for projects to help make them more affordable.

Home Program – This program provides formula grants and loans to state and local participating jurisdictions to expand housing opportunities for low and moderate income individuals and households.

Community Development Block Grant (CDBG) – CDBG's are grants to jurisdictions which can be used to support affordable housing through land acquisition and infrastructure development.

HUD Section 811 Housing Choice Vouchers (HCV) – These vouchers are dispersed directly by HUD to persons with disabilities to spend on the housing option of their choosing.

HUD Section 8 HCV – This voucher program is for individuals with below 60% of the area median income, including disabled persons.

Home and Community Based Waivers (HCBS) – Some states may offer a variety of services to consumers under an HCBS waiver program. These programs may provide a combination of both traditional medical services (dental services, skilled nursing services) as well as non-medical services (i.e. respite, case management and/or environmental modifications). Family members and friends may be providers of waiver services if they meet the specified provider qualifications.

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One of the challenges of some residential options is that often the housing unit and the services within the home are provided by one agency. Because the services are tied to the housing, if a young adult or adult with autism is unsatisfied with the services in the home, in many cases he or she will need to leave the home.

Skills to consider for Independent Living

Some skills that individuals may need to master in order to live more independently include:

- Safety Skills
- Phone Skills
- Cleaning and maintaining a home
- Laundry and Clothing care
- Budgeting
- Nutrition and Cooking
- Grocery Shopping

It may be helpful to have these skills included in your young adult's IEP so that there can be a focus on these skills prior to adulthood.

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An example of supported living from Jay Nolan Community Services can be found below http://jaynolan.org/nick_essay.php

One look at the smile on Nick Anderson's face and you get a sense of just how fun loving and personable this young man is. Whether he is talking about his businesses—he has two—his love of the outdoors, his affinity for animals or his obsession with pizza, Nick is a delight. He is also an adult living with autism.

Nick's journey with Jay Nolan Community Services began at age 11 when he began attending JNCS Saturday Program. It was there that he learned about riding public transportation, interacting with community members, and trying new and different things. Later as a teenager, he again broadened his horizons spending two summers at JNCS' summer camp.

However, it was not until 2007 after graduating high school that Nick would experience his most dramatic successes. As part of his support plan, JNCS has helped Nick start two ventures—a dog walking and a vending machine business. Nick's support staff keeps him organized and teaches him business basics (i.e., keeping up with billing, stocking, customer service, etc.). Every day after walking his five canine friends, Nick returns home to hand write his customer invoices. Once a week, he and a support staff member stop by his soda vending machine at JNCS to collect the change and check on the stock.

Nick shares a Northridge home with Evan, one of his former one-on-one aides and his wife, Nadia. Since moving into supported living, Nick is more open to change…to trying new things. He now exercises at a gym, and loves to hike, bike and do almost anything physical. His affinity for pizza hasn't wavered though. If he could, he would eat it for breakfast, lunch and dinner. One of his favorite places is Marcelino's Italian Kitchen. Marcelino has become a family friend and lets Nick behind the counter to make his favorite pizza—meatballs, onions and mushrooms. Likes being around other people—and his family, friends, and support staff provide just that.

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Some parents may feel guilty about moving their child out of their home. But, "In some situations, the family may decide that a professional setting might be better able to provide the amount of structure and support this child or adult needs to continue to grow. Others feel that it is time for the adult to move from the shelter of his family and experience the independence that supervised living can provide. Families must understand that moving an adult into a residential program is not signing them over to the state or an agency and then losing their parental rights. This decision can be reversed at any time the family decides the placement is not meeting the child's or adult's needs."

- Guiding Your Teenager with Special Needs through the Transition from School to Adult Life: Tools for Parents
by Mary Korpi

Unfortunately, at this time there are many more people waiting for appropriate supported living settings than there are openings in these settings.

Waiting lists are long – so start the process early!

It is important for parents to work with the Service Coordinator at the Developmental Disabilities Office in their area as soon as possible to complete and submit residential applications to the appropriate adult service agencies. You may even want to add your child's name to the waiting list even if you are not yet ready to consider this move. Completing an application places your child in a 'waiting pool' from which appropriate individuals are selected depending on the opening. After an individual is selected, there is an interview process, discussions, etc.

Long-term planning is the best way to avoid crisis situations.

Involving your Young Adult in the Moving Process

Although housing options can be difficult to find it is important to involve your young adult in as much of the process as possible. This can include:

- Choosing the home
- Deciding on the décor – especially in personal spaces such as bedrooms
- Interviewing staff (if appropriate)
- Organizing their belongings
- Shopping for groceries

A new home for your young adult will be a change for both of you. The transition will be easier if you work together to plan out the new space and involve your young adult to the best of their ability. You may want to consider visiting the home several times before the move in date and take pictures or video of the space. This will assist your young adult in familiarizing themselves with their new surroundings. If there are other residents in the home you may want to consider having your young adult spend time with them both in the home and community before they move in.

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Housing Resources

Opening Doors: A Discussion of Residential Options
Produced by the Urban Land Institute Arizona, Southwest Autism Research & Resource Center and Arizona State University
www.autismcenter.org/openingdoors.aspx

Homes for Autism
www.homesforautism.org/housing.html

Housing Choices Coalition
www.housingchoices.com

Autism Residential Placement Options
www.child-autism-parent-cafe.com/residential-placement.html

Community Development Block Grant Program
www.hud.gov/offices/cpd/communitydevelopment/programs

The Disability Opportunity Fund
thedof.org

Foundation for Autism Support and Training: ARCHWay
www.foundationforautismsupportandtraining.org/archway.html

Autism Links: Service Provider Directory
www.autismlink.com/services

U.S. Department of Health and Human Services Administration on Developmental Disabilities
www.acf.hhs.gov/programs/add

U.S. Department of Housing and Urban Development (HUD)
http://portal.hud.gov/portal/page/portal/HUD

Supplemental Security Income
www.ssa.gov/ssi

Medicaid Title XIX
www.ssa.gov/OP_Home/ssact/title19/1900.htm

To search for some residential options in your area, visit the Autism Speaks Resource Guide (AutismSpeaks.org/community/resources), and search for "Residential Services."

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Housing Options in my Community

Agency and Contact	*Phone Number*	*Date Called*	*Service Requested*	*Appointment Date*	*Documents Needed*	*Status*	*Follow – Up*

LEGAL MATTERS TO CONSIDER

What is Long-Term Planning?

You may have subconsciously avoided the topic of long-term planning for a long time. This is not unusual. You may suddenly feel that you are back to the beginning stages of accepting the diagnosis. However, it may help to remind yourself that with planning, you may find some peace of mind.

There are changes when a person with autism reaches the age of majority, which is 18 years old in most states (it is important that you check what the age of majority is for your state on the state page of this kit). Parents no longer have the legal rights that they were entitled to throughout their child's youth. This can include accessing confidential health and school records.

It can be difficult to take the first steps in planning for your child's future. As parents, you are often busy with the daily challenges of raising a child with autism. By taking action early on, you can help protect your child's future wellbeing and rest a bit easier.

Before your child with autism reaches the age of majority, we suggest that you consult with professionals: attorneys, financial planners, and others who can help you make critical decisions about your child's future.

Many of these topics are state-administered programs, and each state sets its own guidelines. You will want to check with your state agencies for guidance.

You can find the contact information for your state agencies on your state page of this kit or in the Autism Speaks Resource Guide at AutismSpeaks.org/community/resources.

Health Insurance

If your child has been covered under your private health insurance policy, it is important to know what happens when your child reaches the age of majority.

Medicaid health benefits are available for individuals who qualify for Supplemental Security Income (SSI). Medicaid provides government-funded health insurance for children and adults with disabilities who have limited financial resources.

Parents need to review private insurance policies carefully, in order to make effective decisions. Some policies allow the adult child to continue coverage if he or she is a full time student. Most policies will now allow continued coverage for dependents up to age 26. Some will allow indefinite continued coverage for adult children if they are disabled, and if the parent continues to provide 50% or more of that adult child's support and maintenance. This needs to be considered carefully if the child will be receiving Supplemental Security Income (SSI), because some aspects of SSI payments are based on whether or not the young adult is claimed as a dependent by his or her parents. Others will allow the parents to continue to support the individual.

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Guardianship

In the eyes of the law, even a person with a significant developmental, cognitive, or mental health disability is legally permitted to make decisions on his or her own behalf at the age of majority. The only way parents can continue making decisions for their child is to become their legal guardian.

Families need to keep in mind that guardianship is not the same as serving as a substitute parent. A guardian is an individual that is truly person-centered and focused on the needs of the individual with disabilities. They will not be required to provide parental types of support.

Guardianship is a court-ordered arrangement in which one person is given the legal authority to make decisions on behalf of another person whom a court has deemed to be "incapacitated." The guardian's decision-making authority extends to all areas specified by the court.

Limited Guardian: A limited guardian makes decisions in only some specific areas, such as medical care. Limited guardianship may be appropriate if the person with a disability can make some decisions on his or her own.

General Guardian: A general guardian has broad control and decision-making authority over the individual. General guardianship may be appropriate if the person has a significant intellectual disability or mental illness and, as a result, is unable to meaningfully participate in important decisions that affect him or her.

Conservator: A conservator manages the finances (income and assets) of a person with a disability. A conservator has no authority to make personal decisions (medical, educational, etc.) for the person whose funds he or she is managing.

Deciding Whether Guardianship is Necessary

For parents, the decision to seek guardianship can be difficult. You need to protect your son or daughter with autism, but there may be some areas where he or she can make sound decisions. Fortunately, legal guardianship is not an "all or nothing" proposition. It is possible to carve out some areas where you son or daughter can retain important decision-making rights and control of his or her own life.

When considering how much authority you need—and how much independence your son or daughter should retain—you should begin with an assessment of the different areas in which your son or daughter may need your assistance. These areas may include: medical, educational, financial, vocational/adult services, living arrangements, legal, self-care, safety, and communication. For each area, assess whether your son or daughter can do the following:

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Medical

- Seek medical care when he or she is sick or injure
- Weigh the risks and benefits of any particular medical procedure that is being proposed
- Understand the need for routine medical care
- Understand that even if a medical procedure is painful or unpleasant, it may still be necessary
- Assess whether a particular medication is desirable, even though it may have unpleasant side effects
- Provide accurate information about his or her medical condition
- Follow medical advice

Education

- Grasp the essentials of his or her leaning problems and understand the services needed to learn effectively
- Advocate for himself or herself to obtain necessary education services

Finances

- Understand money basics, including the purpose of money, how to count money, and how to make change
- Safeguard his or her money so that it is not lost or stolen
- Budget money so that some funds are available to pay expenses at the end of the month

Vocational/Adult Services

- Apply for services from the Dept. of Disability Services, Dept. of Mental Health or other agency that serves people with disabilities
- Access necessary services and supports such as job training, employment support, or a day habilitation program
- Negotiate with the agency overseeing his or her care to obtain the best possible services

Living Arrangements

- Provide for his or her own physical care and well-being such as purchasing proper food, clothing, and shelter
- Live harmoniously in a group setting, respecting others' needs for quiet, privacy, and cleanliness

Legal and Decision-Making

- Understand the implications of signing documents
- Make sound decisions in important areas such as living arrangements, school, and work

Self-Care and Safety

- Have personal safety skills, such as staying out of dangerous areas, not talking to strangers, and keeping doors locked
- Know how to summon help in an emergency such as a fire or accident
- Have basic safety skills such as being careful around fires, stoves, candles, etc.

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Communication

- Communicate effectively (verbally or by other means)
- Understand that he or she has choices and be able to express them

Even if your son or daughter needs help with any of the above items, you should also consider whether he or she could be assisted by any means short of guardianship. For example, sometimes a person who needs help to make medical decisions can appoint a health care agent to act on his or her behalf. A person who receives government benefits such as Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) can have a representative payee manage them.

Obtaining Guardianship

To obtain guardianship, an attorney is not legally required. But you may want to consider hiring an attorney with expertise in this area. Each family is unique in that there are many significant choices and decisions to be made in this process.

Conservatorship

Conservatorship must be filed in Probate Court of Superior Court, in the courthouse where the proposed individual resides based on zip code. Most courthouses use Judicial Counsel forms and local court-required forms. Conservatorship is a lifelong process. The conservator must comply with the court for lifetime of the individual.

Resource for above Guardianship information: Special Needs Alliance, www.specialneedsanswers.com

Special Needs Trusts

The below information comes from the Autism Speaks Legal Guide provided by Goodwin Procter LLP (www.autismspeaks.org/docs/family_services_docs/GP_Legal_Guidelines.pdf)

A Special Needs Trust is a trust to hold assets for a special needs beneficiary. Such Trusts can be used for a special needs beneficiary receiving public benefits, such as Supplemental Security Income or Medicaid, in order to supplement the beneficiary's income without impacting eligibility to receive benefits. There are generally two kinds of Special Needs Trusts:

(1) A Third-Party Special Needs Trust is designed to hold property provided by someone other than the special needs beneficiary. A parent, custodial or non-custodial, or anyone else can put money in a Trust for the benefit of the special needs beneficiary. The person who sets up the trust has the right to determine where any money left in the trust will go after the death of the special needs beneficiary.

(2) A Self-Settled Special Needs Trust is designed to hold property belonging to the special needs beneficiary. As such, if the special needs beneficiary is a recipient of a state Medicaid program, the state program must be repaid out of

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the remaining funds upon the special needs beneficiary's death prior to distribution to those designated to inherit what remains.

A Special Needs Trust can ensure that money will be available for a child throughout his or her lifetime and that such money will not impact their access to means-tested benefits. A trustee, often the custodial parent, is designated to manage the Trust for the benefit of the special needs beneficiary. The trustee would be responsible for ensuring that payments from the Trust do not exceed the amounts that would render the beneficiary ineligible to receive benefit.

Upon divorce, a parent may want to revise his or her will and change beneficiary designations on insurance and retirement benefits so that property and proceeds are diverted to the Special Needs Trust rather than directed to their ex-spouse or to the child directly. Because child support payments are viewed as belonging to the child, there is a danger that such payments could disqualify the child from means-tested benefits. In order to avoid this issue, a parent may want to assign some or all child support payments to a Special Needs Trust. In many states, child support obligations do not terminate at the death of the non-custodial parent and future support can be obtained from the deceased parent's estate. It may be worth convincing the non-custodial parent to obtain life insurance and arrange for the proceeds to be deposited in a trust that continues to make the child support payments on his estate's behalf.

Does your child need a special needs trust? Here are some things to consider when answering this question:

- Diagnosis is not required.
- Consider whether or not your adult child can manage his or her contracts, finances, and resist fraud and undue influence
- Consider hiring a lawyer. There are many important choices and decisions to be made in the process.
- The Special Needs Trust needs to be stand-alone from any other living trust your family may have.
- Trust is irrevocable in your child's name once funded. But the trust owns the assets, not the child.

For additional considerations in planning for your special needs child, see the online appendix for Top Ten Tips When Planning for Special Needs.

Support Programs

The Social Security Administration (SSA) has two kinds of benefits for people with disabilities over the age of 18: *Supplemental Security Income* (SSI) and *Social Security Disability Insurance/Disabled Adult Child Benefits* (SSDI). To qualify for these programs, a person must meet the Social Security Administration's definition of disabled.

The *SSA definition of disability* is "the inability to engage in any substantial gainful activity by reason of medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months." There is an actual number that is used to measure substantial gainful activity and it varies by year.

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SSA will review if the applicant's disability is on a list of conditions that are considered "severe" and that the disability would prevent a person from working for a year or more.

Benefits and Qualifications

Not all children that receive special education services may be considered disabled under the SSA definition. Even if a family is receiving SSI for a child under the age of 18, they will need to go through a re-determination process to maintain SSI benefits as an adult.

To determine if an applicant meets the criteria the parents must submit the child's detailed medical records, along with a list of all current medications as well as all doctors, hospitals, clinics and specialists that the child has visited.

In addition, the child will be asked to go through an examination paid for by the Social Security. This process can take several months.

Supplemental Security Income (SSI)

Supplemental Security Income (SSI) is available to people whose disabilities prevent them from gainful employment. In order to be eligible, an individual must not have greater than $2,000 in countable resources and must have a limited monthly income. At age 18, the income and resources of family members are not counted even if the individual continues to live at home. The amount of benefits is determined by a number of factors including where the person lives and what other income he or she may have.

Disabled Adult Child Benefits/Social Security Disability Insurance (SSDI)

Anyone whose disability developed prior to age 22, and whose parent or guardian is either deceased or getting Social Security retirement or disability benefits, may qualify for a form of insurance called Disabled Adult Child Benefits. This benefit is available regardless of the individual's income and resources.

Representative- Payee

The SSA appoints an administrator called a representative-payee (rep-payee), for all beneficiaries who are incapable of managing their own SSI or SSDI benefits. Parents seeking to become the re-payee for their disabled child's benefits must file an application in person with SSA. A parent can be established as a rep-payee without gaining guardianship over the child. If the child does not have income or resources aside from Social Security benefits, parents may prefer to avoid the guardianship appointment and pursue the simpler rep-payee process instead.

It is important that careful records be kept of the disabled child's monthly income, and that it is reported on time to the SSA. A copy of everything sent to the SSA should be kept.

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Appealing Decisions

If the SSA rejects an adult child's application for SSI or SSDI benefits, or if it simply reduces benefits, parents can take several steps to reverse the decision. There are four levels of the appeals process, described below. Beneficiaries have 60 days to file an appeal at each level of the appeal process.

- *Reconsideration*: An applicant denied benefits may ask for his case to be reviewed by the person who originally decided it.
- *Appeals Hearing*: If the applicant is denied benefits again in reconsideration, he can request a hearing before an Administrative Law Judge. The judge will listen to testimony and review any additional documents that may help the applicant's case. At this hearing, applicants have the right to bring a representative.
- *Appeals Council Review*: An applicant has the right to appeal the decision of the Administrative Law Judge to the Appeals Council. The Appeals Council will review the applicant's file but will not hear new testimony
- *Federal Court*: If the Appeals Council rejects an application, the applicant may then file an appeal in the U.S. Court system.

Resource: *Transition Matters: From School to Independence*, developed by the Resources for Children with Special Needs, Inc.

Medicaid Benefits

Individuals who qualify for SSI are eligible to receive Medicaid. Medicaid pays for a wide array of services for people with disabilities and provides government-funded health insurance for children and adults with disabilities who have limited financial resources. Medicaid also provides government funding for long-term services and supports, including institutional care in nursing facilities and, in some cases, in non-specialized placements for people with disabilities.

Medicaid Eligibility

- Categorical—persons who fit in a specific category whom federal law permits coverage (age 65 or above, be blind, have disabilities).
- Financial—income and assets do not exceed state threshold.

Home and Community-Based Waiver Services

The HCBS waiver program is an option available to states to provide integrated community-based long-term care services and supports to qualified Medicaid recipients. The programs "waive" some of the rules of Medicaid to serve children and adults otherwise requiring an institutional level of care who can; instead, be served at home or in the community. Medicaid is a state-administered program and each state sets its own guidelines.

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Other Legal Considerations

- Obtain a state I.D. card or driver's license from the Bureau of Motor Vehicles
- Register for Selective Service (Note that all males, regardless of disability, must register for Selective Service at age 18. They may register at the post office or online at www.sss.gov.)
- Register to vote
- Explore options for transportation; including driver's training

The Letter of Intent

A Letter of Intent is a document written by you (the parent or guardian) or other family member that describes your son or daughter's history, his or her current status, and what you hope for him or her in the future. It would be wise to write this letter today and add to it as the years go by, updating it when information about your son or daughter changes. To the maximum extent possible, it is also a good idea to involve your child in the writing of this Letter, so that the Letter truly "presents" and represents your child. The Letter is then ready at any moment to be used by all the individuals who will be involved in caring for your son or daughter, should you become ill or disabled yourself, or when you should pass away.

Even though the Letter of Intent is not a legal document, the courts and others can rely upon the Letter for guidance in understanding your son or daughter, as well as your wishes. In this way, you can continue to "speak out" on behalf of your son or daughter, providing insight and knowledge about his or her own best possible care.

Adapted from: http://specialchildren.about.com/od/longtermplanning/a/letterofintent.htm

For more information about a Letter of Intent as well as an example please see the online appendix of this kit.

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The following is a blog post by Marianne Sullivan, Autism Speaks Assistant Director of National Outreach and Resources. Marianne is also the mother of two young men, one of whom has autism.

This past year has been filled with a special kind of pride along with lots of anxiety as my son Hunter turned 18. I am so proud of all the hard work he has done in order to excel, despite his disability. There has also been anxiety anticipating the many challenges ahead for him as he prepares to live an adult life in the community as independently as possible.

Our recent trip to the local Social Security Office to apply for Supplemental Security income (SSI) was an event that marked this birthday and captured both the pride and anxiety I was feeling at the time. In preparation, I read articles and web postings about the application process. Once there in front of the eligibility clerk, I had some powerful reactions: Do they care about my son? Do they want him to succeed as much as I do? Will the income he receives be enough for him to live a comfortable adult life? Will he be able to deal with the system should a check not arrive or some other problems occur at some future time when I am no longer around to assist?

The eligibility clerk was a genuinely nice man, although he didn't become a surrogate parent as I had fantasized he might. Without too much difficulty, I was able to check myself on this and was reassured that he was doing his job in a manner that would help Hunter be more independent as an adult. The clerk asked a lot of questions and he typed with impressive speed.

And at one point, he asked me to ask my son to turn down his iPod. My internal thought was that this seemed to an easy request. But then memories of past parent-child struggles flashed by from the past 18 years. I reminded myself that Hunter had successfully learned a lot of life's lessons from those struggles. As I then asked him to comply with the clerk's request, Hunter appeared bored with the process but quickly agreed to turn down his music, perhaps realizing to some degree that this was an important event for his future.

An hour and half later, the application was complete. Hunter and I had our own sense of relief as we stood up to leave.

For others about to go through this rite of passage, it goes without saying that it pays off to have your paperwork organized in an accessible file, including medical providers contact information, and copies of relevant medical records, the original birth certificate and official social security card. By the way, you can complete a large part of your application on their website at www.socialsecurity.gov. It is very important to not just show up but rather, you should call (800) 772-1213 to set up an appointment with your local Social Security office. Once eligible for SSI, depending on which state you live in, you may also be eligible for additional services from your state. For example, in California you will receive a supplemental income that is added onto your federal benefit. In California, the full benefit is $846 a month.

The transition to adulthood stirs many emotions and creates anxieties. The visit to the Social Security Office was a big transition event for us. But, like any rite of passage, there is a lot worth celebrating as you look back at accomplishments while facing the new challenges that will arise on each step of the way.

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Legal Issues Resources

Legal Planning for Special Needs in Massachusetts: A Family Guide to SSI, Guardianship and Estate Planning
by Barbara D. Jackins, attorney

Goodwin Procter LLP Legal Guide for Autism Speaks
www.autismspeaks.org/docs/family_services_docs/GP_Legal_Guidelines.pdf
www.goodwinprocter.com

Academy of Special Needs Answers
www.specialneedsanswers.com

Transition Matters: From School to Independence
developed by Resources for Children with Special Needs, Inc.
www.resourcesnyc.org

Adolescents on the Autism Spectrum: A Parent's Guide to the Cognitive, Social, Physical and Transition Needs of Teenagers with Autism Spectrum Disorders
by Chantal Sicile-Kira, foreword by Temple Grandin

National Association of Councils on Developmental Disabilities
www.nacdd.org

The Clearinghouse for Home & Community Based Services
www.hcbs.org

U.S. Social Security Administration
www.ssa.gov

Social Security Income
www.ssa.gov/disability
Eligibility Information: www.ssa.gov/ssi/text-eligibility-ussi.htm

What You Need to Know When You Get Supplemental Social Security Income (SSI)
www.ssa.gov/pubs/11011.html

Writing a Letter of Intent
by Amy Baskin and Heather Fawcett
http://specialchildren.about.com/od/longtermplanning/a/letterofintent.htm

The Medicaid Reference Desk: Information About Medicaid for People with Cognitive Disabilities
www.thedesk.info

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Understanding Medicaid Home & Community Based Services: A Primer
U.S. Department of Health and Human Services:
http://aspe.hhs.gov/daltcp/reports/primer.htm

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Benefits Planning

Agency and Contact	*Phone Number*	*Date Called*	*Service Requested*	*Appointment Date*	*Documents Needed*	*Status*	*Follow – Up*

HEALTH

"While little is known about the interaction of ASD and aging, it is generally accepted that adults with ASD 1) tend to be fairly poor self reporters when it comes to health issues, and 2) as a group tend to be fairly sedentary. As such, concerns related to the long term health and wellness of adults with ASD should be at the forefront of any discussion of appropriate services."
– The Current State of Services for Adults with Autism, prepared by Peter F. Gerhardt, Ed.D., Organization for Autism Research

When thinking about the health of an adolescent or young adult with autism, physical health, mental health, and sexuality are three of the most critical issues to be addressed. All three areas are vital to the overall wellbeing of your young adult with autism.

Physical Health

As children mature into young adults, pediatricians are no longer appropriate as their primary care physicians. It can be challenging to find a primary care physician who accepts the insurance or Medicaid of adults with autism, and who understands autism - more specifically, young adults with autism. It is important that the primary care physician treats the patient as an individual like every other patient, not just as an individual with autism. You should advise the primary care physician to make sure not to see every health or behavior problem as a result of autism.



It is important to start early to find a PCP (primary care professional) for all young adults who are transitioning from pediatrics to other forms of health care. Ideally, there should be communication at the beginning between the pediatrician and the new doctor to ensure that everyone involved is fully informed of the individual's state of health. It may be a good idea to ask your pediatrician for the names of some primary care physicians in the area that may be appropriate for your son or daughter. The transition should occur around age 21.

Minnesota Medicine and Children's Clinics in Minnesota have provided a road map for transitioning between healthcare providers, which can be found at www.childrensmn.org/ForHealthProfessionals/ForHealthProf.asp.

Since your young adult will likely have a long-term relationship with his or her new doctor, it is extremely important that he or she feels comfortable with the physician. It

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may be helpful if the new doctor can start off with similar services that the individual was using with his or her pediatrician, in order to cushion the changes that come with this transition. Young adults with autism should be able to make choices and have a rapport or comfortable relationship with their doctors before starting routine check-ups or any other forms of treatment. The process of changing doctors is another important time to self advocate.

Dr. M. Paige Powell, and Dr. Sherry Sellers Vinson of Texas Children's Hospital and Baylor College of Medicine stress the importance of ensuring that the primary care physicians and dentists are adhering to all age-related preventative health guidelines, not just issues involving autism.

Other Considerations

According to Dr. M. Paige Powell and Dr. Sherry Sellers Vinson, individuals with autism are more likely to have new onset seizures during puberty than at any other time since before they entered school, or after they have completed puberty. While the likelihood of new onset seizures for young adults with autism is not very high, if an individual with autism has one, he or she will require immediate medical attention and investigation. A neurologist can provide further medical interventions.

For some additional information about seizures, see the Daniel Jordan Fiddle Foundation Epilepsy Brochure: http://fiddle.readvantage.com/news/attach/DJF-EpilepsyBrochure.pdf.

In addition, like with any adolescent entering puberty, adolescents with autism who have tics are likely to have more as they enter adulthood. Catatonia is also most likely to occur when an individual with autism is entering puberty. Visiting a neurologist or psychiatrist will be helpful in dealing with these conditions.

Female Health Needs

Most doctors suggest that all women should start seeing a gynecologist at 18, unless the teenager is experiencing pain and irregular periods before then. To prepare a young woman for her first gynecological check-up, you may want to discuss the reason for the visit and explain that this is something that all women do. As with many of the other skills that you have taught your daughter over the years, you may need to break the process down into small steps. A social story or visual schedule may also be helpful. Some professionals suggest that it may be helpful to bring young women with autism to their mother's check-ups at the gynecologist, so that they can ask questions and see what will happen during their own check-ups.

Mental Health

Psychiatric diagnoses are not developmental disorders. Oftentimes symptoms of these diagnoses may not be visible during childhood. Unfortunately, mental health diagnoses can complicate the transition process. The teenage years are already a time of turmoil and change, and an adolescent with psychiatric diagnosis can

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have a more difficult time managing the emotions that come along with these years. This is often further complicated by the assumption that certain behaviors and emotions are connected to the individual's autism diagnosis, when the diagnosis in fact may not be related to the behavior at all. The most common mental health issues that affect individuals with autism include anxiety, depression, and obsessive compulsive disorder.

If you suspect that your young adult may be suffering from a psychiatric disorder, you may want to speak with his or her primary care physician about a screening. The screening will consist of questionnaires that will indicate if the individual needs further evaluation and/or interventions. You may want to keep in mind that screening results are not a formal medical diagnosis. The results of screening may indicate if a visit with a trained medical professional such as a psychiatrist is needed to make a diagnosis and develop a treatment plan.

Personal Hygiene

Personal hygiene is an important life skill that all young adults with autism must understand no matter what level of support is needed. Skills such as bathing, using deodorant, brushing teeth, washing hands, and shampooing hair are all important skills that need to be taught for young adults with autism to become as independent as possible. Teaching these important skills to children and young adults also decreases the risk of possible molestation or abuse.

If you haven't begun to teach your child about these issues, it is never too late to start. *Taking Care of Myself* by Mary Wrobel provides a curriculum about healthy hygiene, puberty and personal care for young people with autism. It includes easy-to-understand directions, as well as visuals for many of the topics that need to be addressed. Teaching hygiene associated with private parts can serve as a good bridge to sex education.

Physical Changes

Parents often times need specific information on how to best prepare their young adults with autism for some of the changes that will happen to his or her body and for events such as menstruation or erections and ejaculation. Young adults with autism should understand what is happening to their bodies, as well as what will happen in the future. It is important to stress that these changes are a natural part of life for everyone, and should not be viewed as odd or scary. There are several books listed in the resource section at the end of this section that address the changing bodies of adolescents and ways in which these subjects can be addressed.

Sexuality

Many parents feel nervous and anxious about teaching their children about sexuality, especially children with autism. Many feel that it is less important to teach young adults with autism about this subject because they feel that they are less likely to be exposed to issues related to this topic. But sexuality education is arguably more important for individuals with autism because they are less likely to learn about it from other sources such as peers, movies, etc. It is also crucial for them to

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understand the difference between appropriate and inappropriate behavior, and to distinguish between the various types of health relationships.

Though the idea may seem overwhelming, it is critical to start as EARLY as possible and to be as DIRECT as possible!

Autism and Sexuality
by Dr Peter F. Gerhardt

Although generally difficult to talk about in an open and honest manner, sex and sexuality are central to our understanding of ourselves as individuals and are integral to our individual determination of quality of life. Contrary to some preconceived notions about sexuality instruction it is not designed to titillate, arouse or excite and it does not focus primarily on the physical act of having sex. Sexuality instruction, instead, focuses first and foremost on personal safety and self knowledge. So while sexuality education may be both frightening and complex, it should be considered an integral element of a comprehensive transition plan assuming that the goal of such a plan education is to be a safe, competent, and confident adult.

Perhaps surprisingly, sexuality education starts very early in life (differences between boys and girls; using the boys room or girls room, etc.) and continues well into adulthood (dating, marriage, and parenting). Comprehensive sexuality education consists of instruction in three distinct (yet interrelated) content areas: 1) Basic facts and personal safety; 2) Individual values and; 3) Social competence. As such, an instructional focus on some basic safety skills should be considered both necessary and appropriate for individuals on the autism spectrum. These skills would include, but not be limited to, closing and locking bathroom or stall doors, understanding personal privacy and who can and who cannot help you in the bathroom or with personal care skills, body part identification using adult terminology (e.g., penis instead of peepee), using public restrooms independently, the restriction of nudity to personal bathroom or bedroom, and the issue of personal space for both self and others.

Sexuality education with learners with ASD is often regarded as a “problem because it is not an issue, or is an issue because it is seen as a problem.” (Koller, 2000, p. 126). In practice this means we generally ignore sexuality as it pertains to learners with ASD until it becomes a problem at which point we generally regard it as big problem. A more appropriate and, ideally, more effective approach is to address sexuality as just another, albeit complex, instructional focus, the teaching of which promotes the ability of the individual to be safer, more independent and more integrated into their own communities resulting in a more positive quality of life.

References: *Koller, R., (2000). Sexuality and adolescents with autism.* *Sexuality and Disability*, ***18,*** (125-135).

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"For a long time our son was a little boy with autism, which was a certain kind of challenge. Now that he's a teenager with autism – and a teenager who notices girls – we're faced with something else altogether."

– "Adolescence, Without a Roadmap"
by Claire Scovell LaZebnik, New York Times

Start Early!

Major preparation is key to sexuality education. TEACCH (**T**reatment and **E**ducation of **A**utistic and **C**ommunication related handicapped **CH**ildren) suggests that parents and professionals begin discussions about sexuality around age 10, two to three years before the average child enters puberty. Individuals with autism are very resistant to change. It is important to give them plenty of notice regarding what will happen as they enter adolescence and adulthood. You should teach them about these changes long before they occur. Starting early eases the process significantly.

Be Clear and Direct!

Clear and direct education is essential and a developmental approach is most effective when teaching sexual education to young adults with autism. Each skill and behavior should be taught as a series of developmental sequences or hierarchy of events which can be analyzed and broken down into several levels.

For example, Shana Nichols, PhD, a specialist in autism and sexuality, suggests it may help to teach girls a road map to certain relationships:

> Girl and boy meet → girl and boy start say hi to one another → girl and boy keep talking as friends → girl and boy start to spend more time together, may go to the movies, etc → girl and boy hold hands → girl and boy go on dates. This roadmap can continue all the way until marriage and family if applicable.

Teach these subjects as if you would teach any other subject. Be sure to promote and emphasize appropriate behavior, and stop and redirect any kind of inappropriate behavior. Encourage your young adult to ask you any questions.

The skills and knowledge regarding sexuality that come so naturally to young adults are generally gained indirectly from social cues, peers, movies, etc. People with autism often don't pick up the same information from these sources, which leads to a huge gap in sexual knowledge and understanding. Direct education will help close this gap.

Dr. Nichols suggests that a sexuality education curriculum include: the body, privacy, boundaries/touch, expressing affection, social skills, and exploitation prevention.

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Advice for Parents

In *Puberty and Children on the Autism Spectrum* from Living with Autism, the Autism Society has provided advice for parents when teaching their children about puberty and sexuality:

- Before you can effectively communicate your values about sexuality to your children, you need to know what you believe and why.
- You are the main educators of sex for your son and/or daughter. Whether you are comfortable or not, wouldn't you rather they get factual information from you than follow a classmate's or friend's advice?
- You must be "askable" (Gordon & Gordon, 2000). This means you should be prepared for any question or incident that involves your son or daughter's sexuality. Always say "That is a good question." You can decide to answer the question immediately or say "We'll discuss it when we get home." If you answer with a positive tone, then your child will continue to ask questions. Also, remember to answer the questions simply and directly. Don't give too much information to your adolescent.
- Children are not perfect. They make mistakes and it's up to us to turn their mistakes into lessons.
- Remember to use the same teaching strategies that you have used to teach your children other skills. Apply these strategies to teaching them about menstruation and nocturnal emissions as they go through puberty. Some of these strategies may include visual schedules or check off lists, videos, facts in books, pictures of what is happening to their bodies, stories to predict what might occur, or specific terminology. Think of puberty as just another stage of development. Embrace this time and move forward.
  www.autism-society.org/site/DocServer/LWA_Puberty.pdf?docID=4182

Basic Skills to Remember

The concept of *public versus private* is extremely important. Lots of inappropriate behavior can be avoided if young adults with autism are able to understand these two concepts. For example, it is critical to understand the concepts of public versus private parts, public versus private places, public versus private activities, public versus private subject matters, and so on.

It is also important to teach children and young adults with autism that there is an appropriate time and place for everything. For example, it is okay to disrobe, only in private places, before showering or changing.

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Relationship Skills

Dr. Shana Nichols, PhD, reports that relationship skills are often overlooked for young adults. The focus on teaching social and relationship skills often happens in the pre-school years, but these skills are just as important later on, most especially during adolescence. At this time, there are new concepts to learn and understand. It is time to move past basics onto subtleties, nuances, etc. Dr. Nichols suggests that parents and professionals explicitly teach young adults with autism about different types of relationships, and how they are similar and different. These types of relationships include: relationships with strangers, acquaintances, service providers, classmates, teachers, bus drivers, doctors, family members, etc. All of these relationships need to be addressed very directly to understand what makes each of them both healthy and appropriate.

Prevention of Abuse

The concept of appropriateness when it comes to relationships is critical in sexuality education, in order to prevent abuse. Unfortunately, with lack of knowledge about inappropriateness and abuse, individuals with developmental disabilities are more likely to be victims of sexual abuse. According to Dr. Nichols, "individuals with autism are extra vulnerable due to difficulties recognizing 'red flags' and interpreting thoughts, feelings, and behaviors of others." It is essential for young adults with autism to understand what types of behavior are inappropriate. You should teach them to be aware and assertive, as well as to come back and tell you when anything happens that they feel may have been inappropriate.

"The true issue is prevention of abuse, not pregnancy. So it comes down to education directed to personal and sexual safety – starting with closing and locking the bathroom door, knowing who can and can't help with menstrual care, and understanding the difference between good touching and bad touching."
– Dr. Peter Gerhardt

There are several resources in the back of this section that may be helpful as you work with your young adult with autism to understand sexuality.

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Health Resources

Mental Health

Autism and Mental Health Issues
Center for Autism and Related Disabilities at the University of South Florida
http://card-usf.fmhi.usf.edu

Mental Health Aspects of Autism and Asperger Syndrome
by Mohammad Ghaziuddin

Taking the Mystery Out of Medications in Autism/Asperger's Syndrome
by Luke Tsai

Autism, Epilepsy & Seizures: How to Recognize the Signs and Basic First Aid When You Do
The Daniel Jordan Fiddle Foundation
http://fiddle.readvantage.com/news/attach/DJF-EpilepsyBrochure.pdf

National Institute of Mental Health (NIMH)
www.nimh.nih.gov

Sexuality

Girls Growing Up on the Autism Spectrum: What Parents and Professionals Should Know About the Pre-Teen and Teenage Years
by Shana Nichols, Gina Marie Moravcik and Samara Pulver Tetenbaum

What Autistic Girls Are Made Of
by Emily Bazelon (*New York Times* Magazine, August 5, 2007)

Taking Care of Myself: A Healthy Hygiene, Puberty and Personal Curriculum for Young People with Autism
by Mary J. Worbel

Autism-Asperger's and Sexuality: Puberty and Beyond
by Jerry and Mary Newport

Sex, Sexuality and the Autism Spectrum
by Wendy Lawson

Asperger's Syndrome and Sexuality: From Adolescence Through Adulthood
by Isabelle Henault

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Sexuality and Autism
TEACCH Report (**T**reatment and **E**ducation of **A**utism and **C**ommunication related handicapped **Ch**ildren)
www.autismuk.com/index9sub1.htm

Growing Up with Autism: Developing a Healthy Sexuality Curriculum for Young Adults
presentation by Shana Nichols, Ph.D.

Adolescence, Without a Roadmap
by Claire Scovell LaZebnik
New York Times
www.nytimes.com/2005/10/16/fashion/sundaystyles/16LOVE.html

Living with Autism: Puberty and Children on the Autism Spectrum
Autism Society
www.autism-society.org/site/DocServer/LWA_Puberty.pdf?docID=4182

Sexuality Information and Education Council of the United States
www.siecus.org

General Transition Resources

The Current State of Services for Adults with Autism
prepared by Peter F. Gerhardt, Ed.D., Organization for Autism Research
http://nyc4a.org/pdf/oar_survey_11309.pdf

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

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Health Care and Providers

Agency and Contact	*Phone Number*	*Date Called*	*Service Requested*	*Appointment Date*	*Documents Needed*	*Status*	*Follow – Up*

Medication Information & History

Current Medication

Date	Name of Medication	Dosage	Prescribing Doctor	Reason for Medication	Comments

Medication History

Date	Name of Medication	Dosage	Prescribing Doctor	Reason for Medication	Comments

INTERNET SAFETY, SOCIAL NETWORKING AND TECHNOLOGY

Internet Safety and Social Networking

It sometimes seems that our world revolves around the internet. "Google it!" or "I'll 'friend' you later!" or "Tweet me!" are just a few of the popular phrases associated with the internet and online social networking that can be heard almost everywhere we turn.

Individuals with autism are just as interested, if not more interested, in using the internet as a connection to mass amounts of information and millions of people. To ensure the safety and success of internet usage, it is critical that individuals with autism learn how to protect themselves online, and that they understand what is and isn't appropriate on the internet.

Some organizations have specific classes to teach individuals with autism safe and fun ways to use the internet. Parents should closely monitor their young adult's internet use and constantly make sure that his or her internet activity is safe and appropriate.

Social Networking Sites – Safety Tips for Teens and Tweens
from *Federal Trade Commission Facts for Consumers*:

- Think about how different sites work before deciding to join a site. Some sites will allow only a defined community of users to access posted content; others allow anyone and everyone to view postings.
- Think about keeping some control over the information you post. Consider restricting access to your page to a select group of people, for example, your friends from school, your club, your team, your community groups, or your family.
- Keep your information to yourself. Don't post your full name, Social Security number, address, phone number, or bank and credit card account numbers — and don't post other people's information, either. Be cautious about posting information that could be used to identify you or locate you offline. This could include the name of your school, sports team, clubs, and where you work or hang out.
- Make sure your screen name doesn't say too much about you. Don't use your name, your age, or your hometown. Even if you think your screen name makes you anonymous, it doesn't take a genius to combine clues to figure out who you are and where you can be found.
- Post only information that you are comfortable with others seeing — and knowing — about you. Many people can see your page, including your parents, your teachers, the police, the college you might want to apply to next year, or the job you might want to apply for in five years.
- Remember that once you post information online, you can't take it back. Even if you delete the information from a site, older versions exist on other people's computers.
- Consider not posting your photo. It can be altered and broadcast in ways you may not be happy about. If you do post one, ask yourself whether it's one your mom would display in the living room.

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- Flirting with strangers online could have serious consequences. Because some people lie about who they really are, you never really know who you're dealing with.
- Be wary if a new online friend wants to meet you in person. Before you decide to meet someone, do your research: Ask whether any of your friends know the person, and see what background you can dig up through online search engines. If you decide to meet them, be smart about it: Meet in a public place, during the day, with friends you trust. Tell an adult or a responsible sibling where you're going, and when you expect to be back.
- Trust your gut if you have suspicions. If you feel threatened by someone or uncomfortable because of something online, tell an adult you trust and report it to the police and the social networking site. You could end up preventing someone else from becoming a victim.

Social Networking Sites Specifically for Individuals with Autism

You may want to help your child try to navigate social networking sites. Keep a list of questions that your child may have and use this opportunity to help him or her be proactive. Sit down at the computer with your son or daughter and point out dangers. Keep a list of red flags that might be harmful and dangerous. Once again, partner with your child in creating this list. He or she will become more familiar with the dangers if you talk it through and write down points of reference.

WeAreAutism.org - Share, talk, and communicate in a user-led social network for individuals, family members and those members of the community. Share the wealth of your experience and plan for the future with those like you. Find others with similar interests and goals.

WrongPlanet.net - Wrong Planet is a web community designed for individuals (and parents / professionals of those) with Autism, Asperger's Syndrome, ADHD, PDDs, and other neurological differences. We provide a discussion forum, where members communicate with each other, an article section, with exclusive articles and how-to guides, a blogging feature, and a chat room for real-time communication with other Aspies.

AutismSpeaks.Ning.org - Autism Speaks Social Networking Site
This online community was created as a support forum for those affected by autism.

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Technology

The goals and uses of technology are very different for adolescents and young adults. Technological tools can be very empowering for adolescents transitioning into young adulthood, especially individuals with autism.

"Throughout the years, a large variety of strategies and tools, including technology, have been used to enhance both the functional capabilities and the quality of life of people with developmental disabilities. The varied use of these strategies and tools—especially those with the power of technology with individuals with autism spectrum disorder (ASD)—continues to receive limited attention in spite of the fact that technology tends to be a high interest area for many of these individuals. Frequently, consideration of assistive technology is limited to augmentative communication purposes; that is, as an alternative way for individuals with limited verbal expression (speech) to communicate. Although the use of augmentative communication can be significant for individuals with ASD, there are many other ways in which assistive technology may be used. This section will discuss how various tools and strategies, including no, low, mid, and high technology methods can be used with individuals with ASD. While our focus is on students, most of this information applies to adults as well. The needs of students from early childhood through high school and transition into postsecondary life are also addressed."

- *Assistive Technology Supports for Individuals with Autism Spectrum Disorder*
Wisconsin Assistive Technology Initiative
February, 2009
www.wati.org/content/supports/free/pdf/ASDManual-1.pdf

Assistive Technology: According to the *Technology-Related Assistance for Individuals with Disabilities Act of 1988* (Public Law 100-407), assistive technology device means any item, piece of equipment, or product system, whether acquired commercially, off-the-shelf, modified or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities. In IDEA 1997 and 2004 this definition remained unchanged. IDEA 2004 added an exception that states: "The term does not include a medical device that is surgically implanted or the replacement of such device" (Public Law 108-446, 602 (1) (B)).

Assistive technology service is any service that directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device. These definitions were incorporated into the Individuals with Disabilities Education Act (IDEA) in 1990 and remains today. In addition IDEA 2004 continued the requirement that "…each public agency shall ensure that assistive technology devices and assistive technology services are made available to a child with a disability if required…" (300.105 (a)).

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Using Technology to Promote Independence

Bluetooth Technology

- Used to fade proximity to instructors
- Connected to cell phone – used as unseen device on ear to allow instructor to walk individual through certain processes such as purchasing items at stores (locating items, waiting in line, paying for items)
- Proximity to instructor gradually decreased over time – started off with blue tooth device and instructor physically guiding process if audio cues not helpful right away – continues until individual on their own

Auditory Prompts via MP4 and iPods

- Walking individual through workout (finding machine, setting up machine, completing the exercise)
- Participants wore MP4 player watch or iPod attached to earphones
- Written schedule and portable timer used
- Verbal directions and favorite music used – again goal was to decrease proximity of instructor and increase independence over time

Video Modeling

- Used to teach adolescents domestic skills, self care skills, daily living skills, job tasks.
- Study focused on showering and other hygiene skills
- Used digital picture frames and portable DVD players
- Start with additional assistance like gestures or physical prompts along with videos, progress to just use videos

PAAL: The Use of Technology to Promote Independence and Social Acceptance for Adolescents with Autism
http://mecaautism.org/downloads/Technology-Independence-Social-Acceptance.pps

Areas where technology can be used: Visual Representation Strategies, Sensory Input, Motor, Receptive Communication, Expressive Communication, Academics, Organization, Behavior, Social Interaction, and Transition.

Various types of technology can help with communicating in a non-verbal way.

Additional Devices and Programs

- PDA's (personal digital assistants) – schedules, reminders, tips, etc.
- iPods – music and sounds
- Laptops and computers – social networking (see other section), assistive computer programs, fun activities, etc.
- iPhones/iPads– see apps below – lots of tools!
    - Significantly cheaper than Dynavox and other types of technology
- Computer games and software programs: Some individuals with autism find sensory regulation in various computer software programs.
- Tape Recorder/Recording Device

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- Keyboarding and other portable word processors: talking word processing programs such as Word Q and Write: OutLoud, can be used to speak text that is entered or selected by the student
    - Dragon NaturallySpeaking Solutions:
        - Speech recognition tool can turn speech into type
    - Write: Out Loud
        - Simple to use and reads words as they are written, providing real-time auditory feedback.
    - WordQ: suggests words for you to use and provides spoken feedback to help you find mistakes
- Speech Generating Devices- AAC
    - One message and multi-message devices available
    - www.speechgeneratingdevices.com
    - www.dynavoxtech.com
- VoicePod: The VoicePod is a digital recording and playback system ideal for photos, language cards and communication symbols
- Online Learning: The learning and teaching opportunities available through the Internet are amazingly numerous and varied
- Bluetooth
- Digital picture frame
- Websites specifically for young adults/adults with autism
    - Topic-specific such as college, employment
    - Social networking sites

Communication devices, computer programs, apps and other technological resources can be extremely beneficial tools for individuals with autism. It may be helpful to look into these resources, and determine if one or more might be a good option for your young adult. These resources can often improve the communication skills of individuals on the autism spectrum, and as a result, provide them with greater access to the community, and an increased ability to express their opinions and advocate for themselves.

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Jennifer is 15-years-old and has moderate autism. Her language is repetitive and she often has difficulty making her needs known. Her mother tries to encourage independence and suggests that Jen order her own drink at Starbucks. At first, Jen's mom carried pictures around with her and had Jen point at the coffee or the chocolate picture, and then the cold or the hot picture. Jennifer's mother realized that this process was a challenge for Jennifer, and wasn't maximizing her potential for independence in making these decisions.

Jennifer's mom decided to use an iPad to help with Jennifer's communication skills. She purchased an app that allows Jen to make menu choices right on the screen. Now, Jen can go into Starbucks with her iPad and place her order using the options she sees on the device. She can use this program to make menu decisions at other shops as well. Jennifer is thrilled that she is now able to get the drink she wants, all on her own.

In speaking with Jennifer's mother about this new process, she explained that there was a time when she would have answered for Jennifer, and may or may not have ordered what Jennifer wanted. In the past, this had been a cause for outbursts. But ever since she purchased her iPad, Jennifer can now use the device to communicate her wants, and outings such as trips to Starbucks are much more successful.



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GETTING ORGANIZED

The transition process can be more manageable when you have a system in place to keep yourself organized. For some that may seem easier said than done, we know parents of children with autism don't have a lot of extra time, but if you start at the beginning of the transition process, you will minimize your stress and maximize your time for other things you need to do.

Getting Started

Many families find that three-ring binders are a great tool for organizing large amounts of paperwork, as a alternative hanging files that are kept in a filing box are also very popular and the box is portable. What's important is to choose a system that works best for you and your family!

As you begin the transition process, you may want to pick up some office supplies; three-ring binders, paper, dividers, several 3 hole punched pockets that fit into binders for loose papers, and a flash drive or memory stick to file electronic documents. You may want to set up one binder with Medical Information and Legal Matters.

The Medical section may include:

- Included would be a copy of a contact list with medical professionals
- Diagnosis
- Medications log
- Other medical paperwork

Legal Matters section may include:

- Transition Planning Log
- Special Needs Trust – if appropriate
- Guardianship – if appropriate
- Conservatorship – if appropriate
- Social Security Information
- Medicaid Information
- Home and Community Based Waivers Information
- Letter of Intent

You may want to consider another binder for Transition with sections such as:

- Contact log people that support your adolescent or young adult
- Post Secondary Goals from the Transition Plan
- IEP Goals
- Transition Plan Tracker – to log progress
- Community Living
- Employment – if applicable
- Day Programs – if applicable
- Post Secondary Education – if applicable
- Housing

You may want to consider scanning all important documents and keeping a copy on a flash drive as back up. As with many large tasks or projects the transition process is best managed in shorter segments, the same is true with keeping the process organized. If possible, try and set aside a little time each month to keep the paperwork updated and organized so that it does not become overwhelming.

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Individual Transition Plan (ITP) Tracker

Date	Activity	Goals Mastered	Goals Making Progress	Goals Just Started	Goals Not Started
9/6/10	Started program	0	0	10	6
11/6/10	Team Meeting Review	2	10	3	3
1/6/11	Team Meeting Review	4	10	2	1

Transition Planning Tool

Agency and Contact	***Phone Number***	***Date Called***	***Service Requested***	***Appointment Date***	***Documents Needed***	***Status***	***Follow – Up***
Supplemental Security Income (SSI)	800-555-1212	1/7/	Begin Application for SSI	9/9/2010	Social Security Card Birth Certificate	Priority	Who is going to be payor?

Important Contacts

Important contacts may include friends and family of the individual with autism and people involved in person-centered planning.

Name	Type of Contact	Phone Number	Address	E-mail Address	Notes

CONCLUSION

As you can see after reading this kit, there are many factors that go into making the transition to adulthood as effective and successful as possible for a young adult with autism. Every individual with autism is different, so each adolescent and young adult will require different supports and services throughout the transition process. It is so important to start early, evaluate your child's likes and dislikes, strengths and weaknesses, and make a plan to help create as independent and enjoyable of a life as possible for him or her. The future may seem uncertain and scary right now, but taking the proper steps during the transition to adulthood will help ease these fears.

There is plenty of information in this kit that we hope will help you find the resources and supports you need during this time critical time in your adolescent's life. Be sure to check the timeline we have provided for the transition process in your specific state, and use it as a guide to help you navigate this process. Remember to involve your young adult in the journey to adulthood as best you can. In order to one day live an independent life, an individual with autism must have as much of a say as possible in decisions made regarding his or her future. It is critical to teach young adults with autism how to advocate for themselves, and ensure that they know how to get not just the services they might need, but the services they want as well. This process will take time, but if you start early and take the right steps, you will be able to successfully lay the foundation for the future of your young adult with autism.

We hope this kit has served its purpose in helping you and your young adult with autism travel the road to a happy and fulfilling adult life! We welcome any feedback or input that you would like to provide in order to make this kit as helpful as possible. Please email us at TransitionToolKit@AutismSpeaks.org.

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RESOURCES

In addition to the resources at the end of each section, below is a listing of some books and websites that provide information about the transition process and adult life. Please feel free to submit additional resources that may be helpful by e-mailing us at TransitionToolKit@AutismSpeaks.org

Books and Tool Kits

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

Autism & the Transition to Adulthood: Success Beyond the Classroom
by Paul Wehman, Marcia Datlow Smith, Carol Schall
Publisher: Woodbine House

Essentials of Transition Planning
By Paul Wehman
Publisher: Paul H. Brookes Publishing Co.

Guiding Your Teenager with Special Needs Through the Transition from School to Adult Life: Tools for Parents
by Mary Korpi
Publisher: Jessica Kingley Publishers

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

Websites

Advancing Futures for Adults with Autism
www.afaa-us.org

Autism Speaks: The Autism Safety Project
www.AutismSafetyProject.org

Autism Speaks
www.AutismSpeaks.org

The Daniel Jordan Fiddle Foundation
www.djfiddlefoundation.org

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National Dissemination Center for Children with Disabilities
http://www.nichcy.org/EducateChildren/transition_adulthood/Pages/Default.aspx

National Secondary Transition Technical Assistance Center
http://www.nsttac.org

Organization for Autism Research (OAR)
www.researchautism.org

Southwest Autism Research and Resource Center (SARRC)
http://www.autismcenter.org

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Our Mission

At Autism Speaks, our goal is to change the future for all who struggle with autism spectrum disorders.

We are dedicated to funding global biomedical research into the causes, prevention, treatments, and cure for autism; to raising public awareness about autism and its effects on individuals, families, and society; and to bringing hope to all who deal with the hardships of this disorder. We are committed to raising the funds necessary to support these goals.

Autism Speaks aims to bring the autism community together as one strong voice to urge the government and private sector to listen to our concerns and take action to address this urgent global health crisis. It is our firm belief that, working together, we will find the missing pieces of the puzzle.

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