

COMMUNITY LIVING

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

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

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

Picking the Right Activities

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

*- Life's Journey Through Autism, A Guide for Transition to Adulthood
Organization for Autism Research, Southwest Autism Research and Resource
Center and Danya International, Inc.*

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

Some things families and adolescents with autism may want to think about:

- What are your child's likes and dislikes?
- What makes your child tick or motivates him or her?



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

School Activities

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

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

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

Community Activities

- There are many opportunities for activities for individuals with autism in most communities. Activities in the community may include:
 - Public/private facilities: pools, parks, YMCAs, fitness clubs, programs at local universities. Search these to find inclusive activities, or those specifically for students with developmental disabilities.
 - Trips and outings
 - Exercise and sports
 - Hobbies, games, arts and crafts
 - Social events
 - Youth groups or religious community activities
 - Special Olympics



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

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

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



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

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

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



Social Skills in the Community and the Workplace

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

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

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

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

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

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

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

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

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

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



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

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

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

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

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

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

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

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



A Success Story While Learning to Travel

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

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

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

Travel Training

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

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


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



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

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

Safety

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

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

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

Learning to recognize that men and women in uniform are people you can go to and stay with during an emergency is a lesson we all learn. Individuals with autism may only be able to learn these lessons if we teach these safety skills at home, reinforce them at school, and practice them in the community. You may want to make building safety skills a part of your daily routine. Safety skills are learned best when they are delivered early and often, and are suited to a child or adult's age and ability levels.

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

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



Building Skills for Children and Less Independent Adults

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

Formally or informally, invite a variety of law enforcement officers and other safety professionals to sit among, not stand in front of, the students. The session should be designed to last about ten minutes, be delivered as frequently as possible, and by as many different officers as possible. Rotation of officers reinforces the message to students that police officers can and will look and sound differently. Rotation also makes safety skills easier to generalize for the student, and will allow more officers to participate without generating extraordinary time constraints for one particular officer. Officers can be asked to speak in their own words about the life skill that is being taught at the time.

Additional Skills to Build:

1. Recognize and respond to law enforcement officers, their uniforms, badges and vehicles.
2. Stay with—do not run from— safe “go to” police officers or other uniformed first responders.
3. Keep an appropriate distance when interacting with a law enforcement officer—or anyone else.
4. Avoid making sudden movements, i.e. putting hands into pockets.
5. Carry and safely show an ID card.
6. Disclose your autism, carry and safely show an autism information card.
7. Recognize inappropriate touching or sexual come-ons directed at them.
8. Effectively report bullying or other incidents.
9. Tell someone you need help, or use the phone to request it.

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

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

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

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

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



Community Life Resources

Recreation & Leisure:

What Leisure Activities Are Good Options for Adults with Autism, and Is It Important to Exercise Regularly?

by Toni Thomas, Family Program Manager, Emory Autism Center, Emory University School of Medicine

ABC News, October 23, 2008

www.abcnews.go.com/Health/AutismLiving/story?id=5930840

Safety:

Autism Risk & Safety Management

By Dennis Debbaudt

www.autismriskmanagement.com

Autism Speaks: The Autism Safety Project

www.AutismSafetyProject.org

Travel:

Travel Training for Youth with Disabilities

National Dissemination Center for Children with Disabilities' (NICHCY) Transition Summary

www.nichcy.org/InformationResources/Documents/NICHCY%20PUBS/ts9.pdf

General Community Life Information:

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

by Chantal Sicile-Kira

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

by Mary Korpi

Autism & the Transition to Adulthood: Success Beyond the Classroom

by Paul Wehman, Marcia Datlow Smith and Carol Schall

The Autism Transition Guide: Planning the Journey from School to Adult Life

by Carolyn Thorwarth Bruey, Psy.D. and Mary Beth Urban, M.Ed.



Americans with Disabilities Act

www.ada.gov

Life's Journey Through Autism, a Guide for Transition to Adulthood

Organization for Autism Research, Southwest Autism Research and Resource Center and Danya International, Inc.

www.researchautism.org/resources/reading/documents/transitionguide.pdf

Alpine Learning Group: Teaching Teenagers to Answer Cellphones

www.alpinelearninggroup.org/resources/documents/teaching_teenagers_answer_cellphones.pdf



