SELF-ADVOCACY

Where Do I Start?

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

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

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

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

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

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

Valerie Paradiz, PhD – Developing Self Advocacy Skills: An Integral Aspect of Transition Planning

Self-Advocacy is:

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

*It is never too early to begin to teach self-advocacy skills.*
Introducing Self-Advocacy

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

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

Matthew is a 15-year-old boy with autism and limited verbal skills. Matthew and his family frequently go to the local ice cream shop. Matthew’s dad worked with him to teach him to order his own ice cream. Matthew was fairly competent at doing this, and so his dad suggested that he go into the shop by himself and order. Matthew’s dad would watch through the store front window. Matthew went in with his money and ordered his ice cream. When Matthew came out of the store, he was unhappy because he didn’t get the mint chocolate chip ice cream that he had asked for.

Matthew’s dad guided him through his options. They identified three options: Matthew could get very upset because he didn’t get the ice cream flavor that he wanted and have no ice cream; he could eat the ice cream that he got; or he could go back into the store and let the server know that he had asked for mint chocolate chip. Matthew decided to go back into the store. Before Matthew went in, his dad helped him practice what he needed to say. Matthew was very nervous, but he went back into the shop. He showed the server the ice cream he got and he told him that he wanted mint chocolate chip. The server apologized for the error and gave Matthew the mint chocolate chip that he had wanted. Matthew was so happy to have his mint chocolate chip ice cream, and his dad was very pleased with Matthew’s new found self-advocacy skills.
**Disclosure**

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

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

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

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

**How Do We Teach Self-Advocacy Skills?**

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

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

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

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

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

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

- **Hiring of staff** – asking individuals to serve on hiring committees.
As described in “It’s My Choice” from the Minnesota Governor’s Council on Developmental Disabilities (page 83)

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

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

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

Self-Advocacy and the Transition Process

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

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

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

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

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

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

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

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

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

**PATH: Planning Alternative Tomorrows with Hope**

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

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

PATH Information: [www.ont-autism.uoguelph.ca/PATH-jan05.pdf](http://www.ont-autism.uoguelph.ca/PATH-jan05.pdf)
You can find more PATH related resources at [www.inclusion.com/path.html](http://www.inclusion.com/path.html)

**MAPs: Making Action Plans**

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

1. **What is a map?**
   Allows the facilitator to welcome the group, to review the purpose of the gathering, and to give people a general description of what they can expect.

2. **What is the person’s history or story?**
   Provides everyone in the room an opportunity to contribute along the way as the story unfolds.

3. **What are your dreams?**
   Critical question so that everyone involved knows where he or she is headed when it comes time to do the hard work of developing a plan of action.

4. **What are your nightmares?**
   Serves as the guideposts for the journey so that planning can incorporate strategies to avoid creating, or recreating, the nightmare in someone’s life while heading toward the desired future.

5. **Who is the person?**
   Brainstorming, group participants are asked to use words that come into their mind that describes the person with whom the planning is being conducted.
   The focus person, this time, is asked to listen.

6. **What are the person’s talents, gifts, and strengths?**
   Provides the opportunity to present a multi-faceted picture of the person that is based on capacity and contribution.

7. **What does the person need?**
   Participants are drawn to consider what it will take in terms of people and resources to make the dream become a reality.
8. **What is the plan of action?**

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

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

For more information please visit: [www.ilr.cornell.edu/edi/pcp](http://www.ilr.cornell.edu/edi/pcp)

This is an example of MAP planning.

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

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

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

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

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

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

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

It’s My Choice
by William T. Allen, Ph.D.
Minnesota Governor’s Council on Developmental Disabilities

Youths4Advocates (Y4A)
www.self-advocate.org

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

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

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

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

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

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