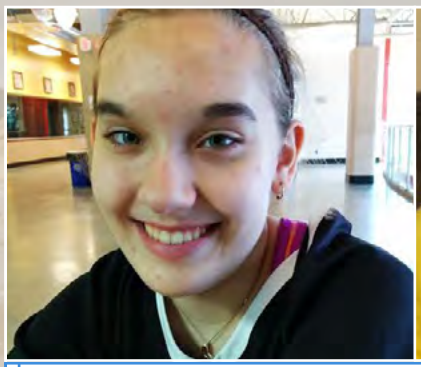

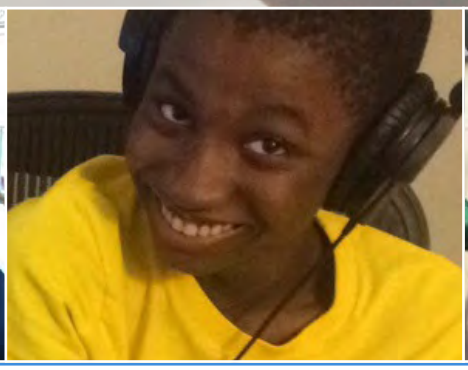

Transition Tool Kit

For Families on the Journey from Adolescence to Adulthood

AUTISM SPEAKS® FAMILY SERVICES

It's time to listen.

The Transition Tool Kit is designed to assist families of individuals with autism on the journey from adolescence to adulthood.

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ACKNOWLEDGEMENTS

Autism Speaks would like to extend special thanks to the Parent Advisory Committee for the time and effort that they put into reviewing the Transition Tool Kit.

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We wish to express our appreciation and gratitude to all of the adolescents and young adults with autism spectrum disorders and their families for their perseverance and inspiration.

Autism Speaks thanks the following supporters whose generous contributions helped to fund Version 1.0 of the Transition Tool Kit in 2011:

- Bank of America

- NYSE Euronext Foundation

- MassMutual Financial Group

- The Karma Foundation

- Susan Logan Evensen and Peter Evensen

- Jenny and Joe Zarrilli

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Introduction

The future can often seem uncertain for a young adult with autism. 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. Many families have spent years researching, negotiating and advocating for services and supports to maximize their child's potential during his or her school years. And the thought of doing this again with a whole new system can seem daunting.

To ease your fears and help you start developing your child's transition plan, you have come to the right place!

As overwhelmed as you might be, try to be positive when thinking about the future. Take a look back and think about all of the strides that your child has made so far, and how much you have learned along the way. One lesson you may have learned over and over is the importance of being proactive.

Keep in mind, too, that many others have traveled this road before you, and lots of information and resources have been developed to help you along the way. Additionally, experts in the field have researched and investigated the process and we have compiled a great deal of this information and many of these resources into this guide. 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 like your child!

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 a life filled with purpose, dignity, choices and happiness.

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

This kit will provide you with suggestions and options for you to consider as you set out on this journey toward finding your child's own unique path to adulthood.

With the importance of finding your child's own specific path in mind, the development of self-advocacy and independent living skills is highlighted throughout this kit. We have broken the kit down into different sections. At the end of the kit, we have provided resources specific to each section. 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.

When it comes to transition planning, it can be helpful to start thinking about the future as early as possible. Some parents even start the transition conversation with their child's school by age 12 or 13. And while it is never too early to think about the future of your child, if your child is older and close to finishing high school or aging out of the school system, rest assured that it is also never too late!

It can also help to work backwards. Think about where you see your child in the future based on his or her strengths, challenges, abilities and preferences. What type of job will he or she have? Where will he or she live? The transition plan should be developed and then adjusted through the years with these ultimate goals in mind. Where do you see your child in ten years? To get there, where do you see him or her in five years? Two years? Six months? Working backwards can help you stay on track and take the necessary steps now to get to the future you and your child dream of.

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: that your young adult with autism will lead a fulfilling and happy adult life. With some planning and collaborative efforts with your child, family members, educators and other professionals involved in his or her life, you will succeed in accomplishing this goal!

Happy reading!

Self-Advocacy

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

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.

Remember that transition planning is not a single conversation, but rather a process that will evolve over time.

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.

What is Self-Advocacy?

For most of your child's life, you have probably been doing the advocating – making decisions for him or her and making sure your child has gotten what he or she needs, wants and deserves. However, as individuals with autism age, they will need to learn 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 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.

- Valerie Paradiz, Ph.D., *The Integrated Self-Advocacy Curriculum*

Self-advocacy involves speaking up for yourself, asking for what you need, negotiating for yourself, knowing your rights and responsibilities and using the resources that are available to you. It is never too early to begin to teach self-advocacy skills. 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.

Disclosure

It is important to note that part of self-advocacy may involve disclosure. Therefore, it is important that an adolescent be told that he or she has autism. Be sure to share with your child or adolescent that autism has provided him or her with strengths, as well as certain challenges. Each person will react differently, but many individuals with autism have shared that they were relieved to know that there is a label for what may make things more difficult. These individuals realized that their challenges are not due to any fault of their own, but only because their brains work differently. It may be helpful for the individual to join a support or social skills group for those with similar abilities. You may be able to find groups in your area in the Autism Speaks Resource Guide at **AutismSpeaks.org/resource-guide**.

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.

How Do We Teach Self-Advocacy Skills?

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. Teaching self-advocacy skills will be a process and it will take time to acquire these skills.

It is important to teach your child or adolescent about the decision-making process, i.e. clearly defining the decision, weighing pros and cons and learning from each choice for next time. Start with decisions as simple as what clothes to wear each day. You can eventually build up to decisions about making his or her own schedule, all the way up to decisions like what therapists to work with and what topics should be discussed at an IEP meeting.

There are several tools that are available to help you and your child think about what he or she wants and build the skills necessary to communicate his or her desires for the future. See the Resource section of this tool kit for more information.

Person-Centered Planning

As mentioned, the development of the transition plan should be driven by your child's desires, preferences, strengths and challenges. This is the theory behind person-centered planning.

The process usually starts with an initial team meeting to identify opportunities for the focus person to participate in the community, find employment or postsecondary education and live as independently as possible. To the best of his or her ability, your child should play a central role in the meeting. He or she should even choose who to invite to this meeting – this might be family members, friends, teachers, therapists, etc. The process will provide you and your adolescent with a vision for his or her future and some specific steps to get there. Team members are responsible for implementing the strategies discussed in planning meetings. It is best to prepare your child as much as possible for these meetings so he or she is able to participate as much as possible.

More information about person-centered planning can be found on the PACER Center website and individuals and families can get assistance with person-centered planning by contacting their local University Center on Excellence in Developmental Disabilities or Parent Training and Information Center.

There are several person-centered planning tools available to families. Below is information about two tools that families have found helpful.

PATH: Planning Alternative Tomorrows with Hope

PATH is a person-centered planning and goal-setting tool used to map out a vision of a desirable future for the individual. This tool helps families to think about the future and then work backwards to determine the steps necessary to achieve that future.

PATH, developed by Jack Pearpoint, John O'Brien and Marsha Forest, starts with identifying the individual's "dream" and creating a portrait for the future he or she desires. Based on this ultimate vision, the team then thinks about the goals for 1-2 years ahead, followed by the next few months and continuing to the present. The team next determines the immediate steps that should be taken to achieve that long-term vision.

PATH resources can be found at inclusion.com/path.html.

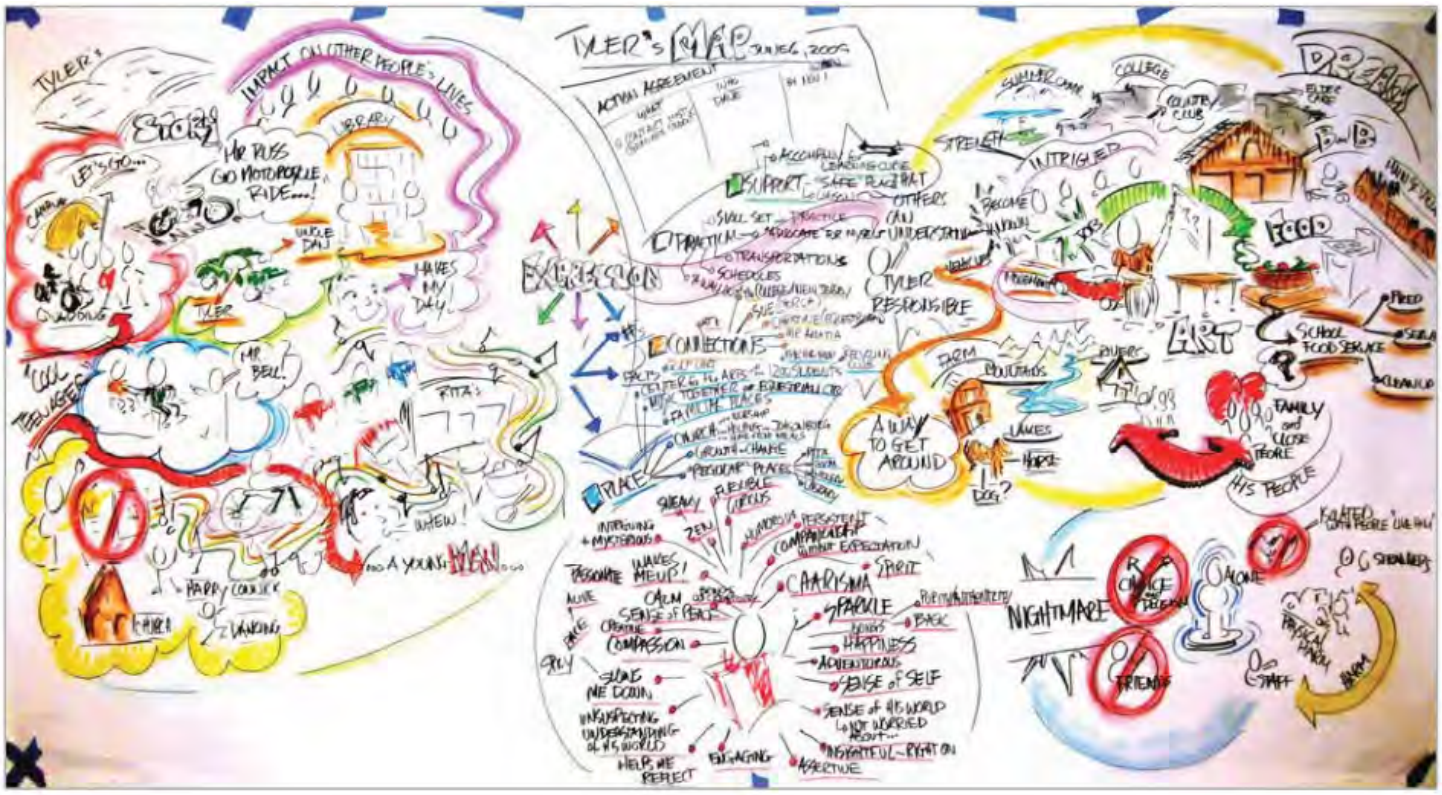
MAPS: Making Action Plans

MAPS is a collaborative action planning process used to help an individual create a plan for his or her own life. During the meeting, the team develops a MAP to serve as the compass that points in the direction of a positive future for the individual with autism. Some essential elements of a MAP meeting include a personal and informal atmosphere, the presence and participation of the focus person and the key actors in his or her life, the discussion of key issues and the development of a concrete plan of action to begin right away.

There are eight questions that should be covered by the facilitator in the MAPS meeting, divided into 2 parts:

PART I

1) **What is a MAP?**
2) **What is the person's story?**
3) **What is your dream?**
4) **What is your nightmare?**



This is an example of map planning.

PART II

5) **Who is the person?**
6) **What are the person's talents, gifts and strengths?**
7) **What are the person's likes and needs?**
8) **What is the plan of action?**

The answers to these questions should drive the development of a MAP for the individual. Above is an example of the MAP of an adolescent with autism: MAPS information and resources can be found at **inclusion.com/maps.html**.

Conclusion

So when thinking about all aspects of transition planning, keep in mind that teaching your child to advocate for him or herself can make a big difference in helping him or her to secure the supports and services needed to live the life that he or she wants and deserves. It may seem overwhelming to you to think about teaching these important skills, but remember that you can start very small and build upon these skills gradually and to the best of your child's ability. Even just teaching your child that he or she has the right to make or contribute to decisions big and small can go a long way. You may not think your child has the ability to make decisions for him or herself, but remember that even though it may not be easy to communicate them, your child has thoughts and feelings just like any other young adult who wants to shape his or her own future.

Start small, start early and you can succeed in providing your child with a life of happiness and dignity.

Developing Independent Living Skills

In addition to self-advocacy skills, teaching your child skills that will foster his or her independence on the journey to adulthood is also of utmost importance. As autism is a spectrum disorder, every individual is different, and as a result, the independent living skills that will be taught, as well as the pace at which they are taught, will vary significantly across the spectrum. For example, one young adult with autism may ultimately be able to live on his or her own with very little, if any, outside support, while another may require supports and services 24 hours a day, 7 days a week.

As with self-advocacy, starting to develop independence skills to the best of your child's ability at a young age will make a difference in terms of the ease of this transition period. Building these skills little by little is an effective way to teach skills you may not have thought your child would need one day.

Teaching your child independent living skills - home living, personal care, etc. - can be easier said than done, especially if he or she is accustomed to having things done for him or her. You may be rushed, your child may be fighting you every step of the way, you may be too exhausted, but teaching life skills early on is an important part of raising a child with autism.

Ten Ways to Build Independence

This list from Autism Speaks Autism Response Team member Emily Mulligan provides information on how you can help your child increase his or her independence at home, at school and in the community. By introducing these skills early and building block by

block, you can help your loved one with autism gain the tools that will allow him or her to be more independent throughout his or her life.

1. Strengthen Communication

If your child struggles with spoken language, a critical step for increasing independence is strengthening his or her ability to communicate by building skills and providing tools to help express preferences, desires and feelings. Consider introducing Alternative/Augmentative Communication (AAC) and visual supports. Common types of AAC include picture exchange communication systems (PECS), speech output devices (such as DynaVox, iPad, etc.) and sign language.

2. Introduce a Visual Schedule

Using a visual schedule with your child can help the transition from activity to activity with less prompting. Review each item on the schedule with your child and then remind him or her to check the schedule before every transition. Over time, he or she will be able to complete this task with increasing independence, practice decision making and pursue the activities that interest him or her. You can learn more about using visual supports by downloading the **ATN/AIR-P Visual Supports and Autism Spectrum Disorder Tool Kit.**

3. Work on Self-Care Skills

This is a good age to introduce self-care activities into your child's routine. Brushing teeth, combing hair and other activities of daily living (ADLs) are important life skills, and introducing them as early as possible can allow your child to master them down the line. Make sure to include these things on your child's schedule so he or she gets used to having them as part of the daily routine.

4. Teach Your Child to Ask for a Break

Make sure your child has a way to request a break – add a "Break" button on his or her communication device, a picture in his or her PECS book, etc. Identify an area that is quiet where your child can go when feeling overwhelmed. Alternatively, consider offering headphones or other tools to help regulate sensory input. Although it may seem like a simple thing, knowing how to ask for a break can allow your child to regain control over him or herself and his or her environment.

5. Work on Household Chores

Having children complete household chores can teach them responsibility, get them involved in family routines and impart useful skills to take with them as they get older. If you think your child may have trouble understanding how to complete a whole chore, you can consider using a task analysis. This is a method that involves breaking down large tasks into smaller steps. Be sure to model the steps yourself or provide prompts if your child has trouble at first! Also, try using **My Job Chart**: a great tool to help both kids and adults learn to complete tasks and manage time.

6. Practice Money Skills

Learning how to use money is a very important skill that can help your child become independent when out and about in the community. No matter what abilities your child currently has, there are ways that he or she can begin to learn money skills. At school, consider adding money skills to your child's IEP and when you are with your child in a store or supermarket, allow him and her to hand over the money to the cashier. Step by step, you can teach each part of this process. Your child can then begin using these skills in different settings in the community.

7. Teach Community Safety Skills

Safety is a big concern for many families, especially as children become more independent. Teach and practice travel training including pedestrian safety, identifying signs and other important safety markers; and becoming familiar with public transportation. The **GET Going pocket guide** has many useful tips to help individuals with autism navigate public transportation. Consider having your child carry an ID card which can be very helpful to provide his or her name, a brief explanation of his or her diagnosis, and a contact person. You can find examples of ID cards and other great safety materials.

8. Build Leisure Skills

Being able to engage in independent leisure and recreation is something that will serve your child well throughout his or her life. Many people with autism have special interests in one or two subjects; it can help to translate those interests into age appropriate recreational activities. The **Autism Speaks Resource Guide** contains activities that your child can get involved with in your community; including team sports, swim lessons, martial arts, music groups and more. For more information about participation in youth and community organizations, see the **Autism Speaks Leading the Way: Autism-Friendly Youth Organizations guide**.

9. Teach Self-Care during Adolescence

Entering adolescence and beginning puberty can bring many changes for a teen with autism, so this is an important time to introduce many hygiene and self-care skills. Getting your teens into the habit of self-care will set them up for success and allow them to become much more independent as they approach adulthood. Visual aids can be really useful to help your teen complete his or her personal hygiene routine each day. Consider making a checklist of activities to help your child keep track of what to do and post it in the bathroom. This can include items such as showering, washing face, putting on deodorant and brushing hair. To stay organized, you can put together a hygiene "kit" to keep everything your teen needs in one place.

10. Work on Vocational Skills

Starting at age 14, your child should have some vocational skills included on his or her IEP. Make a list of his or her strengths, skills and interests and use them to guide the type of vocational activities that are included as objectives. This is also a time to start planning for the future. Consider all of the ways up to this point that you have been fostering your child's independence: communication abilities, self-care, interests and activities and goals for the future. The **Community-based Skills Assessment** (CSA) can help you evaluate your child's current skills and abilities to create an individualized transition plan.

Teaching Daily Living Skills

A 2015 study funded by Autism Speaks and Foundation of Hope, presented at the International Meeting for Autism Research (IMFAR), found that the single most important predictor of positive outcomes in adulthood is the mastery of self-care skills such as bathing, dressing, cleaning and cooking. According to the researchers who tracked children with autism into middle adulthood, these skills prove more important than language, intellectual ability or the severity of autism symptoms when it comes to maintaining employment and achieving life satisfaction.

> **We can't necessarily change IQ or symptom severity, but we can teach daily living skills.**
>
> *Laura Kling, lead researcher, University of North Carolina's TEACCH Autism Program*

One tip for teaching independence skills like self-care is to think of the specific skill you'd like your child to learn and work backwards so that you can break down lessons piece by piece and eventually build to your goal. For example, if you are teaching your child to bathe on his or her own, you can teach him or her step-by-step, gradually lowering your involvement in the process:

1. **Identify when a shower is necessary.**
2. **Turn on the shower.**
3. **Find the desired water temperature.**
4. **Use soap to wash arms, legs and stomach.**
5. **Use soap to wash underarms and private parts thoroughly.**
6. **Wet and use shampoo to wash hair.**
7. **Rinse off soap and shampoo until no more bubbles.**
8. **Turn off the shower.**
9. **Dry off with towel.**
10. **Get dressed.**

Be sure to reinforce your child with positive feedback once he or she masters each step. Motivation is critical to learning and as your child becomes familiar and more competent with new skills, confidence, interest and motivation will increase. Keep in mind that each step might take a long time, some more than others, but the ultimate goal remains the same – to teach your child appropriate self-care and hygiene, an important skill as he or she ages into young adulthood.

Conclusion

Whether your child will move on to postsecondary education, live in a group home or continue to live with you and your family, independence skills are important for individuals with autism of all ages and abilities. You may look at your child and think that the challenges he or she faces will keep him or her from learning any skills that foster independence. At times along the way, you may feel frustrated with the progress or lack thereof, but keep trying and little by little, your child will learn some of these skills. Celebrate the little things and don't dwell on the bumps in the road.

Be patient. Remember, the transition to adulthood, and teaching the skills that go along with it, is a marathon, not a sprint!

Planning for Transition

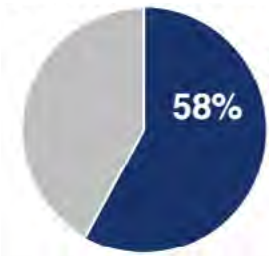
When thinking about the transition process, a great place to start is by consulting with your child's school. Whether it is a school counselor, school psychologist, teacher, case manager or school administrator, a school professional with experience can be very helpful in getting the ball rolling when it comes to planning for the transition to adulthood.

As you have hopefully learned throughout your child's school years, 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 also 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 should begin a few years before that. The funding and services available through IDEA are not available once the student has received a high school diploma or aged out of the school system, so it is important to take advantage of these services when they are available.

Federal law requires schools to have a transition plan for every special education student exiting high school.



of youth with autism had a transition plan by the required age according to their teachers.

Source: National Autism Indicators Report Transition into Young Adulthood. AJ. Drexel Autism Institute, Drexel University.

Transition Planning and the IEP

As outlined in Section 300.43 of IDEA, transition services means a coordinated set of activities for a child that…

1. **Is designed to be within a results-oriented process that is focused on improving the academic and functional achievement of the child 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:**
   - 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

The transition process will continue to evolve, as the transition plan is a work in progress that should be monitored several times a year. You and your adolescent will continue to learn and grow during this process, and you will need to adjust your plan accordingly.

Getting Started: Preparing for the Transition IEP Meeting

As far in advance of the first meeting as possible, you should talk with your adolescent about what he or she may want to do in the future. While out in the community, you can identify different jobs or activities that may be of interest to him or her. It is important to remember that the future may seem like a scary topic for adolescents with autism to discuss and they may not be ready. Some families have shared that they scheduled a specific day of the week and a specific time to discuss future plans with their young adult. 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 plan should be shared with the transition IEP team prior to the meeting. There are also several tools available to help prepare for the meeting – two such tools are *It's My Choice*, a transition workbook from the Minnesota Governor's Council on Developmental Disabilities; and Chapter 3 of *Keeping It Real* on the Elizabeth M. Boggs Center on Developmental Disabilities website. Both can be found in the resource section of this kit.

> **Life for all adults, autistic or not,** is very much about this ongoing process of identifying and making adjustments when they need to be made. Every person with autism has a path; making the adjustments is the journey.
>
> *– Valerie Paradiz, Ph.D.*

Assessments

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

Level I Assessment:

- Parents, students and teachers all complete a questionnaire to help them focus on the student's long term career goals
- Helps explore possible areas of interest that can be used in the transition plan
- Should be updated yearly

Level II Assessments:

- Parents, students and teachers provide feedback as to a student's skills and aptitudes when compared to his or her peers
- Can often help pinpoint areas where further skills can be developed

Level III Assessments:

- Student tries out different areas of work in different settings with the proper supports in place (situational assessment)
- Allowed students to get some hands-on work experience and see what they enjoy and in what fields they excel
- Staff on hand assesses the student's response to each environment
- For students who do not perform well on tests or thrive in testing environments

The Community-based Skills Assessment, developed for Autism Speaks through a contract with Virginia Commonwealth University's Rehabilitation Research and Training Center, can help you and your child's team develop a comprehensive personalized transition plan by assessing his or her current skill levels and abilities beginning at age 12 and continuing into adulthood. An app for the CSA is coming soon! Learn more at **autismspeaks.org/csa**.

Preparing Your Adolescent for the Transition Meeting

The transition meeting is a perfect place for your child to work on his or her self-advocacy skills. Making sure that he or she is involved in the transition process is a great way for your child to learn how to express his or her thoughts and feelings about future plans. Topics you may want to review with your child before the meeting include his or her autism, entitlements and ideas for accommodations to help provide the greatest support possible. Make sure he or she understands what an IEP is and what the purpose of the meeting is to the best of his or her ability. For those with limited verbal ability, pictures or written statements may be helpful.

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.

- Stephen Shore, Ed.D., *Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum*

Just as when transitioning to any other new activity, prepare your child in advance of the IEP meeting and describe its purpose. His or her involvement can take place on a sliding scale of responsibility. Initially and/or for students at a lower cognitive or developmental stage, familiarizing your child 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 of 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 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.**

The Transition Meeting

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

The transition IEP meeting can involve a wide array of people, including:

- **The student (as appropriate)**
- **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 who can support your child**

You may feel overwhelmed sitting at a table with all of these people making recommendations about your child's future. Remember, nothing is "written in stone" and the plan continues to be a work in progress. Goals are set in order to move forward and with a proper plan, your child will reach new vistas.

During the meeting, it is important to respect your adolescent's wishes and needs and encourage others to do so as well. Try to model appropriate behavior by addressing questions about your child to your child. If your child is having trouble answering a question, provide visual supports or choices to further encourage him or her to be an active participant in the meeting.

Many parents want to highlight their child's successes, while downplaying struggles. In believing that your adolescent has mastered a skill that may not be possible independently, you are doing him or her a disservice. 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.

Be prepared to discuss a wide variety of topics at your transition meetings – planning for adulthood requires a focus on employment, housing, community living, postsecondary education, independence and more. Lots of factors go into creating a life that allows your child to be as independent and fulfilled as possible.

Steps for Creating a Transition Plan

Several steps have been outlined that will be important in developing a transition plan:

1. **Describe the student's strengths and present levels of academic achievement and functional performance.**
2. **Develop measurable postsecondary goals based upon the student's strengths and challenges.**
3. **Develop corresponding IEP goals that will enable the student to meet his or her post-secondary goals.**
4. **Describe the transition services needed to help the student achieve his or her desired post-school goals.**

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

In addition to stating the goals, the transition plan should include logistical information on how the plan will be implemented and monitored, such as: a timeline for achieving goals, responsible people or agencies to help, clarification of how roles will be coordinated and a plan for identifying post-graduation services and supports, including methods to obtain funding to access these.

If you are not in agreement with the transition services proposed, you can try to reach an acceptable agreement with the school district. If this is not possible, you and your family have the right to go to mediation or an impartial hearing.

Diploma Options

As you plan for transition, 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 or certificate. The list below outlines some of the different types of diplomas and what opportunities they may provide for postsecondary education. Remember that each state has different options and guidelines for diplomas, so be sure to check in with your school administrators:

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

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

IEP/Local Diploma or Certificate of Completion: This diploma is awarded to students who have reached the goals on their Individualized Education Programs. It is not accepted for admission to any postsecondary degree program without other testing or certification.

Conclusion

Again, 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 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* from the Organization for Autism Research

Evidence Based Predictors for Post-School Success

Ohio Employment First Transition Framework
Evidence Based Predictors Tool

ohioemploymentfirst.org

Predictor One: Collaborative Networks for Student Support

Research shows that youth benefit from having a support network. Both 'formal' (agency based) networks and 'informal' (friends, family, community members) networks enhanced youth success.

Predictor Two: Individualized Career Development

Career Development refers to the process used by an individual to form a work identity. It is ongoing and spans a lifetime. Individualized career development means that the strategies, supports and services are selected to align with how the youth learns and also provides access to careers that reflect the youth's preferences, interests and skills.

Predictor Three: Authentic Community Based Work Experience

During the high school years, participation in real life work experiences that closely resemble adult environments has been identified as a high predictor of successful adult outcomes.

Predictor Four: Social and Social-Emotional Instruction and Skills

Social competencies are critical to successful participation in the adult community life. Employers report that inability to meet the social expectations of the community and workplace remains as a top reason why employees (disabled or not) lose their jobs.

Predictor Five: Academic, Vocational, Occupational Education and Preparation

Youth with disabilities require a well-designed, coordinated, and unique education and preparation program. The program requires aspects of academic preparation as well as vocational/ occupational preparation

Predictor Six: Supporting Parental Involvement and Expectations

Parent, guardian or other caretaker participation is essential to an individual's ongoing success. Involvement means parents/families/guardian are active and knowledgeable participants in all aspects of transition planning. Parental impact also encompasses the expectation of the family.

Predictor Seven: Self-Determination, Independent Living Skills Instruction and Skill Building

A successful adult reflects self-management and direction, often referred to as Self-Determination. Many skills can support the development of self-determination such as the ability to make choices, solve problems, set goals, evaluate options, and take initiative to reach goals, and accept the consequences of actions.

Predictor Eight: Inclusive Practices and Programs

Participation in inclusive settings during the school years provides opportunities to prepare for integration into the adult community. Inclusive practices refer to engagement and participation, not simply access to an environment.

ohioemploymentfirst.org/up_doc/Evidence_Based_Predictors_for_Post_school_Success3_25_15.pdf

Legal Matters to Consider When Planning for the Future

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. It can help to remind yourself that with planning, you will begin to feel much better about what lies ahead!

There are changes when a person with autism reaches the age of majority, which is 18 years old in most states. Parents no longer have the legal rights to which they were entitled throughout their child's youth. This can include accessing confidential health information and school records.

It can be difficult to take the first steps in planning for your child's future. By taking action early on, you can help protect your child's future well-being and rest a bit easier.

Before your child 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 involve state-administered programs, and each state sets its own guidelines. You will want to check with your state agencies for guidance.

When planning for the transition to adulthood, there are several important legal matters to think about, including health insurance laws, special needs trusts and more. This section provides an overview of these topics. More information can be found on the Autism Speaks website.

Health Insurance

Obviously a key component to think about for your child as he or she becomes an adult is health insurance. One of the most significant changes in healthcare law that came from the Affordable Care Act of 2010 is that insurers must now cover dependents on a parent or guardian's plan up to age 26, no longer age 18. Insurers cannot deny or restrict coverage based on certain factors about the child's status. To learn whether your plan or policy offers dependent coverage, check the plan materials or ask your insurer or employer.

Another significant change under the Affordable Care Act is that insurers can no longer deny coverage for pre-existing conditions, even if you have been refused coverage in the past. A diagnosis of autism has been treated as a pre-existing condition in many states and under the new law, this will not affect your child's access to health insurance.

The Affordable Care Act also allows states to choose whether to expand their Medicaid programs to low-income adults, many of whom have never been eligible for coverage before. The new law allows states to expand Medicaid coverage to most adults with incomes up to 138 percent of the poverty level. You can learn more about these options and enroll in

Medicaid at **healthcare.gov**. In addition, the Children's Health Insurance Program (CHIP) provides low-cost health coverage to families that earn too much money to qualify for Medicaid. Each state offers CHIP coverage. To learn if your child is eligible for CHIP, you can visit **insurekidsnow.gov**.

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 his or her legal guardian. There are a few options to consider:

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

There are two types of guardians. A **limited guardian** can make decisions in only some specific areas, such as medical care. This may be appropriate if the person with autism can make some decisions on his or her own. A **general guardian** has broad control and decision-making authority over the individual. This 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.

With **conservatorship**, 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.

With a **Power of Attorney** (POA), your child will need to appoint you as the authority to make decisions on his or her behalf under agreed upon terms in the legal document. Unlike guardianship, with a Power of Attorney, courts are not involved and the arrangement is often simpler and easier to change. The individual maintains more control over decisions than with a guardianship arrangement and as a result, this option is more common among more independent individuals.

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 your child 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 assistance.

The below list covers some of those areas – for each area, assess whether he or she can do the following:

Medical

- Seek medical care when he or she is sick or injured
- 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 learning problems and understand the services needed to learn effectively
- Advocate for him 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 Department of Disability Services, Department 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

- Understand 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.

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 or 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 one with expertise in this area. Each family is unique in that there are many significant choices and decisions to be made in the process and an attorney can help you with those. You can search for an attorney in your area by visiting the Autism Speaks Resource Guide at **autismspeaks.org/resource-guide**.

Conservatorship

Conservatorships must be filed in the 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 the lifetime of the individual.

Special Needs Trusts

The information below comes from Autism Speaks' Legal Guide provided by the law firm Goodwin Procter LLP:

A Special Needs Trust is a trust to hold assets for a special needs beneficiary. Such trusts can be used for an individual receiving public benefits, such as SSI or Medicaid, in order to supplement his or her income without impacting eligibility to receive benefits.

A Special Needs Trust can ensure that money will be available for your child throughout his or her lifetime and that such money will not impact his or her access to means-tested benefits. The trustee, often the parent, is designated to manage the trust for the benefit of the child.

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 individual.

(2) A Self-Settled Special Needs Trust is designed to hold property belonging to the individual.

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 and 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 stand alone from any other living trust your family may have.
- The trust is irrevocable in your child's name once funded. But the trust owns the assets, not the child.

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). In order for your child to qualify for these programs, he or she must meet the Social Security Administration's definition of disabled.

The SSA's 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.)

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

Not all children who receive special education services may be considered disabled under the SSA definition. Even if your family is receiving SSI for your child when he or she is under the age of 18, you will need to go through a redetermination process to maintain his or her SSI benefits as an adult.

To determine if your child meets the criteria, you must submit his or her detailed medical records, along with a list of all current medications, as well as all doctors, hospitals, clinics and specialists that he or she has visited. In addition, he or she will be asked to go through an examination paid for by the SSA. This process can take several months.

Social Security Income (SSI)

SSI is available to people whose disabilities prevent them from gainful employment. In order to be eligible, your child must not have greater than $2,000 in countable resources and must have a limited monthly income.

At age 18, your family's income and resources are not counted, even if your child continues to live at home. The amount of benefits is determined by a number of factors, including where your child lives and what other income he or she may have.

Social Security Disability Insurance (SSDI)

SSDI provides income supplements to people who are restricted in their ability to be employed because of a disability. Unlike SSI, this benefit is available regardless of the individual's income and resources.

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.

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. If you are seeking to become the rep-payee for your child's benefits, you must file an application in person with the SSA. You can be established as a rep-payee without gaining guardianship over your child. If he or she does not have income or resources aside from the Social Security benefits, you may prefer to avoid guardianship appointment and pursue the simpler rep-payee process instead.

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

Appealing Decisions

If the SSA rejects your child's application for SSI or SSDI benefits, or it simply reduces benefits, you 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: You may ask for your child's case to be reviewed by the person who originally decided it.

Appeals Hearing: If you are denied benefits again in reconsideration, you can request a hearing before an Administrative Law Judge who will listen to testimony and review any additional documents that may help your child's case. At this hearing, you have the right to bring a representative.

Appeals Council Review: You have the right to appeal the decision of the Administrative Law Judge to the Appeals Council which will review your file but not hear new testimony.

Federal Court: If the Appeals Council rejects your application, you may then file an appeal in the U.S. court system.

Medicaid Benefits

Individuals who qualify for SSI are eligible to receive Medicaid, which 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.

Medicaid Eligibility:

Categorical: Persons who fit in a specific category for whom federal law permits coverage (age 65 or above, blind, disabled, etc.)

Financial: Persons whose income and assets do not exceed the state threshold

Home and Community-Based Waiver Services

In the past, Medicaid funding was limited to those who live in certain types of facilities. But now, through the use of Medicaid Home and Community-Based Waivers, people with autism and other disabilities can use these funds more flexibly. Waiver services are 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.

These programs may provide a combination of both traditional medical services (dental services, skilled nursing services) and non-medical services (respite, case management, environmental modifications, etc.). Family members and friends may be providers of waiver services if they meet the specified provider qualifications.

Each state set its own guidelines.

All states operate HCBS programs for people with developmental disabilities (some states also have specific HCBS waivers for people with autism). Services in HCBS waivers vary across waivers and states but may include respite, employment supports, residential services (e.g. group homes, supported living, etc.), family support and many other community supports. The state Medicaid agency or the state Developmental Disabilities agency is usually responsible for the operation, eligibility and enrollment into these programs – individuals interested in waiver services should contact these agencies to find out about enrolling and/or placing their name on the waiting list.

Other Legal Considerations

- Obtain a state identification card or driver's license from the Bureau of Motor Vehicles.
- Register for Selective Services. (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 sss.gov.)
- Register to vote.
- Explore options for transportation, including driver's training.

Achieving a Better Life Experience (ABLE) Act of 2014

The Achieving a Better Life Experience (ABLE) Act, passed by Congress and signed by President Obama in December 2014, allows people with disabilities and their families to set up a special savings account for disability-related expenses, similar to the current 529 education savings plans that help families save for college.

Earnings on an ABLE account are not taxed and account funds are generally not considered for the SSI program, Medicaid and other federal means-tested benefits, which generally cap (usually at $2,000) the amount an individual with a disability may save. An eligible individual is someone who becomes disabled before age 26 and (1) receives SSDI or SSI; or (2) files a disability certification under IRS rules.

Expenses made for the benefit of a disabled individual include education, housing, transportation, employment training and support; assistive technology and personal support services; health, prevention, and wellness; financial management and administrative services; legal fees; expenses for oversight and monitoring; funeral and burial expenses; and any other expenses approved under regulations.
It is important to keep in mind that individual states may regulate ABLE accounts differently.

You can learn more about the ABLE Act and check on its status in your state at autismspeaks.org/advocacy/federal/able.

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, current status and your hopes for his or her future.

You might want to start the letter now and add to it as years go by, updating it when information about your child changes. It is also a good idea to involve your child when writing the letter, so that the letter truly "presents" and represents your child, to the best of his or her ability. 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.

The letter is not a legal document, but it can provide the courts and others with insight and knowledge about the best possible care for your child.

Conclusion

As you can see, there are many factors to consider when thinking about long-term planning for your child's future. This information may seem overwhelming, but if you start early, you will feel better prepared for the time when he or she transitions into the world of adulthood. Determining finances, benefits and decision-making, or even starting the conversation about these important issues when your child is still young, can help ensure the correct services and supports are in place in advance. Keep in mind you have successfully navigated your child through the special education system and other childhood-related issues, now it is time for step two.

And with effort and work, you can be sure your child will be equally supported and provided for as an adult!

Community Living

As you plan for the transition to adulthood, 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. You may want to think early on about introducing your child to members of the community. 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.

Whether your child 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

There are a number of programs available that vary from athletic to creative, one-on-one instruction to full inclusion, recreational to competitive. Some things you may want to think about:

What are your child's likes and dislikes?

What makes your child tick or motivates him or her?

What are your goals for your child with this activity? (e.g. 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?

Does your child need a one-on-one aide to participate?

Answering these question will help you and your child decide on which activities will make him or her the happiest and which will help most with integration into the community.

Community Activities

There are many opportunities for individuals with autism in most communities. These may include:

Public/private facilities: pools, parks, YMCAs, fitness clubs, programs at local universities

Exercise and sports

Hobbies, games, arts and crafts

Social events

Youth groups or religious community activities

Special Olympics

Title II of the American 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.

Prepare your child for participation in these activities with social stories, schedules, behaviors to expect, etc. In some cases, it may be helpful to have an aide who knows your child to go with him or her to the sessions in order to ensure that participation in the activity is a success. In addition, before you register for an activity, it is important that you speak to the activity leader about your child's positive attributes, as well as his or her challenges. If necessary, ask if you can bring him or her on a trial basis and arrange the most practical time.

For a list of recreational opportunities in your area, search the Autism Speaks Resource Guide at **autismspeaks.org/resource-guide**. You can also search the Autism Speaks Grants database for recreational programs Autism Speaks has funded for young adults near you at **science.grants.autismspeaks.org/search**.

Below is an example of a community life experience by Robyn Schneider, mother of Alex and Jamie, two young men with autism. Robyn is the author of *Silent Running: Our Family's Journey to the Finish Line 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!

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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!

Travel Training

The issue of transportation is an important part of allowing your child to integrate into the community. In order to be able to gain more independence and greater access to the community, travel training is very important. Travel training should begin at an early age to get your child as prepared as possible for community life.

You should be aware that travel training is available to your child and can be part of his or her transition IEP. In addition, your state office of vocational rehabilitation can help with training your child to travel to work. Postsecondary programs often have a travel curriculum as well.

Travel training is a proactive tool that will play a big role in establishing more independence for your child. 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. Others might know everything about trains but have trouble with the hustle and bustle of a train or subway station.

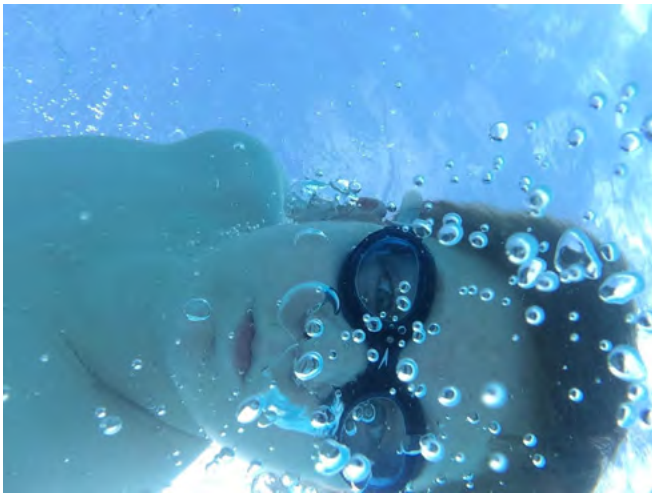
For many travel training programs, there is a prerequisite skill of being able to cross the street safely. Your child may be a pro at riding the train, but often a skill that seems as basic as crossing the street can be difficult, especially for those with autism who struggle with understanding danger. Make sure you start to teach your child this skill as early as possible. Knowing he or she has mastered this skill will make you feel more at ease when your child is out in the community.

A comprehensive approach to training is helpful because there are most often many components involved when traveling from one place to another. It is important to think about all of these factors that go into taking public transportation. Teach your child what to do in an emergency in all travel-related settings. Let him or her know what to do when lost or confused. Be sure to teach your child that there are often delays in some public transportation systems, and that traffic might affect the time it takes to get somewhere.

You may want to start small, like a weekly trip to the train station, and slowly build up to riding the train to a desired destination. The earlier you can start with these small steps, the easier it will be for your child to navigate life in the community as he or she enters adulthood.

Safety

Safety is a very real concern for all parents, but especially parents of children and adolescents with autism. Your child may be seeking more independence and as a parent, you want to foster this growth. But you may also be concerned about the many risks associated with him or her 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 basic skills to consider include the ability to:

Identify strangers

Identify community members who can offer assistance

Ask for help

Know what to do when he or she gets lost

Communicate name, address, phone number and emergency contact person – either verbally or with a card

Use a cell phone, to both call and text

Identify public versus private spaces

Navigate your neighborhood, downtown and surrounding area safely

Wandering

A 2012 study from the Interactive Autism Network found that 49% of children with autism are prone to wandering from safety. And unfortunately, many children do not grow out of this tendency as they enter adulthood. You may have heard some of the tragic stories in the news that result after an individual on the spectrum wanders from his or her home, school or the company of loved ones. Teaching the skills necessary to prevent wandering incidents at a young age will help maintain your child's safety once he or she is out in the community.

If your child has a tendency to wander, it is critical to address this issue in his or her IEP. Be sure to carefully document all wandering-related incidents so you can identify the triggers and eliminate them as much as possible. You can also practice safety skills out in the community and teach your child what to do if he or she gets lost.

Unfortunately, the leading cause of death among individuals with autism after wandering is drowning. It is critical that your child not only knows how to swim, but understands the importance of water safety. Autism Speaks provides grants to swim programs to award scholarships for swimming and water safety lessons for financially disadvantaged individuals with autism. See if there is a program near you at **autismspeaks.org/family-services/grants/swimming**.

There are also many safety products available that can help prevent wandering and respond to wandering incidents. These include locating devices, which you can use to make sure you can locate your child if he or she goes missing. There are a number of these devices available with a wide variety of features. Many people with autism carry ID cards that they can show first responders or members of the community to let them know about their autism diagnosis and may include contact information as well. You can also share this information with neighbors and other members of your community so they can keep an eye out for your child and help get him or her home if he or she wanders from safety. Find these and other safety products on the Autism Speaks website at **autismspeaks.org/family-services/resource-library/safety-products**.

Interacting with First Responders

Another important skill to teach individuals with autism to help maintain their safety in the community is how to interact with first responders. It is estimated that children and adults with autism are seven times more likely to have interactions with first responders than their typical peers. To make sure these interactions are safe and effective, it is critical to teach your child about first responders, and if possible, to teach your local first responders about your child and others with autism.

It is important that your child knows how to identify first responders and understands that these men and women are there to keep the community safe so that he or she feels comfortable approaching them if a situations arises. It might help to bring your child down to the local police station to introduce him or her to the policemen and women there so that if they meet when there is a safety issue in the community, both parties will be able to reach a safe and effective solution as soon as possible.

Providing first responders with key information before an incident occurs may improve response. You may want to develop informational handouts that contain all pertinent information to circulate to first responders, as well as family, neighbors, friends and co-workers. This might contain information about your child's challenges, other medical conditions, the most effective ways to communicate with him or her, favorite attractions where he or she might be found and more. Autism Speaks offers safety trainings as well as first responder trainings and has a wide variety of resources for both families and first responders. Find them at **autismspeaks.org/safety**.

Preventing Abuse

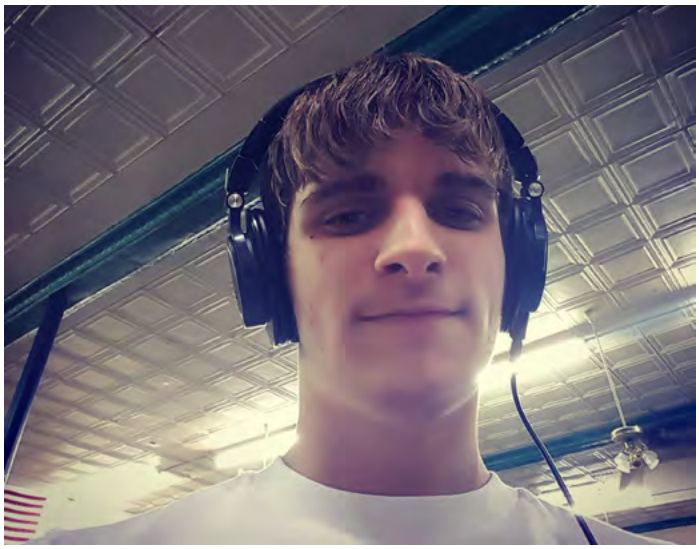
Sadly, individuals with disabilities are far more likely to be victims of abuse of all types than their typical peers. Many abuse cases are never reported because the individual may not be aware that another's actions are constituting abuse, may not be able to communicate the abuse to his or her parents or may feel ashamed and not want to share the information. It is important to teach individuals with autism from an early age what is appropriate versus inappropriate treatment by others so they can easily identify when they are being abused, emotionally, physically, sexually, etc. Make sure your child understands that abuse comes in many forms and can identify the red flags and feel comfortable telling you if suspicions arise that he or she might be a victim of abuse.

In terms of sexual abuse, an important factor in preventing it is teaching your child about sexuality and the difference between public and private places and between “okay” and “not okay” touches. While many children learn about sexuality through movies, magazines or gossip at school, children with autism often need to be taught more explicitly about issues related to sex and puberty, especially because they are more likely to be sexually abused. Teach your child very concretely about boundaries and personal safety, and make sure he or she feels empowered to make decisions about his or her own body. It is important that your child understands that saying “no!” is okay when he or she feels scared or threatened by someone else.

Educate yourself on how to identify warning signs and how to report it if you suspect abuse or neglect. It is important to trust your instincts! If you have a suspicious or uneasy feeling about the way your child is being treated in the community, speak up. Encourage your child to share his or her feelings with you and keep the lines of communication constantly open so he or she can more easily report if something is wrong. Learn more about sexuality education in the Health section of this tool kit.

It is important to note that abuse is most often committed by people known to the child (a family member, staffer, respite care provider, etc.). Shockingly, research suggests that 97 to 99 percent of abusers are known and trusted by the victim. Make sure you evaluate the relationships your child has with the people in his or her life and be on the lookout for warning signs. When teaching your child about boundaries, make sure you emphasize how there are different boundaries for different people – for example, your sister can hug you but an aide at your school should not; only Mom, Dad and Dr. Smith are allowed to see your private parts.

As with so many other topics in this kit, self-advocacy skills play a role in preventing your child from becoming a victim. If he or she is able to “speak up” or express his or her feelings in the best way possible when an uncomfortable situation arises, your child will be less vulnerable to abuse. Start teaching your child as early as possible about the dangers of abuse



and helping him or her build the skills necessary to keep it from happening. Learn more at **autismspeaks.org/family-services/autism-safety-project/abuse**.

Conclusion

It is essential to keep in mind that community integration is a big part of life for all people and that your child with autism is no different. It may seem like a far off thought, but it is important to teach your child at a young age about the skills he or she will need to become a part of his or her community as a young adult and adult. Lessons like social skills, travel training, safety precautions and abuse prevention education can start small and build gradually over time. These skills take time to learn so keep in mind that patience is key! The better prepared that he or she is, the more likely it is that your child will one day thrive as a member of his or her community.

Employment and Other Options

For many of us, our job represents 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, volunteer opportunities, internships, job sampling and job matching all play important roles in preparing a young adult for employment.

Preparation

While your child is still in high school, you may want to begin the process of learning and educating him or her about possible future careers. Go over the various types of jobs available with your child and start to make a list of those that might match his or her interests and strengths. Try to expose him or her to those specific career areas as much as possible, and continue to build upon the skills that will allow him or her to succeed in the workplace.

Work experience while your child is still in school is an important way to help you understand his or her strengths and challenges within different types of work. Examples of ways to explore careers while still in school include volunteer opportunities, internships and job sampling. There may even be opportunities at school to practice work – such as general office tasks, working in the school store or helping out at after school programs for younger children.

Experiences such as internships can often help with skill building, job training and eventually the job application process. Your child may be able to connect to a peer or mentor at the internship or volunteer site who can lend a hand if needed. For young adults with autism who have more significant challenges, job coaches can help them reach their full potential. A job coach will assist your child in obtaining a job and provide onsite support and assistance. Your school district may be able to help you find an agency that can supply a job coach.

It is also important to keep in mind when exploring career opportunities that your child may need to build up the endurance and stamina needed to complete his or her workday. It may be helpful to start with one hour per week and slowly build up to more hours on multiple days per week. You will know best what your child is able to do at work, but don't be afraid to gradually build his or her endurance until an adequate level is reached for him or her to accomplish career goals.

Types of Employment

There are many different employment options for individuals with autism. It is important to note that a young adult on the spectrum can go from one type of employment option to another over time.

Below is a list of several possible types of employment:

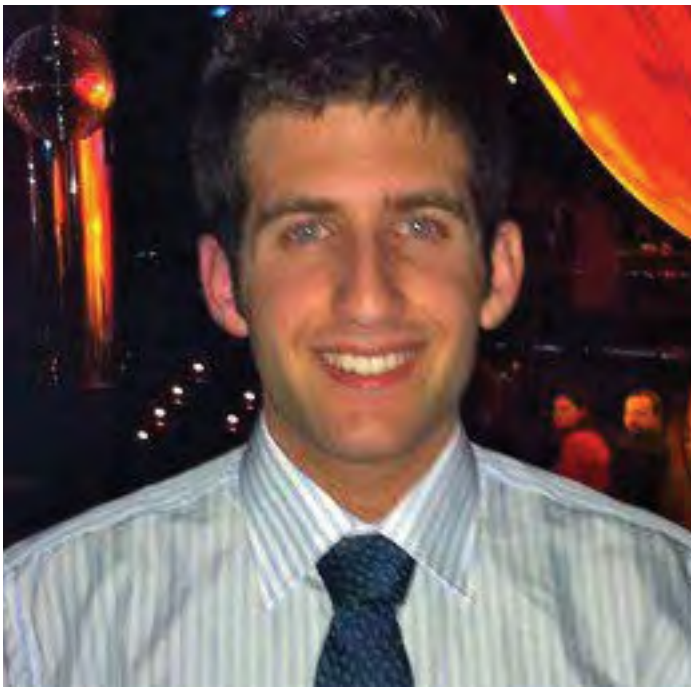
Competitive Employment: a full-time or part-time job with market wages and responsibilities; generally no long-term support is provided

Supported Employment: a competitive job where the individual receives ongoing support services while on the job; can be funded through state developmental disabilities or vocational rehabilitation agencies

Customized Employment: a job in which the individual's strengths and abilities are used to develop a specific role uniquely created for the individual

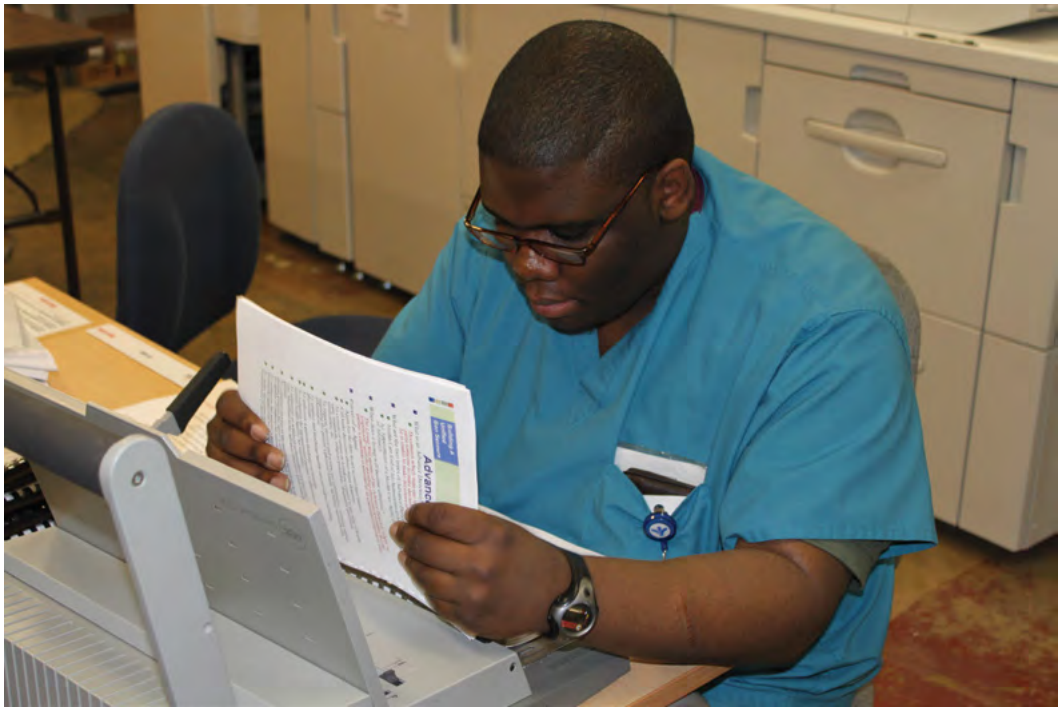
Self-Employment: a job situation in which the individual's interests and strengths are matched to a product or resource that can allow him or her to make money, i.e. a bakery for those who love to cook; can increase the opportunity to tailor the work environment to the individual's needs

Sheltered Employment: a job setting where individuals with disabilities are not integrated with workers without disabilities; generally supported by a combination of federal and/or state funds; some argue that this system more often hinders the independence of people with autism in the community



Job Matching and Searching

Finding the best possible match is the most important component of securing successful employment. Sometimes even your child's passions or intense interests can be converted to a career. If your son is very interested in trains, maybe there is a job available at the local station. If your daughter loves to rearrange her closet in perfect order, bring her down to the local department store to see if they need help with restocking. Many individuals with autism have found great success pursuing their unique passions. For example, when Dr. Temple Grandin was a young girl, she became obsessed with cattle handling equipment at her aunt's ranch. Though that did seem different at the time, she was encouraged to pursue these interests and today she is the world's leading expert on the design of cattle handling facilities.



The information below regarding job matching is excerpted from *Life Journey through Autism: A Guide for Transition to Adulthood*, by the Organization for Autism Research:

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

Workplace Skills

It is essential for young adults with autism to learn proper skills in the workplace, not just related to the job itself, but also social skills and rules of a work environment. Example of these skills include:

Initiating interactions with coworkers, as well as ending them

Understanding and respecting boundaries

Asking questions when help or clarification is needed

Being patient in situations that may be frustrating

Learning the best ways to respond when agitated, i.e. taking breaks in a quiet room or walking outside for fresh air

Maintaining proper hygiene

Knowing what topics are appropriate in the workplace and what should be kept private

Practice these skills at home and out in the community so your child is prepared for the workplace. Make sure he or she feels comfortable telling you in the best way possible if there are situations at work that might be improved with better understanding of these "soft" skills.

Remember that learning these skills will be an ongoing process and may take time. With practice and dedication, your child can and will succeed when the right fit is found!

Below is an excerpt from *Autism and the Transition to Adulthood* by Paul Wehman, Marcia Datlow Smith and Carol Schall.

Social Skills in the Community and the Workplace

Using Social Amenities: Phrases such as please, thank you and you're welcome are simple, short and easily taught.

Using Appropriate Greetings: Some students fail to greet or acknowledge others; others greet people over and over again. Teaching the appropriate use of greetings can be helpful.

Terminating Conversations: A common complaint of peers, supervisors and coworkers is that the worker or participant with autism walks away while being spoken to.

Accepting Correction: Many people do not like to receive correction or criticism, which can be especially upsetting to an individual with autism. 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 taken advantage of. Social skills training may be required to teach them how to stop this from happening, for example, how to say, "Leave me alone" if someone is bothering them.

Accepting Suggestions: If a teacher or parent provides a suggestion, this can sometimes result in a 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 the opportunity to practice this skill can be effective.

Asking for Help and Revealing a Problem: One of the most important social skills is to ask for help when it is needed. 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.

Other Options

Some individuals with autism, especially at a young age, may not be ready for employment. You may feel that there aren't any options that seem to be the right fit for your child. That in no way means he or she has to be home all day. Other options to consider include:

Day Habilitation Programs

Day habilitation programs are person-centered programs that provide structured activities and specialized supports that will allow your child to participate in non-employment related activities in the community. These services can be provided almost anywhere in the community based on the desired skill being taught. Day programs are available for adults with disabilities who have exited the school system and may not be ready or able to participate in the workforce in an effective way. These structured programs focus on independent living skills and integration into the community.

Day Treatment Programs

These programs combine therapeutic treatment with daily life skills. This type of program is administered at a program site rather than in the community. Many day programs for individuals with autism and other disabilities are administered through your state's Department of Developmental Disabilities. Contact your local office for more information on the programs available in your area. It is important to note that many programs may have waiting lists, so start the process of getting on a list as soon as possible.

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. Brian, who was diagnosed with autism at age six, 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) served up with CulinaryWorks®, a program the organization launched through a partnership with notable Arizona chefs that offers adults with autism spectrum disorders hands on job training through the preparation, packaging, distribution and sale of classic soups. 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 Merring 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 SARRC, visit *autismcenter.org*.**

Additional Resources

Vocational Rehabilitation

Each state has a Vocational Rehabilitation (Voc Rehab or VR) agency that provides employment service supports to people with disabilities, including autism. VR agencies can give your child vocational assessments that lead up to the development of an Individual Plan for Employment (IPE). A variety of employment-related services can be provided under an IPE, including training, counseling, job placement and supported employment.

State Developmental Disability Agencies/Home and Community-Based Waivers

State and local Developmental Disabilities services operate under a variety of names across the country. Frequently the funding for these services comes through the Home and Community-Based Services Waivers (HCBS), which are made available through Medicaid. The requirements for gaining access to these services vary from state to state. Several employment services can be accessed through this funding source, including supported employment, case management services and counseling and treatment services. Reach out to your local agency or the Centers for Medicaid and Medicare Services (CMS) to see if your child is eligible for these waivers and if so, when you can get him or her on the wait list. You can find more information in the Legal Matters section of this kit.

Autism Speaks Employment Tool Kit

Autism Speaks has developed an Employment Tool Kit for young adults and adults with autism to help them find and maintain employment. This helpful guide covers a wide array of topics, including benefits and funding, various employment options, building a resume and cover letter, interviewing, accommodations and personal stories. Download the kit at **AutismSpeaks.org/Family-Services/Tool-Kits/Employment**.

Conclusion

As you know from your own life and those of your family members and friends, employment can play a vital role in the well-being of all people. It is important to keep in mind and let the world know that adults with autism can be positive contributors to the workplace when given the opportunity to display their strengths and abilities. Encourage employers to look past the communication and other such challenges your child might face, and see the skills that will allow him or her to succeed in a specific job. Start helping your child identify his or her greatest strengths and interests from an early age so you can start a list of some employment ideas for his or her future. Job sampling, internships, volunteer opportunities and more can help you see what type of work your child can do and enjoys. With a little research, assessment and advocacy, you and your child can help find a job, training opportunity or day program that works!

Postsecondary Educational Opportunities

There are many opportunities for education when your child leaves the school system or graduates from high school, including traditional two- and four-year colleges. Each model offers different levels of supports and types of services. In addition, in some models, students are integrated with students without disabilities, and others are kept separate. Some allow students to receive individualized services based on his or her vision and career goals.

Types of Postsecondary Education

Below is a list of some options for postsecondary education programs for individuals with autism.

Four-Year College

More and more four-year colleges and universities are providing support services for students with disabilities, including autism. However, you are encouraged to research these options and make sure that the supports offered meet the needs of your child. Self-advocacy skills are very important in postsecondary education because your child must know how to ask for necessary services and accommodations, such as housing supports, extended time on exams and access to assistive technology. Most schools have counselors and tutors available to help with this process. A good place to start is the school's office of disability services. It is important to note that some schools have autism-specific programs and others are more general for all students with some type of disability.

Cooperative Education

One option at some colleges and universities is cooperative education. In this type of program, your child would alternate between taking academic classes and working in the field of his or her choice. This 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. It also allows students to explore the fields that interest them and work on the soft skills they will need in the workplace after school ends. Be sure to reach out to colleges and universities or check their websites to see if this type of program is available.

Community College

Many community colleges have developed or are currently developing programs to meet the needs of young adults with developmental disabilities. Community colleges put more of an emphasis on the needs and goals of each student. For some students, the services provided can include necessary life skills like money management and problem solving. Others may focus on more traditional academic subjects and some may have a combination of both. A 2013 study, funded in part by Autism Speaks, found that community colleges may play a particularly important role in fostering transition into productive lives for individuals with autism. The study also found that graduation rates are higher when college students with autism start in a community college, especially those focused on technology, engineering or math.

Vocational/Technical/Trade Schools

Vocational or technical schools can provide your child with the opportunity to experience hands-on learning in a variety of fields. There are some programs that provide this training along with academic skills such as reading, writing and math. These programs also provide vocational 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.

Life Skills Programs

There are many life skills programs available for people with autism that offer services to help your child live as independently as possible. These programs cover a wide array of skills – from basic skills like money management, shopping and transportation, to employment training skills in work settings. The programs also teach social skills and provide services such as recreational and leisure activities that will help integrate your child into his or her community, an important part of adult life.

504 Plans

Once you choose the right program, 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 to which he or she is entitled.

IDEA requirements no longer apply when your child has left high school and is enrolled in an institution of higher education. However, Section 504 and the Americans with Disabilities Act (ADA) are civil rights laws that help protect individuals with disabilities including autism 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, your child has to have a physical or mental impairment that *substantially limits* one or more major life activity, as well as a history of this impairment in a major life area. Reasonable accommodations can include audio books, readers or note-takers, access to the instructor's notes, extended time for assignments and tests, preferential seating and other similar supports.

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 your child to receive accommodations, he or she or an advocate must request them. Remember that the level of supports, as well as their efficiency and effectiveness, varies from school to school, so be sure to do as much research as possible.

Learn more about Section 504, IDEA and the general responsibilities of a public school from the National Association of School Psychologists by **clicking here** or using the link in the resources section of this kit.

Differences between High School and College

The following chart, adapted from Kay McVey, Faculty Development Specialist, PROJECT Connect, at Henderson State University, provides a clear illustration of the differences between high school and college:

HIGH SCHOOL	COLLEGE
All students have the right to an education.	College education is a privilege, not a right.
Protections include Individuals with Disabilities Education Act, Section 504 of the Rehabilitation Act, Americans with Disabilities Act.	Protections include Section 504 of the Rehabilitation Act, Americans with Disabilities Act; IDEA no longer applies.
School district designs Individualized Education Program (IEP).	Student is responsible for providing documentation that establishs verification of learning or other type of disablility.
School district ensures that the IEP is implemented.	Student indentifies his or her needs in collaboration with his or her counselor.
Teacher functions as advocate.	Student is responsible for his or her own progress.
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 or impose an undue burden on an instruction/institution.
Personal services are provided (e.g., aide) - success is more of a right.	Personal services are the 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 to the best of their ablitiy

When preparing your child for college, below are some important points for you to remember:

In order to apply for or attend college, your child 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. Some colleges will require these for admission. If you think your child may need extra support taking these tests, oftentimes accommodations can be arranged.

Find out if colleges that your child may be interested in require IQ or achievement test scores to receive accommodations under Section 504.

Assess if your child needs any remedial classes before going on to college. Some students do this at college, others spend an extra year in high school. Summer courses may be an option at a college in your area.

Work closely with your child's guidance counselor to begin to explore available options. One option is dual enrollment, when a student who is still officially in high school is also taking one or more classes at a college for credit. This allows your child to begin to get used to the college setting, life and workload while still in high school.

Discuss your child's postsecondary options with your local Division of Vocational Rehabilitation Services (DVRS). They may have funding available to help defray costs.

Choosing the Right School

Choosing the right school is important for any student's happiness and success, but often especially for students with autism. There are many factors to consider and questions to ask when exploring post-secondary education options. *The Autism Transition Guide: Planning the Journey from School to Adult Life* by Carolyn Bruey and Mary Beth Urban offers 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 teachers where some of their past students have attended college.
- Ask other parents of students with ASD.
- Consult local autism organizations to see listings of colleges that offer supports.
- Make sure to arrange visits to any potential schools where you can speak to staff and students. The school may also be able to 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 insti tutes, state schools, liberal art schools and also the variation of two-year versus four-year programs.
- Factors that come into 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 them selves with the college.

Self-Advocacy in Postsecondary Education

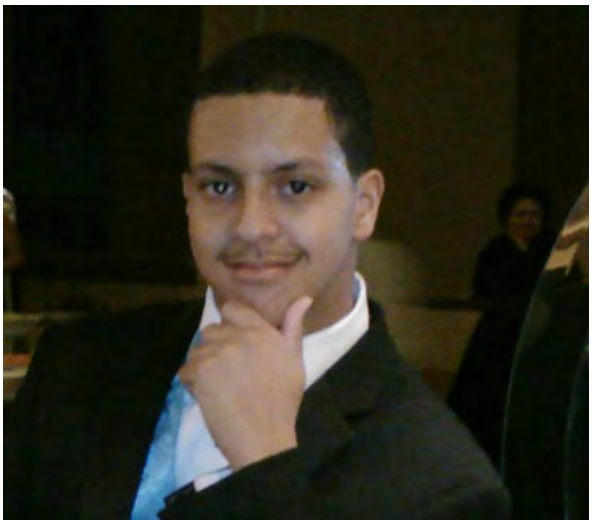
Postsecondary education is the one of the best opportunities for your child to advocate for him or herself. College counselors are more readily willing to listen when the student, not the parent, approaches them. You may want to remind your young adult that his or her "voice" will make a difference. You may also want to help him or her make a list of his or her most significant concerns about colleges or other postsecondary programs. Young adults should be encouraged to share these concerns with their advisors. Creating a solid support system may lower the chances of future problems.

Because the mandatory supports available in high school are no longer available, it is far more important to advocate for services and supports in postsecondary education. Rather than receiving them automatically, it is now up to your child to ask for what he or she needs in all situations, both academic and social. Aside from the necessary services, there will be other areas in which your child needs to communicate and advocate for him or herself – including knowing when and how to disclose his or her autism diagnosis, understanding his or her rights and asking for assistance when necessary.

Once again, it is never too early to start teaching self-advocacy skills. The more prepared your child is to advocate for him or herself in postsecondary programs, the more supports he or she will receive and the more successful and effective the program will be as a result.

Expert Advice for Parents

Barbara Kite, M.Ed., Assistant Director of the PACE program at National Louis University, offered Autism Speaks six tips to share with parents regarding preparing for postsecondary education:



1. Plan Ahead – It is never too early to learn about the different kinds of programing available for your child.

2. Know Your Goals – What is it you want for your child? Independence? A four-year degree? A job?

3. Go and Look – Be sure to visit the programs that you are interested in. There is a good chance that what you THINK the program is in actuality may be quite different.

4. Ask Questions! – Not all programs are what they appear to be.

5. Think About Cost – Unless you are going to use government programs, the price of postsecondary programs can be high. You may have to be creative when it comes to financing your child's postsecondary experience.

6. Make A List – Think about what environment you want your child in. Do you see him or her at a community college? Or going away from home? Does he or she need a program that offers academic support? Consider whatever YOU learned by osmosis is what you need someone to teach to your child.

Autism Speaks Postsecondary Educational Opportunities Guide

In 2013, Autism Speaks released the Postsecondary Educational Opportunities Guide, a tool written for young adults with autism to help them and their families explore the different opportunities and learning environments after leaving high school. Sections include: Preparing for Postsecondary Education, Obtaining Services and Asking for Accommodations, Peer-to-Peer Advice, Life on Campus and more. Download this tool kit at **autismspeaks.org/family-services/tool-kits/postsecondary**.

Conclusion

When your child graduates from high school or ages out of the special education system, it is important to continue to educate him or her, whether it's at a college, a local day therapy program, in your home, or anywhere in between. The more your child continues to learn, the more opportunities that will become available to him or her at work, out in the community or in other local programs. Be sure to research and explore the postsecondary education options available to your child from an early age so you can decide together what might be the best fit.

Housing and Residential Supports

One of the most difficult parts of the transition process is finding the right residential option for your child's future. Coordinating choices for the physical home, as well as the necessary support services can be complicated, often leaving families unsure of where to start. The information below, along with the **Autism Speaks Housing and Residential Supports Tool Kit,** can help assist you and your family in planning for the future in the areas of housing and community living.

There are different options to choose from, but several hurdles to get over before your child is settled in the right place. The most important thing is to build the skills necessary for him or her to live as independently as possible as an adult. And remember - start early!

Where Do I Begin?

It is critical to be proactive when it comes to choosing the right residential option. Think first about what is best for your child as an individual based on his or her needs, abilities, strengths, challenges, etc. Some important questions to ask might be:

Where would your child thrive?

Where would he or she be happiest?

Where would he or she feel safest?

What type of setting would best help him or her achieve an independent and successful future?

What supports does he or she need and what types of options can best provide those supports?

What setting can help your child expand upon his or her strengths and abilities?

Many of these questions can be answered through the person-centered planning process which can help families and individuals with autism identify the right types of residential and support services based on the individual's goals and needs. More information about person-centered planning can be found in the Self-Advocacy section of this kit.

A great place to start is with your school district. They can help or 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 or local autism organizations. 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! Below are some you may want to consider when looking into a specific option or speaking to a housing agency:

What type of housing models do you offer?

How long have you been providing residential services?

What type of training does your staff receive to work with an adult with autism?

What level of support does the staff provide to the adults with autism? Is support available 24 hours a day?

Can I speak with other families who are using your service?

How do the residents spend their time during the day and on weekends?

How close is the local community and how often do you access community resources?

Who provides transportation during the week and on weekends?

How close are hospitals?

What is done in a medical and/or behavioral emergency?

What is done to support medical and/or behavioral needs?

What type of training do staff receive?

It is important when researching residential placement for your child, that you keep him or her as involved in the process as possible. Allow your child to contribute to the discussion in the best way he or she knows how. Though some young adults with autism may not be able to decide on their own what type of housing they'd like to live in for their future, do your best to keep your child's preferences and strengths in mind. This is likely one of the most important decisions your family will make, so it is critical to make sure everyone is on the same page and that an outcome is reached that everyone can be happy about, especially your child.

Most residential service providers that receive public support, including all providers that receive Medicaid, are regulated by state agencies. For Medicaid providers, the state agency conducts routine monitoring – often referred to as "survey and certification." Before choosing to use any provider, ask to see the latest monitoring, survey or licensure reports conducted by the state. You can also contact the state regulatory agency to find out if any complaints of abuse and neglect have been filed against a provider or if the provider has violated any licensure or regulatory standard.

Models for Residential Support

There are many different community-based residential service options. Some of these options combine housing and support services, while others allow the housing and support services to be purchased and arranged separately. As you read these descriptions, bear in mind that states may use different terms to describe similar models:

Supported Living offers services to individuals with disabilities who are able to live independently in a home or an apartment. The services, typically minimal in nature, are based on the individual's specific support needs and are provided by caregivers working under the direction of the individual.

Supervised Living (semi-independent living) offers more direct and intensive structured supports available 24 hours a day, if needed. The individual may live in a house or apartment, either alone or with others. Functional life skills such as banking, shopping, cooking and going to doctor appointments can be taught or supported by staff.

Group Home Living has been the traditional model for residential services for individuals with developmental disabilities. In a group home, several unrelated people (all of whom have a disability) live together with onsite staff who are present 24 hours a day, 7 days a week. Instruction focuses on independent living skills and community activities. The house is owned and operated by a provider agency that also employs and supervises the staff. Typically group homes have eight or fewer residents.

Group Living/Ownership (co-op) is similar to group home living, except that the house is owned by a group of families or individuals who have formed a cooperative agreement. Caregivers hired by the cooperative, in some cases, by an agency contracted by the cooperative, provide support services.

Teaching Family Model/Foster Home Living offers family-style living with support services available 24/7 by professional teaching parents, usually a married couple. The individual may be the only person with a disability living in the home or there may be others with or without disabilities.

Farmstead Communities provide residential supports and services for a number of individuals within the context of a working farm. These models generally combine residential living arrangements with agriculture science and community-based employment.

Assisted Living Facilities/Intermediate Care Facilities (ICF) provide assistance with personal care and activities of daily living such as bathing, grooming, dressing and more. In some states, ICF programs also provide medication assistance and/or reminders. Each ICF is responsible for providing active treatment, consistent training and health support. Assisted living communities differ from nursing homes in that they don't offer complex medical services.

Developmental Centers are large residential facilities clustered on a campus-like setting where residents have intensive needs related to their developmental disabilities. Most states no longer run large developmental centers and some states that do are looking to shift people to more community-based settings and will only place a person in a developmental center on an emergency basis.

Funding Options

It can be challenging and confusing to navigate the funding streams for housing for your young adult with autism. Below is some information about options and programs for you to look into when finding the right housing fit for your child:

Self-Funded Housing

Self-funded housing is purchased by the family and/or the individual using private money and/or public dollars. The funds are secured and directed by your child and family, not an outside agency.

When exploring ways to pay for housing, you should consider all resources available to you and your child, including:

Donations

Income

Grants

Foundations

Banks

Community Development Financial Institutions (CDFI)

Credit unions

Private insurance

Special Needs Trusts

Individual Development Accounts (IDAs)

Pooled trusts

Tax credits

Individuals with autism and other disabilities are often eligible to participate in state and federal programs designed to provide funding to build and renovate houses. It is important to know that each program has distinct guidelines and that programs can often vary by state.

Most public funding for projects will be contingent on your child's ability to pay for rent/mortgage and a social-service plan that addresses health and safety. There are many public programs that offer assistance to people with disabilities and others with low and limited income.

Below we have highlighted programs that are more frequently used for people with disabilities. For a more comprehensive review of federal programs, visit the United States Department of Housing and Urban Development's (HUD) website at **hud.gov**.

HUD Section 811 provides interest-free capital advances to nonprofit sponsors to develop rental housing for low-income persons with disabilities. HUD Section 911 Housing Choice Vouchers (HCV) are dispersed directly by HUD to persons with disabilities to spend on the housing option of their choosing.

Low Income Housing Tax Credit (LIHTC) allows qualified for-profit and nonprofit developers to apply on a state-by-state basis 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% of area median income.

Home 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 Grants (CDBG) are grants to jurisdictions that can be used to support affordable housing through land acquisition and infrastructure development.

Federal Resources

The HUD programs above provide funding for families or groups of families to purchase or rent their own apartment, condominium, house, etc. for their family member with autism. It is important to note, however, that very often costs for the physical home and costs for the services provided within the home are kept separate.

You should discuss funding options with the state agency responsible for serving adults with developmental disabilities. Below is a list of some federal entitlements that can help with residential support costs and other services. You can find more information in the Legal Matters section of this kit:

Medicaid Benefits

In most states, individuals who need residential support will need to be eligible for Medicaid, a program designed to pay for intensive services. Medicaid pays for a wide array of services for people with disabilities, including long-term services and supports. To be eligible for Medicaid, a person must fit in a specific category of coverage and meet income and assets requirements.

Home and Community-Based Waiver Services

Through the use of Medicaid Home and Community-Based Services (HCBS) Waivers, people with autism and other disabilities can use Medicaid funds more flexibly. Waiver services are an option available to states to provide integrated community-based long term care services and supports to qualified Medicaid recipients. These programs may provide a combination of both traditional medical services (dental services, skilled nursing services) and non-medical services (respite, case management, environmental modifications). Family members and friends may be providers of waiver services if they meet the specified provider qualifications. The exact type of residential support included in an HCBS waiver as well as who is eligible for the program varies within and across states.

Supplemental Security Income (SSI)

SSI is a federal program through the Social Security Administration that provides cash benefits directly to recipients. In order to receive SSI, an individual must be disabled and have a limited income, including a maximum asset limit of $2,000. In 40 states, individuals who qualify for SSI are automatically qualified for Medicaid. Learn more and determine if you qualify at **ssa.gov/ssi**.

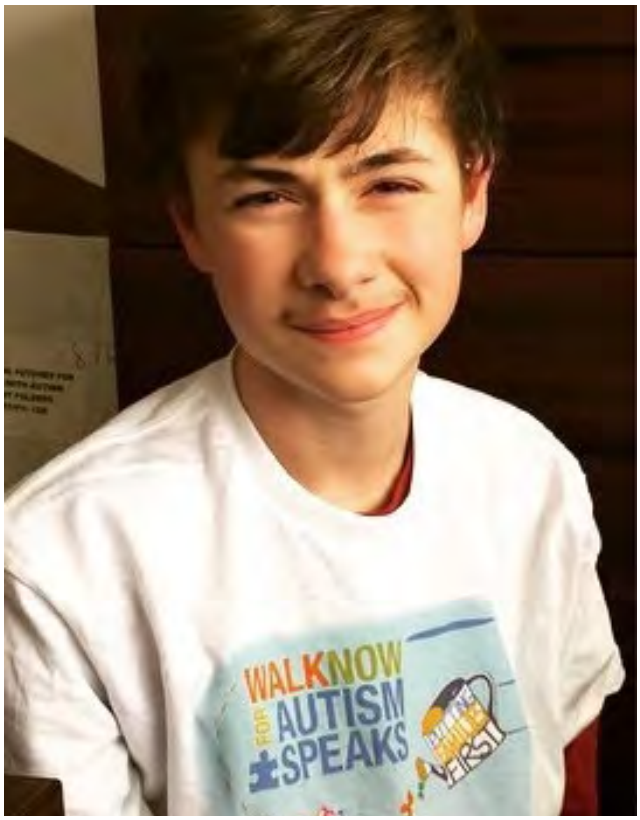
Waiting Lists are Long – Plan Ahead!

Regardless of the funding mechanisms available, the most important thing when it comes to housing and residential supports is to plan ahead. Unfortunately, at this time there are many more people waiting for appropriate supported living settings than there are openings in these settings.

Although there are state-funded day services and/or vocational rehabilitation programs for young adults when they transition to adult life, many families are surprised to learn that there can be a waiting list of five, ten and even 15 years or more for residential services and supports that are funded with public dollars, specifically Medicaid HCBS waivers.

It is important to understand and monitor the waiting list in your state and stay vigilant in pursuit of accurate information. Begin planning as early as possible and take the time to research your state's funding structure for housing and supports to minimize waiting time.

Be sure to put your child's name on the HCBS waiver waiting list as soon as possible – it may be many years before he or she is offered services.



Conclusion

The thought of your child living outside your home at this point might seem very overwhelming. But regardless, it is never too early to start researching residential plans and the corresponding funding mechanisms, even if you aren't quite sure of when, if at all, you think might be the best time for the move. With diligent and proactive research and planning, you can help guarantee that whether his or her future home is down the hall from you, two blocks away or across the state border, your child will live in a place that will allow him or her to be as happy and as independent as possible.

Health

Ensuring and maintaining your child's health as he or she becomes an adult will be critical. It is important to understand and be on top of the changes that are happening for your child – physically, mentally and emotionally – as well as the shifts in many health-related policies, benefits and entitlements as he or she ages into adulthood.

Finding the Right Doctor

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 insurance or Medicaid of adults with autism and more importantly, who understands young adults on the spectrum.

It is important that the primary care physician treats your child as an individual like every other patient, not just an individual with autism. Remember to advise the primary care physician to make sure that he or she doesn't see every health or behavior problem as a result of autism and understands your child as a whole person.

You should begin the search for a primary care physician early, though the transition doesn't usually occur until age 21. Start by asking your pediatrician for some names of doctors in the area who may be appropriate for your son or daughter. Ideally, there should be communication at the beginning between the pediatrician and the new doctor to ensure that everyone involved is fully informed of your child's state of health.

One of the most essential things to consider when selecting a doctor is that your child feels comfortable with him or her, as it is critical that your child is able to express any health-related feelings or concerns. This process is another important time for him or her to self-advocate.

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.

Mental Health

Unfortunately, mental health issues can complicate the transition process. The teenage years are already a time of turmoil and change and an adolescent with a mental health diagnosis can have a more difficult time managing the emotions that come along with these years.

Many individuals with autism are also diagnosed with mental health disorders like depression, anxiety and Obsessive Compulsive Disorder. Psychiatric diagnoses are not developmental disorders and often times they may not be visible during childhood.

This is often further complicated by the assumption that certain behaviors and emotions are connected to the individual's autism diagnosis, when the behavior may not be related to the diagnisis at all. It is important that your child's primary care physician is able to distinguish between the two so that he or she can treat these conditions and behaviors effectively.

If you suspect that your young adult may be suffering from a psychiatric disorder, you may want to speak with his or her doctor about a screening, which will consist of questionnaires that will indicate if your child needs further evaluation and/or interven-

tions. Keep in mind that screening results are not a formal medical diagnosis. The results 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.

Common psychiatric disorders among individuals with autism include anxiety, attention deficit hyperactivity disorder (ADHD), Obsessive Compulsive Disorder and depression. The Autism Speaks website contains detailed information about the signs and symptoms of each of these conditions, as well as effective ways to treat them.

A number of research studies have found that a significant percent of children with autism lack access to mental health services when they need them. Parents often have a stigma around mental health issues which unfortunately prevents their children from getting treatment and making progress. In addition, the mental health care system can be difficult to navigate. If you have trouble finding a psychiatrist for your child, look into mental health clinics that are staffed by social workers. Treatment for mental health issues is of vital importance, especially for individuals with autism, so it is critical to take the necessary steps to access these services so that your child has a better chance of living a life of purpose and dignity.

In addition, individuals with autism are more likely to have new onset seizures during puberty or after they have completed puberty than at any other time since before they entered school. While the likelihood is still not very high, if your child does experience a seizure, a neurologist can administer tests to determine the cause. Most seizure disorders can be managed with the right medication.

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 to become as independent as possible. While other young adults may wake up in the morning and have a set routine, your child may need more explicit instruction and reminders of the steps to take each morning and night. Visuals in the bedroom and bathroom can be helpful. *Taking Care of Myself* by Mary Wrobel is a great 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 early can serve as a good bridge to sex education and help with the prevention of sexual abuse.

See the Developing Independent Living Skills section of this kit for information on the importance of teaching self-care skills and effective ways to make sure your child learns personal hygiene skills to the best of his or her ability, regardless of other challenges.

Puberty and Sexuality

The onset of puberty is a difficult time for all older children and adolescents, and the changes can be especially difficult for those with autism. Preparation is key so it is essential to teach your child in advance about these changes. Your child should understand what is happening to his or her body, as well as what will happen in the future.

The more information you share with your child in advance, the more ready he or she will be for events such as menstruation or erections and ejaculation. Other changes like the growth of pubic hair or under arm hair should be covered as well. While it may be uncomfortable, you can never be too thorough or explicit in getting this information across to your child. 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.

Many parents feel nervous and anxious when it comes to teaching their children about sexuality, especially children with autism. Many incorrectly feel that it is less important to teach young adults with autism about this subject because they think 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 understand the difference between appropriate and inappropriate behavior, and to distinguish between the various types of healthy relationships.

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. For example, you can break the road to sexual intercourse into steps such two people meet, they become friends, go on a date and hold hands, etc.

It is important to teach these subjects as you would any other and to remember that you are the person responsible for teaching your child about sex and sexuality. 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 and answer the questions in a simple and direct manner.

Dr. Shana Nichols, Ph.D., a specialist in autism and sexuality, suggests that a sexuality education curriculum include: the body, privacy, boundaries/touch, expressing affection, social skills and exploitation prevention. It is also important to stress the difference between public and private with regards to places, body parts, behaviors, etc.

Sexuality education is about more than just puberty and sex. Dr. Nichols also reports that relationship skills are often overlooked for young adults. The focus on teaching social and relationship skills often

happens in the preschool 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 like the different types of relationships and how they are similar and different. All relationships, including those with strangers, teachers, doctors, family members, etc. need to be addressed very directly to understand what makes each of them healthy and appropriate.

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

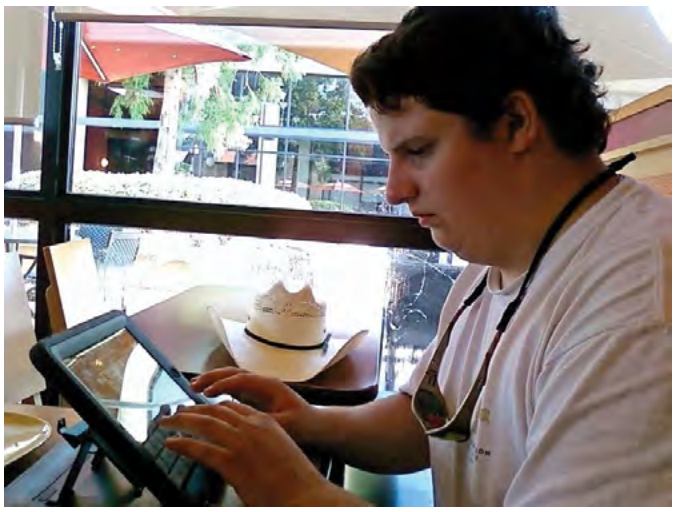
Conclusion

As many physical, mental and emotional changes happen as children enter adolescence and approach adulthood, it is important to monitor your child's health in each of these areas. Talk to your child's doctor about the changes you can expect and make sure you and your child are as prepared as possible for the changes in advance. Preparation and knowledge will make a world of difference when it comes to the health of a young adult with autism.

Technology

In today's day and age, it seems our whole world revolves around smart phones, tablets and the internet. "Google It!" or "I'll 'friend' you later!" or "Did you see that Tweet?" are just a few of the popular phrases associated with the internet and online social networking that can be heard almost everywhere we turn.

The goals and uses of technology are very different for adolescents and young adults. These tools can be very empowering for adolescents transitioning into young adulthood, especially for individuals with autism. Technology can help your child become more independent, work on his or her challenges and improve upon his or her strengths.



How Technology Can Help

Below is a list of just some of the ways technology can help your child:

Communication

Likely the most common use of technology to help children and adults with autism is to improve communication skills. There are hundreds of apps and many built-in features of these devices that can help support individuals with autism at all levels and abilities. One app for example could be geared toward a nonverbal child or adult, while another can help with social cues for an individual with strong verbal communication skills. You can find apps for communication in the Autism Speaks apps database at **autismspeaks.org/autism-apps**.

Visual schedules

Visual schedules on tablets can be a great tool to help your child complete tasks and work on skills like self-care and daily living. For example, a visual schedule for an evening routine can help him or her learn to manage time and gradually master a routine on his or her own – from an after school snack, to homework, to teeth brushing and everything in between. These visual schedules can be very helpful in helping your child learn independent living skills, among others.

Decision-making

Individuals with autism who have more difficulty communicating can use technology to make their "voices" heard regarding decisions, which helps foster the self-advocacy skills that are so important as they age into adulthood. You can start small, like instead of ordering for your child at a restaurant, he or she can use a smartphone or tablet to point to the item he or she wants.

Motivating tool

Technological devices like smartphone and tablets can also serve as motivation for your child. The use of an iPad or a favorite game app can serve as a reward for positive behavior like the completion of a chore or a homework assignment.

Video modeling

Video modeling is a method that involves teaching skills in a visual way. The video could be of the individual him or herself completing a task or assignment, or of a teacher, educator or parent teaching the skills and steps required. Your child can watch these videos as often as he or she likes/needs to help learn important skills. Because the videos involve using a tablet or smartphone, he or she is most likely more interested in learning the skills this way. Video modeling can help with a wide array of skills including hygiene, job tasks and more.

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.

Social networking

It can sometimes be easier for an individual with autism to socialize via social networking than through the more traditional methods. Making friends or communicating with others online can help him or her work on the skills that might translate at school, work or out in the community.

Vocational assistance

Technology can be very helpful to some young adults and adults with autism in the workplace. For example, step-by-step checklists can help your child stay on top of tasks and complete them in an orderly and successful manner. Reminders and notes about each task in case he or she forget something, rather than continuously asking an employer or coworker, can also help your child become more independent in the workplace.

Social Media and Internet Safety

Individuals with autism are just as interested, if not more interested, in using the internet as a connection to mass amounts of information and people. To ensure the safety and success of internet usage, it is critical that these individuals 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 safe and fun ways to use the internet. You should closely monitor your child's internet use and constantly make sure that his or her activity is safe and appropriate.

Below are some social networking safety tips for tweens and teens from the Federal Trade Commission that you should share with your adolescent:

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 or accounts to a select group of people for example, your friends from school, your club, your team or your family.

Keep your information to yourself! Don't post your full name, Social Security number, address, phone number or bank or credit card account numbers – and don't post other people's 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, club and where you work or hang out.

Make sure your screen name or account name doesn't say too much about you. Don't use your name, age or 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 three 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.

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. If you do decide to meet the person, 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 site. You could end up preventing someone else from becoming a victim.

The Importance of Digital Literacy

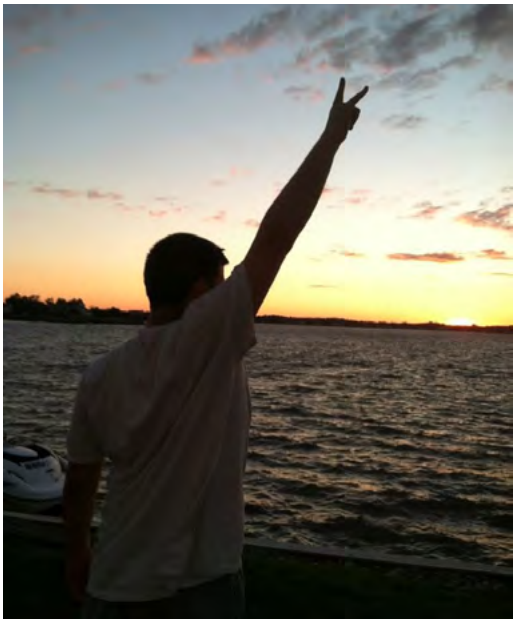
Digital literacy, or knowing how to operate digital devices like smartphones, tablets and computers, has become a very important skill over the last decade. Especially in a world where the large majority of employment opportunities involve the ability to use technology, teaching these skills to individuals with autism should begin at an early age. Your child may not have the ability to communicate in a traditional way or may become very uncomfortable in a workplace setting, but as long as he or she can contribute important work-related skills to his or her job, finding and maintaining one will be much less difficult.

Teaching your child things like email, word processing, internet browsing and more will be beneficial to him or her throughout the teen years and adulthood. These lessons also can include social media use and what is and isn't appropriate to share online. This knowledge can also help with fostering more independence for your child and can open the doors to more opportunities in high school, postsecondary education programs and eventually employment.

Autism Expressed is an online interacting learning system that teaches marketable, digital life skills to promote independence for students in a technology driven society and economy. Learn more and sign up at **autismexpressed.com**.

Assessments

Technology can also be used to conduct assessments that identify your child's strengths and help pinpoint areas where he or she may face challenges. Assessments that are conducted through interviews or by pen and paper can often be difficult for children and adults with autism, so those available through computers and tablets have been found to be very beneficial. These assessments can help you tailor your child's learning programs in a way that will continue to build upon his or her strengths and abilities and improve on skills he or she has trouble with.



For example, **Identifor** is the first digital tool that uses games to reveal how a person likes to spend his or her time and matches that with relevant career options, setting students on a personal path to a fulfilling future.

Ask your child's school about online or digital assessments that can allow you to identify factors that will help you develop a more personalized transition plan for your child.

Conclusion

Technology has the potential to play a major role in your child's transition plan, especially in today's world where it seems like technology rules all. There are definitely dangers out there on the internet that are important to make your child aware of, but for the most part, the internet and technological devices and advances have been and will continue to be vital resources for people with autism.

Do your research and learn how you can best maximize the effects of technology on your child. Find tools, apps and websites that will help prepare him or her for the future by teaching important skills, increasing independence and expanding upon abilities and strengths that will be critical on the road to adulthood. There is truly something for everyone!

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. We hope the information in this kit will help you during this 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.

We hope that 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**.

The Autism Speaks Autism Response Team is here to help provide you with any additional resources and supports you may need during the transition process. Feel free to reach out any time by phone at 888-288-4762 (en Español 888-772-9050) or email at **familyservices@autismspeaks.org**.

We wish you and your family all the best on this exciting journey into adulthood!

There are several main conclusions we want you to take away from the Autism Speaks Transition Tool Kit:

Every individual with autism is different, so each 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 challenges, and make a plan to help create as independent and enjoyable of a life as possible for him or her.

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.

Start teaching independent living skills at a young age and gradually build upon them. These skills may take time for your child to learn, but continue to motivate and support him or her until important life skills like hygiene are learned and understood. Don't be afraid to start small.

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.

The future may seem uncertain and scary right now, but taking the proper steps during the transition to adulthood will help ease these fears.

Resources

GENERAL TRANSITION RESOURCES

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

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

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

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., Claire LaZebnik

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, Danya International, Inc.
researchautism.org/resources/reading/documents/TransitionGuide.pdf

SELF-ADVOCACY

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

The Everyday Advocate: Standing Up for Your Child with Autism
by Areva Martin, Esq.

The Integrated Self-Advocacy ISA® Curriculum: A Program for Emerging Self-Advocates with Autism Spectrum and Other Conditions
by Valerie Paradiz, Ph.D.

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

Keeping It Real: How to Get the Supports You Need for the Life You Want
The Boggs Center on Developmental Disabilities
rwjms.umdnj.edu/boggscenter/projects/keep_real_more.html

Learning the Skills of Self-Advocacy and Disclosure
by Stephen M. Shore for Autism Spectrum Quarterly
autismtoday.com/library-back/Learning%20the%20Skills%20of%20Self%20Advocacy.pdf

Opening Doors to Self-Determination Skills: Planning for Life after High School - A Handbook for Students, School Counselors, Teachers and Parents
Wisconsin Department of Public Instruction
sped.dpi.wi.gov/sites/default/files/imce/sped/pdf/tranopndrs-self-determination.pdf

Person Centered Planning Education Site
Cornell University ILR School and Employment and Disability Institute
personcenteredplanning.org

Project STIR: Steps Toward Independence and Responsibility
Carolina Institute for Developmental Disabilities
self-advocate.org

DEVELOPING INDEPENDENT LIVING SKILLS

Keys to Successful Independent Living, Employment and a Good Social Life for Individuals with Autism and Asperger's
by Temple Grandin
autism.com/grandin_independence

Self-Help Skills for People with Autism: A Systematic Teaching Approach
by Stephen Anderson, Ph.D., BCBA, Amy L. Jablonski, Psy.D., Marcus L. Thomeer, Ph.D. & Vicki Madaus Knapp, Ph.D., BCBA

TRANSITION AND THE IEP

The IEP from A to Z: How to Create Meaningful and Measurable Goals and Objectives
by Diane Twachtman-Cullen, Jennifer Twachtman-Bassett

Individuals with Disabilities Education Act
idea.ed.gov

Individualized Education Program (IEP): Summary, Process and Practical Tips
developed by Goodwin Procter LLP for Autism Speaks
autismspeaks.org/family-services/tool-kits/iep-guide

Transition to Adulthood
Center for Parent Information and Resources
parentcenterhub.org/repository/transitionadult

LEGAL MATTERS TO CONSIDER

Academy of Special Needs Planners
specialneedsanswers.com

BEST: Benefit Eligibility Screening Tool
ssabest.benefits.gov

Centers for Medicare & Medicaid Services
cms.gov

Home & Community-Based Services Clearinghouse
hcbs.org

Legal Guidelines for the Autism Community
developed by Goodwin Procter LLP for Autism Speaks
autismspeaks.org/sites/default/files/documents/family-services/gp_legal_guidelines.pdf

Letter of Intent
child-autism-parent-cafe.com/letter-of-intent.html

The Medicaid Reference Desk: Your Source for State Medicaid Information
thedesk.info

National Association of Councils on Developmental Disabilities
nacdd.org

Understanding Medicaid Home and Community Services: A Primer
U.S. Department of Health and Human Services
aspe.hhs.gov/understanding-medicaid-home-and-community-services-primer-2010-edition

U.S. Social Security Administration
ssa.gov

COMMUNITY LIVING

Autism Speaks Autism Safety Project
autismspeaks.org/safety

Easter Seals Project ACTION: Training, an Online Community and Resources Dedicated to Travel Training
projectaction.org/Training/TravelTraining.aspx

Recognizing and Preventing Abuse
autismspeaks.org/family-services/autism-safety-project/abuse

EMPLOYMENT AND OTHER OPTIONS

Autism Speaks Employment Tool Kit
autismspeaks.org/family-services/tool-kits/employment

An Employer's Guide to Hiring and Retaining Employees with Autism Spectrum Disorders
autismspeaks.org/sites/default/files/docs/employer_guide_to_hiring_and_retaining.pdf

A Parent's Guide to Employment for Adults with Autism Spectrum Disorders
autismspeaks.org/sites/default/files/docs/employment_tool_kit_parent_booklet.pdf

The Spectrum Careers: Jobs Portal for Individuals with Autism, Employers and Service Providers
thespectrumcareers.com

Think Beyond the Label Jobs Portal
thinkbeyondthelabel.com

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

Job Accommodation Network
askjan.org

POSTSECONDARY EDUCATIONAL OPPORTUNITIES

Autism Speaks Postsecondary Educational Opportunities Guide
autismspeaks.org/family-services/tool-kits/postsecondary

AHEADD: Achieving in Higher Education
aheadd.org

Americans with Disabilities Act Q&A: Section 504 and Postsecondary Education
pacer.org/publications/adaqa/504.asp

College Internship Program (CIP)
cipworldwide.org

Postsecondary Education Resources, Autism Speaks Resource Library
autismspeaks.org/family-services/resource-library/post-secondary-education-resources

Section 504: A Guide for Parents and Educators
National Association of School Psychologists
nasponline.org/families/documents/35-1_S8-35_section_504.pdf

Students with Disabilities: Preparing for Postsecondary Education – Know Your Rights and Responsibilities
U.S. Department of Education Office of Civil Rights
2.ed.gov/about/offices/list/ocr/transition.html

ThinkCollege! College Options for People with Intellectual Disabilities
thinkcollege.net

HOUSING AND RESIDENTIAL SUPPORTS

Autism Speaks Housing and Residential Supports Tool Kit
autismspeaks.org/family-services/housing-and-community-living

Autism Speaks Housing and Community Living Initiative
autismspeaks.org/advocacy/advocacy-news/housing-and-community-living-initiative

The Disability Opportunity Fund
thedof.org

HUD's Section 811 Resource Center on Supportive Housing
811resourcecenter.tacinc.org

Medicaid Home & Community Based Services
medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html

National Association of Residential Providers for Adults with Autism (NARPAA)
www.narpaa.org

Opening Doors: A Discussion of Residential Options for Adults Living with Autism and Related Disorders
autismcenter.org/resources

U.S. Department of Housing and Urban Development (HUD)
hud.gov

HEALTH

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

Autism & Mental Health Issues: A Guidebook on Mental Health Issues Affecting Individuals with Autism Spectrum Disorder
card-usf.fmhi.usf.edu/docs/resources/CARD_ASDMH_Brochure092109.pdf

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

National Institute of Mental health
nimh.nih.gov

Sexuality and Relationship Education for Children and Adolescents with Autism Spectrum Disorders: A Profesional's Guide to Understanding, Preventing Issues, Supporting Sexuality and Respond to Inappropriate Behaviors
by Davida Hartman

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

TECHNOLOGY

Autism Speaks Autism Apps Database
autismspeaks.org/autism-apps

Autism Expressed: Digital Skills for Adolescents with Autism
autismexpressed.com

Cyberbully411: Prevent CyberBullying & Internet Harassment
cyberbully411.org

Identifor: Use Games to Identify Strengths, Interests and Develop a Comprehensive Transition Plan
identifor.com

i-SAFE: The Leader in e-Safety Technology & Education
i-safe.org

Wrong Planet: Asperger & Autism Online Community
wrongplanet.net

**Have more questions or need assistance?
Please contact the Autism Response Team for
information, resources and tools.**

TOLL FREE: 888-AUTISM2 (288-4762)
EN ESPAÑOL: 888-772-9050

Email: FAMILYSERVICES@AUTISMSPEAKS.ORG
WWW.AUTISMSPEAKS.ORG
Text ART to 30644

Autism Speaks is the world's leading autism science and advocacy organization. It is dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. Autism Speaks was founded in February 2005 by Suzanne and Bob Wright, the grandparents of a child with autism. Mr. Wright is the former vice chairman of General Electric and chief executive officer of NBC and NBC Universal. Since its inception, Autism Speaks has committed $560 million to its mission, the majority in science and medical research. Each year, Walk Now for Autism Speaks events are held in nearly 100 cities across North America. On the global front, Autism Speaks has established partnerships in more than 70 countries on five continents to foster international research, services and awareness.

To learn more about Autism Speaks, please visit AutismSpeaks.org.