

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](https://www.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?**

