

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 pre-requisite 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 situation 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.