



REAL LIFE
Tips
for kids with autism

from the experts at

RWJBarnabas
HEALTH

**Children's
Specialized
Hospital**



REAL LIFE
Tips
for kids with autism



The Autism Diagnosis





Understanding the Diagnosis of Autism Spectrum Disorder

- Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that is characterized by impairments involving social communication and social interaction in many settings and restricted, repetitive patterns of behavior, interests or activities. The symptoms are present in early childhood but may not be noticed until later.
- The symptoms of ASD cause significant impairments but there is a wide range of functioning and need for support across the spectrum. Many people with ASD can function well in various areas of life including living independently, having mutually rewarding relationships, and meaningful employment and their need for support may be subtle. Others with ASD may need very substantial support in all major areas of functioning.
- Early diagnosis is important because early, specialized intervention helps improve functioning. Some red flags of possible ASD include: no babbling by twelve months of age; no single words by eighteen months; no two words used together by twenty-four months; no response to name or use of gestures by twelve months; or loss of skills at any age. Poor eye contact and not sharing enjoyment or joint attention are also red flags. Talk to your healthcare provider if you have concerns.
- Concerns about possible ASD may first be noticed by a family member, healthcare professional, child care or school staff, or at later ages by the person who suspects he or she has ASD. Talk to your healthcare provider about how to get a diagnostic evaluation.
- Children between the ages of birth and thirty-six months who have developmental concerns may qualify for services through their state Early Intervention Program. A diagnosis is not necessary. Contact information can be found on The Early Childhood Technical Assistance Center website at <http://ectacenter.org/contact/ptccoord.asp>.
- There is value in getting a diagnosis when ASD is present. A formal diagnosis helps link to needed services, helps understand and communicate what is going on, and may help link to support and reduce isolation.
- It is possible to have ASD and other diagnoses, too. These are called “co-morbidities.” Some common co-morbidities with ASD include anxiety, Attention Deficit/Hyperactivity Disorder, sleep or feeding issues, gastrointestinal disorders, or seizure disorders.
- There is a lot of information about ASD but not everything is accurate. Make sure the information source is credible.
- Quality of life is important. Involvement in the community can improve quality of life. In addition to skill development for the person with ASD, it is equally important that members of the community build awareness and acceptance to promote positive inclusion.





After your Child Receives a Diagnosis of Autism Spectrum Disorder

- Receiving a diagnosis of autism spectrum disorder (ASD) can be difficult for a family. Some parents may question if the diagnosis is accurate. If parents have questions, they can ask the provider about his or her training and to explain the types of diagnostic tools used. Discuss any concerns in diagnosing ASD. While some may seek a second opinion, be mindful not to delay getting needed services.
- Along with a diagnosis of autism, parents have many emotions and may feel overwhelmed with all the options for treatment and therapies. After a child has received a medical diagnosis of autism spectrum disorder, parents should seek a reputable healthcare provider, particularly a developmental pediatrician or advanced practice nurse, who specializes in autism and has experience treating the disorder. After meeting with the physician, parents should work together to develop a treatment plan that addresses the child's specific speech and language, occupational, physical, and behavioral needs.
- Parents and caregivers can read books and search the internet to find information about autism as well as resources such as local services, interventions, therapies, programs, and supports. Parents can explore government agencies, organizations, research studies, and local groups that can provide information, guidance, and support. Searches may also help to identify conferences, webinars, and workshops providing current educational, medical, and therapeutic information. By attending, parents can also network to connect with other families, professionals, and community service providers in their area.
- Parents should contact either the early intervention program or the special services department in the local school district as early as possible. These organizations are the primary source of academic and educationally-based therapeutic intervention for the child.
- Parents might find it helpful to set up some folders or large envelopes in a organizational bin or filing cabinet to store information. It will be helpful to have a centralized location to keep information about service providers; medical, therapy and school reports; schedules; receipts and financial information; reading material; and other information related to the person with ASD.
- Revealing the diagnosis of autism to others is a personal decision. Those who work with families of children with ASD on a regular basis find that it is most helpful for families when others are aware of the child's needs. Without this knowledge, people may misunderstand the child's behaviors. People tend to be more understanding when they are educated about the disorder and aware of the child's strengths and challenges. Disclosing the diagnosis to those involved with the child helps them to support the child's needs.
- It's important for children with ASD to be exposed to as many learning experiences as possible. Since many children with ASD have difficulties with communication, social interaction and transitions, community experiences are great opportunities for learning. It may be difficult for parents to bring their child with ASD to common places like the grocery store and library because of the difficulties these children have. It may take additional planning and support, but these experiences provide practice and help the child become more familiar with the community and other people.





Explaining the Diagnosis of Autism to Family and Friends

- No matter what reaction parents have to their child's diagnosis of Autism Spectrum Disorder (ASD), it's important to give sufficient time to come to terms with what the diagnosis means to them and their family. Parents should educate themselves about the disorder and discuss what information they feel comfortable sharing with family and friends.
- The diagnosis can be a challenging experience for parents as they may fear that they may not be accepted or included as they were in the past. Honesty is usually the best policy. Initially, it can be easier for parents to tell others about specific symptoms, rather than the full diagnosis. For example, a parent may initially choose to say that the child is receiving speech therapy for a speech delay before disclosing the full diagnosis.
- When ready to disclose the diagnosis to others, provide information specific to the child. Autism is a spectrum disorder and affects every person differently. Find trustworthy information which describes the characteristics of autism and offer information specific to the child's challenges. Comprehensive information for family and friends can be downloaded from www.childrens-specialized.org/KohlsAutismAwareness.
- Family members and friends will have their own feelings about the child's diagnosis. It's all right to share these feelings together. Even after they learn of the diagnosis, they may not know how to respond to or help the child. Parents should take the time share suggested ways to communicate, interact, respond, to and care for their child.
- Let friends and relatives know that it is important to be treated like other family members and friends, and not excluded.
- ASD symptoms may be subtle. Family members and friends may not realize that the child may have difficulty tolerating lengthy visits, being touched by others, or involved in social demands. Parents should prepare family and friends as well as the child; communicate needs; and establish rules and boundaries, so that gatherings can be more pleasant.
- To help improve the child's social interactions and play skills, it's important to get cooperation and support of family members on a regular basis, . Grandparents and other family members may have more time and energy to engage with the child and help with a parent's demanding schedule.
- Family members may not understand special techniques or interventions that are being used for the child. Many types of early intervention programs are structured to engage the child and family together in the home or a familiar environment. This provides opportunities for other family members to participate in these techniques and get exposure to the therapist working with the child. These interactions can help to demystify some of the interventions that parents use to help their child, by learning directly from the professional. As a result, family members and friends can better support the development of the child's skills.



REAL LIFE Tips

for kids with autism



Family Concerns





Brothers and Sisters of a Child with Autism

- It is important to be aware of the different feelings that siblings of a child with autism spectrum disorder (ASD) may be experiencing. These feelings can change throughout the sibling's life. Although family life and schedules can be time consuming, siblings of a child with ASD need to have time to express their emotions and needs. You may have to initiate these conversations to show that it is all right to discuss and that you are interested in their needs and perspectives.
- Spend a consistent amount of time with the child's siblings to talk and share. Short trips to the grocery store, a ride to a friend's house, and time before bed can be time shared just with them. It is important to recognize their needs as well as to celebrate the successes and good things happening in their lives.
- Provide the siblings with age-appropriate and reliable information about ASD. Without knowledge, brothers and sisters may assume incorrect information. They will be able to better understand their sibling's actions and needs if their understanding is accurate. Ask what they know about ASD in order to correct possible inaccuracies.
- Let the child's siblings know that it's alright to express their emotions honestly, without criticism. Brothers and sisters of children with ASD need to be able to share the way they feel. Honestly share your emotions with the siblings so that they can identify with them and be more open to share theirs, as well.
- Although they will develop a relationship all their own, brothers and sisters may need help figuring out ways to communicate and to play. Help the siblings learn how to interact with their brother or sister. Provide opportunities and choices for sharing without forcing the brother or sister to engage in ways he or she may be uncomfortable. Help them understand that they can interact with each other even if they are different. Find ways to protect the belongings of the siblings. This may involve placing them in secure locations or teaching the children how to prevent and respond to these situations.
- Be careful not to place too many expectations and responsibilities on the child's siblings. The brother or sister may feel increased responsibility caring for the sibling with ASD. Caregivers can contact their local school district, college, community organizations, neighbors, religious communities, family members, case manager, and their physician to find people who could provide respite care. Governmental agencies may also be able to provide respite workers or financial support for the respite needs of families.
- Find ways for the siblings to engage in age-appropriate recreation and leisure activities with friends and family. Develop ways for the siblings to feel comfortable bringing friends to the home. Everyone needs to have some time to have some fun and respite from the challenges that many families experience with a child with ASD.
- It may seem to siblings that they have more responsibilities than their brother or sister with ASD. Involve the child with ASD with household tasks that he or she is capable of accomplishing. Social stories, activity schedules, and charts can be used as tools for these activities. A template for a social story as well as other resources are available at www.childrens-specialized.org/KohlsAutismAwareness. Help the siblings understand that responsibilities may seem unequal, but that they are fair.
- Find ways for the siblings to connect with others their age who have brothers or sisters with ASD. This helps them to feel linked with others who understand.
- Help the child's siblings learn methods to handle comments about their brother or sister. The siblings may help with words to use as a response to questions or remarks from others. Work together so that they are comfortable with what they say.

- When a sibling expresses or shows anger or is upset by the brother or sister with ASD, provide ways for the child to express these emotions in a healthy and safe manner. Support groups, counseling, art, music, and sports are some ways to express these emotions.
- Siblings of children diagnosed with ASD may be at higher risk of developmental problems. Talk to your healthcare professional about developmental screening for the siblings.





Tips for Caregivers

- Sorting through the complex challenges and issues related to caring for a child or children with autism spectrum disorder (ASD) can be challenging. Adding employment demands, the care of other family members, maintenance of a household and other personal matters, caregivers have little time or energy for self care and personal interests. Although it seems difficult to ask others for help, it is important for caregivers to seek assistance to reduce these demands.
- Try to identify the issues which are most difficult to handle. Local governmental agencies that focus on family members who have disabilities can help. Local libraries and the special services department of school districts have a list of these agencies readily available.
- Life may be different for families caring for a child with ASD. With these differences, it is still possible to enjoy various aspects of life with planning and support. As difficult as it may seem to involve a child with ASD in recreation, leisure, and family activities, the more a child with ASD is out in the community, the more he or she has opportunities to become familiar and comfortable. These outings can be pleasant diversions from many of the stresses of everyday life.
- Many children with ASD exhibit challenging behaviors and may not respond to discipline methods effective for other children. Caregivers should seek professionals and resources to help modify these behaviors and develop coping skills. Lists of local service providers can be found on many autism websites, from local libraries, or from the child's school district.
- Connecting with other families who have children with ASD can help. Spending time with other caregivers who have similar interests, challenges, and experiences can reduce anxieties and feelings of isolation. Look for people or support groups that provide positive input and reliable resources. These connections can reduce isolation and help caregivers feel empowered.
- Many hospital and doctor offices have staff who are also parents of children with special needs. Caregivers can contact a social worker or representative from the facility and ask to be connected with staff who have this background and understanding.
- It is helpful for caregivers to set consistent routines as part of daily life. As appointments and meetings are common, try to let the child know about schedule changes ahead of time to help alleviate challenges with disruption in the routine.
- Find areas in the home where the child with ASD feels comfortable and engaged in an enjoyable activity. Caregivers can find comfort near the child to read, exercise, write, or other activity of personal interest.
- Respite care is a basic need for families living with ASD. Respite means finding the time to take a break from many of life's demands. This supports caregiver well being and helps preserve family balance. Respite, in small or large amounts, can happen in or out the home. Caregivers can contact their local school district, college, community organizations, neighbors, religious communities, family members, case manager, and their physician to find people who could provide respite care. Governmental agencies may also be able to provide respite workers or financial support for the respite needs of families.
- When a respite care worker has been identified, start with small amounts of time. Both need to become familiar with each other as well as preferences and routines. The respite time can be expanded once there is a comfort level. Respite can begin while the parent or caregiver is in the house in another room. Then it can be expanded for a short trip out. The goal is for caregivers to have multiple respite providers in place on order for the caregivers to have sufficient time to get the rest and leisure activity they need and for the person with ASD to get used to a variety of helpers.

- Many times caregivers may not realize they are neglecting their health and well being. Family members and friends may suggest counseling or medical intervention. It is all right for caregivers to get the help that they need. Family and friends may want to help in many ways, but may not know how. Caregivers should let them know the ways that they can be helpful in practical and meaningful ways. There is no shame in getting the help needed if it makes the helper feel needed and wanted.





Errands and Outings

Involve your child with autism spectrum disorder (ASD) on community outings as much as possible. Although it can be challenging, it is worth it because it exposes the child to many learning experiences. It may take additional planning and support, but this practice helps to make the experiences more comfortable and enjoyable.

- Try to plan an agenda for the outing or for the day. Use a picture or written activity schedule to provide the child with a plan. Try to include other options that may happen as a result of unexpected occurrences such as bad weather or a store closing early. Explain the activities and expectations in understandable ways. A template to create social stories, as well as other helpful resources, can be found at www.childrens-specialized.org/KohlsAutismAwareness.
- It is often helpful to give the child appropriate tasks to do during the outing. Let the child pick out items, help with the grocery list, compare prices, or find a particular color or size. Create games during errands to help occupy the child or distract him or her from other challenges that may arise.
- Shopping experiences can be challenging for people with ASD. At first, it may be helpful to go for short trips or to get familiar with the environment and social interactions. Going out with other families can provide additional support if challenges arise.
- Many things can happen during an outing, so try to be as prepared as possible. Bring along toys or activities that are enjoyable in the car and during the outing. Understand it may be necessary to leave the location or change plans if behaviors get too challenging.
- When going to a restaurant, try to prepare ahead of time and have a plan. Let the child pick his or her food choice before getting to the restaurant. Ask for the check as soon as possible after the food arrives to save time. It may be helpful to ask to sit at a particular table that is most comfortable or away from distractions. It is acceptable to remove items on the table that may be distracting.
- It is helpful to return to familiar places, particularly those that have been accommodating to the needs of the child and family. Get to know the owner, manager, or staff so that they can learn more about the interests and needs of the child. Typically, the staff want to be helpful but may not know how to help. Open communication helps them to provide support if negative situations arise.
- People in the community may stare or have opinions about how the child with ASD is behaving. Decide ahead of time how to respond. It may be helpful to use the opportunity to educate about autism, as a way to make a positive community connection, or it can be ignored.
- Social outings can be more positive if they can be related to an interest of the child. After a child gets used to these experiences, the child can begin to explore other destinations.



REAL LIFE
Tips
for kids with autism



Communication, Social,
and Sensory Concerns





Building Social Skills

Many children with autism spectrum disorder (ASD) lack important social skills such as taking turns, sharing, and joining in games. These skills are important in school and in life and are essential for developing meaningful peer relationships. Although social skills are often difficult to learn, there are methods that can help to develop these skills to help children with ASD lead full and social lives.

- There are three general ways to approach social skill learning. (A) Request that the school offer social skill lessons and activities in the child's classroom, at lunchtime, and in after school programs. Formal goals and activities can be part of the child's IEP. (B) Seek out outpatient social skills programs from a local healthcare provider. (C) In natural settings, role play and model various types of social interactions.
- There may be social skills groups within the community that are appropriate for your child. Look on the internet, ask your child's pediatrician, contact your local library, or look in a local parent's magazine for suitable groups in your area. Seek out community groups which focus on an area of interest for the child, such as an acting class, chess group, or reading club.
- There are generally four social skill areas that are targeted. (A) Work with the child on conversation skills. (B) Help your child with the skills needed to develop and maintain positive relationships. (C) Share activities that help your child express his or her feelings and emotions appropriately. (D) Develop practical conflict management skills. These skills should be taught and practiced among different people in different environments so that they can be useful in all areas of the child's life.
- Take the time to prepare for social situations before they occur. Use pictures, television shows, and videos to illustrate various scenarios. Watch the shows together to discuss the character's actions, choices, and reactions of others. During social interactions you can cue and reinforce appropriate social skills. Afterward, discuss the interactions with your child and develop strategies to improve challenges that may have occurred. You can take videos of your child and provide feedback and reinforcement.
- Programs are available to help other children understand differences and be more inclusive of children with different challenges. www.childrens-specialized.org/KohlsAutismAwareness has many resources available teachers, after school providers, team coordinators, youth group leaders, and others who work with children.





Communication Challenges

- Motivating a child with autism spectrum disorder (ASD) to communicate may take some creativity. Playing or activating a toy and waiting for a response is difficult but will be worth the wait. It allows you to watch your child's reactions and determine his likes/dislikes without a verbal cue. Create opportunities for the child to initiate communication by avoiding leading questions such as, "Tell me what you want" or "Do you want this or that?"
- Place items which are highly desirable to the child in locations that are visible yet out of reach. This may stimulate the child to communicate in some way to get what he wants. In time, begin to place the items in locations that are not visible to the child in order to further develop communication.
- As there are different forms of communication, take the time to observe behaviors. Movements, gestures, and eye gazes often signal messages that may be overlooked.
- Try to use visual prompts instead of verbal cues. When giving a direction, try to use hand motions or gestures instead of speaking. Children with ASD respond more often to visual cues than to oral commands. Gestures are easier to fade than verbal directions.
- Choice making is part of communication. Instead of asking for the child to choose between items, present the items visually and wait for a response. Watch to see if the child looks or points to the item of choice.
- Although a child may not speak, it is helpful to talk out loud about what he or she is doing and what you are doing. If the child speaks with single words, expand what is said into a simple phrase.
- It is important to know that sign language, picture communication systems, and other alternative forms of communication do not inhibit a child's verbal communication. These methods actually facilitate speech production by relieving stressors from verbal speech difficulties and providing the child with a method to communicate.
- There are many apps that are available on electronic tablets. When using these devices, it is important that the child differentiates which apps are specific for communication and which ones are designated for play or leisure. One strategy is to have two covers for the tablet, each with a different color. Consistently change the cover on the tablet when alternating from speech apps to leisure apps.
- Speech therapists and other professionals provide their best suggestions to help a child with his or her communication challenges. However, every family needs to balance the care of other family members, maintenance of a household, employment demands, and other personal matters. To help you support your child at home, it is very important to openly communicate your family's needs, priorities, and how much time is available to support the recommendations.





Sensory Challenges

Many people with autism spectrum disorder (ASD) experience sensitivities to different types of sensations. Some people may over-react to sensations and others may under-react. They may be overwhelmed by bright lights or loud noises or may seek out sensory input such as active play or chewing crunchy foods. These sensitivities can change in different environments and at different times of the day.

- When going on errands and outings, let people know ahead of time about the child's needs. Adaptations may be able to be made to make it easier for the child to tolerate. Provide some suggestions of how they can help. If going to a new place, try to make the first visit at a time when there are minimal crowds and other sensory challenges. The child may only be able to tolerate a few minutes at the location, but try to increase the time each visit.
- During sensory-challenging activities like hair cuts, you place a heavy toy on the child's lap for comfort.
- Provide the child extra time to listen or to complete tasks. He or she may need some extra time sorting through the sensory input.
- When the child seems to feel overwhelmed, provide him or her with a quiet area. The child may also be calmed by a certain toy, object, or activity. A stress ball or heavy backpack may help to calm the child.
- If a child has difficulty engaging in stimulating activities like craft projects, amusement parks, or hair cuts, try activities such as playing with beans, rice, or pudding beforehand. This can help prepare the child for the sensations in the following activity. If the child needs additional sensory stimulation or to help him or her before a sensory-stimulating activity, arrange for outside play, exercise, or experiences with sensory stimulating activities such as clay, squishy balls, instruments, swinging on a swing, or finger painting, jumping jacks, or running. Chewing on crunchy or chewy snacks may be helpful. Children with ASD may need this extra sensory input to help them to focus and remain calm.
- Ear plugs or earphones may help reduce noises for those with sensitivity to sounds.
- Prepare a social story or activity schedule to show what is involved in an activity or what the person can expect at a location.
- Occupational therapy can help identify those things that help to calm the child and work through challenging sensations. It may take some time, but the child can become more aware of his or her body and find ways to comfort themselves before, during, and after sensory-challenging experiences.



REAL LIFE Tips

for kids with autism



Behaviors





Using Applied Behavior Analysis in Daily Activities

Applied Behavioral Analysis (ABA) is an scientifically-based intervention which focuses on teaching new skills; maintaining or increasing appropriate behaviors; helping to generalize skills in different environments; and reducing or eliminating inappropriate or problem behaviors. ABA has been proven to be an effective intervention for people with autism spectrum disorder (ASD) when supervised by a certified behavior analyst. ABA techniques may sometimes seem un-natural, prompted, and rigid. However, these structured and consistent teaching methods reduce distractions and allow for focused learning.

ABA techniques can be used in all aspects of life and can improve the quality of life for a child and his or her family.

- Often, children ASD need to learn appropriate skills for routine daily activities. When teaching and practicing these skills, it is important to reinforce the child when he or she is successful to encourage these actions to continue.
- Larger activities may need to be broken down into smaller parts and reinforced before a full activity is learned. Sometimes these rewards may seem out of place, as the child may not understand the efforts toward a larger goal. These reinforcers motivate continued learning.
- When working to change inappropriate or challenging behaviors, it is helpful to identify why the child may be engaging in the behavior. See a challenging behavior from his or her point of view in order to intervene effectively.
- Prompting may be needed to assist the child in learning a skill, but should be reduced or eliminated as soon as possible. Use the least amount of prompting necessary. If the child is not doing the activity independently, first try to tell him or her to do it. If the verbal instruction doesn't work, point or make a gesture. Then, if the instruction is not followed, physically prompt to carry out the task but back away to allow the child to complete the task without full assistance. Keep practicing and fading away your prompts to promote independence.
- It is important to teach a child appropriate skills in order to replace inappropriate behaviors. Take the time to observe what happens before and after the behavior occurs. Notice how you or others respond to this behavior as that can be reinforcing the actions. You can use an "A-B-C" (Antecedent, Behavior, Consequences) worksheet to identify behavior patterns and motivators for problem behavior and help to develop strategies to change the behaviors. A blank worksheet can be found at www.childrens-specialized.org/KohlsAutismAwareness .





Challenging Behaviors in Public Places

For children with autism spectrum disorder (ASD), challenging behaviors occur for many reasons. It is important for them to have appropriate skills when trying to get, avoid, or cope.

- Observe a behavior to determine where it happens most and least. Perhaps it happens with specific people, at certain locations, during certain times of the day, or as a result of particular sensory experiences.
- Consider the child's perspective when attempting to determine what's motivating the behavior. Seeing a challenging behavior from his or her point of view can help to prevent or respond more effectively.
- Teach appropriate skills when the child is not in the environment where the behavior occurs. For example, teach walking together, waiting in line, sharing toys, or tolerating transitions at times when these skills can be practiced without other demands. When the child behaves correctly, it can be helpful to provide immediate and meaningful reinforcers to encourage appropriate behaviors and motivate continued learning.
- Visual aids can help the learning process by illustrating and describing appropriate behaviors. These tools can include social stories, schedules, and videos. Timers are helpful to give the child a sense of how long he or she will be doing something. A template to create social stories, as well as other helpful tools, can be found at www.childrens-specialized.org/KohlsAutismAwareness.
- Routine errands such as going shopping can be challenging for children with ASD. At first, it may be helpful to go for short trips or to get familiar with the environment and social interactions. Many things can happen during an outing, so try to be as prepared as possible. Bring along toys or activities that are enjoyable.
- Before you take the child to a new and unfamiliar place, it may be helpful to find out about the location before you go. By going there first, reviewing the website, or calling the facility, you can ask about the location from the perspective of the child's challenges and needs. This information can help you prepare for potential issues at that location.
- People with ASD may need to take breaks when engaging in activities outside of their routine or comfort level. Help the child establish a way to let you know they need a break, help, or a place to go to calm down.
- Although it may be difficult, if challenging behavior occurs, try to remain as calm as possible. Adding additional tension to the situation may aggravate it even more. Take a deep breath and think about what will protect the child and those around and what will help calm him or her. Sometimes it may be finding a safe and quiet location. Going out with other family members or friends can provide additional support if difficult challenges arise. Having back-up from those who understand what to do can provide encouragement and assistance as needed.
- When in public places, people may not understand the behaviors that are related to autism. It may help to have a card available that can be given to others to raise awareness.





Preparing for Transitions Between Activities

- Transitioning between activities or locations can be difficult for people with autism spectrum disorder (ASD). Anticipating some of the challenges and preparing ahead of time can help reduce these challenges.
- Prepare things ahead of time to help to reduce the number of demands on the child during transitions. Having the child's clothes and food ready the night before can make the morning less stressful.
- People with ASD may not understand time alerts, such as "We'll be leaving in fifteen minutes." It may be more helpful to use other signals such as "after one more commercial on TV" or "after two more turns in the game." Be consistent and follow through with specified transition times. Resist the temptation to extend the timeframe as the child will learn that he or she can delay or avoid the transition.
- Try to anticipate what may happen during an expected transition and plan accordingly. For instance, if it is difficult for a child to leave for school after watching TV, then don't allow him or her to watch television during the morning routine. Because you can't always anticipate what might go wrong, communicate that the uncertainty of the next activity and alternatives to the one planned. You never know if a store may be closed or an amusement park ride may be broken.
- When transitioning from an enjoyable activity to one that is less preferred, offer the child a toy, snack, or other item that is interesting to him or her. This helps to distract and comfort the child and ease the transition process.
- Visual aids and other tools such as social stories, activity schedules, timers, and transition cues can help a child understand the transition before it happens. A template to create social stories, a visual countdown tool, and other helpful resources, can be found at www.childrens-specialized.org/KohlsAutismAwareness.
- Families with multiple children often need to attend activities or appointments for the siblings of a child with ASD. To help a child transition to an activity that may not be enjoyable to him or her, pack a bag of preferred items such as toys and snacks to make it more exciting.
- Transitions can be difficult at any time. However, after a long day or after challenging work, these changes can be more difficult. There may need to be a few times when you need to change plans in order to prevent negative reactions or to handle other critical matters.



The ABCs of Behaviors

Antecedent

What happened before the behavior occurred?
Who was there and where did it happen?

What happened before?
Where did it happen?
Who was there?

What happened before?
Where did it happen?
Who was there?

What happened before?
Where did it happen?
Who was there?

What happened before?
Where did it happen?
Who was there?

What happened before?
Where did it happen?
Who was there?

Behavior

What is the specific behavior that occurred?

Consequence

What was done or said after the behavior occurred?

What happened before? Where did it happen? Who was there?		
What happened before? Where did it happen? Who was there?		
What happened before? Where did it happen? Who was there?		
What happened before? Where did it happen? Who was there?		
What happened before? Where did it happen? Who was there?		
What happened before? Where did it happen? Who was there?		



REAL LIFE Tips

for kids with autism



Resources through Life





Accessing Medical and Therapeutic Services

- Evaluations and services are available when there are concerns about a child's early development. Through the Early Intervention Program, parents can request assessments and services for their child between the ages of birth and thirty-six months. Children found eligible for Early Intervention will receive an Individualized Family Service Plan (IFSP) which sets goals to help children learn the basic skills that typically develop during the first three years of life. Early intervention is authorized and available in every state and territory of the United States through the Individuals with Disabilities Education Act (IDEA). The Early Childhood Technical Assistance Center website (<http://ectacenter.org/contact/ptccoord.asp>) lists each state's Early Intervention contact information.
- After the age of three, children with autism spectrum disorder (ASD) and other disabilities can access services through the school system. IDEA ensures that a child with a disability is offered a free appropriate public education (FAPE) which provides special education and related services to meet his or her specific needs. Contact the local school district representative who coordinates these special services for more information about evaluations and services.
- Therapeutic services are available for all children with autism and other disabilities. Access to these services is not income based. Approach your healthcare provider and school district for evaluations to determine the services the child needs. If it is determined the child needs specific therapies and/or supports, these should then be prescribed by the physician or included within the child's Individualized Education Plan (IEP.) Therapies received in school are focused on educational goals. Those therapies received in a clinical setting can support educational goals, but are meant to treat the child therapeutically.
- Develop positive relationships with local agencies, physicians, therapists, and advocacy organizations. Having a network of reliable resources can help to navigate through the complex system of care and education and connect you with the services needed for the child. Because the child's needs will change as he or she ages, it is important to expand relationships with healthcare and educational service providers who are skilled in needs of that age group.
- Laws and services vary by state. Contact the local library or search the internet for state-specific information about medical and educational services and regulations in your state. Ask the child's school or agency case manager for a written document which specifies your child's legal rights.
- Ask questions and listen to healthcare providers, teachers, therapists, administrators, insurance representatives, organizational leaders, and other parents. Listen carefully to determine and understand what is available and possible for the child. Services that may not be available in one area, may be accessible through an alternate method.





Accessing Local Resources

- When there are concerns that a child is not reaching typical developmental milestones or if a child has been diagnosed with autism spectrum disorder or another disability, it is important to find local resources related to educational programs, legal rights, and disability services in the community. Talk to the child's pediatrician, occupational therapist, physical therapist, and other credible healthcare providers to help identify and access local resources.
- If your child is under the age of thirty-six months and you have concerns about his or her development, contact your local state Early Intervention Program for a needs assessment. Contact information can be found at <http://ectacenter.org/contact/ptccoord.asp>.
- If your child is diagnosed with a disability and is over the age of three, you can coordinate a needs assessment for the child and your family. The evaluation process is guided by special education law requirements specified in the Individuals with Disabilities Education Act (IDEA). A case manager can help you to locate and access educational, medical, financial, and other resources based on the child's needs.
- Connect with families and therapists in your area who have or work with children with ASD of different ages. As your child gets older, his or her interests and needs will change. It is helpful to have knowledgeable contacts who have experienced similar issues in your community.
- Revealing the diagnosis of autism to others is a personal decision. It is helpful when others are aware of the child's needs. Others may have similar experiences, needs, or challenges and may be able to share their tips and resources with you. With more awareness, you can better understand what you need, expect, and want from service providers.
- Look at the websites of your town and local school and contact your local library to identify resources for children with special needs in your community. There may be parent support groups, recreation programs, and other helpful resources for your family.
- There are national organizations with websites that map out resources by geographic area (see next page.) You can click on your state or county to find a list of resources surrounding you.
- Always examine the reliability of the source of information. Is the information current? Is the source related to an organization that has reliable knowledge of Autism Spectrum Disorder (ASD)? Does the resource claim that the information is applicable to everyone? Are they promoting or selling a product? Does the resource show personal, social, or political bias? Resources should provide reliable information by those with knowledge and experience, but should not claim they can cure or benefit everyone.





Common Education Challenges

- As part of the educational program of a child, there can be issues related to the amount, variety, or quality of services provided. Every child, every school, and every community is different. It is important to advocate for your child's needs throughout his or her education.
- The Individuals with Disabilities Education Act (IDEA) ensures that a child who has a disability is offered a free appropriate public education (FAPE) which provides special education and related services to meet his or her specific needs. Contact the school Director of Special Services with any questions or issues relating to the child's education program.
- You can call a meeting to discuss issues that are of concern. Because parents are active participants in the decision-making team, you can ask questions and make suggestions. You can provide recommendations from healthcare providers or other professionals that may be valuable to the child's educational program. The child's educational team may not agree with information or recommendations you have offered. However, many times, with some negotiation, a compromise can be reached.
- Take notes when meeting with a representative from the school or other professional who provides services for your child. This lets them know that you are interested in your child's education and what they have to offer. This can also serve as a record of the discussion. You can use a recording device at a meeting, but must let them know ahead of time.
- Whether you agree or disagree with the school team, it is very important to document all communication related to your child's education. E-mail correspondence is an excellent way to communicate as there are times and dates attached with each message. If sending a letter, request a return receipt in order to have confirmation of delivery. When submitting a letter or documentation by hand, ask for a signature of receipt. When contacting the school by phone, follow up with an e-mail to document the points that were made.
- At each Individualized Education Program (IEP) meeting for your child, the school team should provide you with access to a document which contains your child's educational rights. If you disagree with a school's decision and can't find a compromise, identify and review the process to file a complaint, request mediation, or due process.
- There are advocates who can help with educational issues related to your child with ASD. Some advocates can attend IEP and other meetings to help support the child's rights. Credible advocates understand education terminology and laws and can help negotiate with the school system to get the services the child needs.





Transitioning for School to Adult Life

There are so many things to consider as a child with autism spectrum disorder (ASD) gets older and leaves school. As complex as these changes can be, there's a lot of helpful information available.

- Contact your school district and local library for resources. You can search the internet for reliable tools to assist in transition preparation and planning.
- The sooner a parent or caregiver prepares for this transition, the better. From an early age, parents and teachers can begin to teach skills which promote self care and independence.
- It can be helpful to establish overall goals which are important to the family and individual with ASD. By prioritizing a few long-term goals, ongoing decisions in the transition process can be made based on those which are most important. This can keep short-term objectives in focus and help to reduce difficulties in immediate decision making processes.
- There are many skills which can be taught to lead to more independence. Children can learn small tasks with supports and over time progress to more independent activities. Independent living skills include personal hygiene; sleeping and waking independently; meal planning and food preparation; household maintenance; organizational skills; money management; social skills; transportation; safety skills; self advocacy; and recreation and leisure skills. Work with your child's teachers and therapists for help developing these types of skills in school, at home, and in the community.
- As part of the IDEA, Individualized Education Plans (IEP) legally must contain transition plans which include instruction, related-services, and community experience. The execution of IEP transition plans begins in early teen years. IEP plans can include a functional vocational evaluation as well as instruction and supports for daily living skills, employment, and other post-school adult living goals. Work with your child's district to include goals to support post-secondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, recreation, and community participation. These goals should always coincide with the child's capabilities, needs, preferences, and interests.
- When a child with a disability is in school, the Individuals with Education Act (IDEA) provides for his or her educational rights. Once a child is out of school, the IDEA is no longer applicable. At this time, equal access and reasonable accommodations for people with disabilities are the rights protected under the Americans with Disabilities Act (ADA). Unlike the IDEA, the person or legal guardian must self-disclose the disability and take the initiative to seek disability-related services that will meet his or her needs.
- Volunteering, job shadowing, and internships can potentially lead to part-time and full-time employment for adolescents with ASD.
- Some adult services such as housing provisions can take a considerable length of time to coordinate and access. Therefore, conversations and activities related to these long-range decisions should start early. These considerations and action plans should be made among family members. Decisions can change based on the age, interests, health, and needs of those involved.
- Speak to a professional about long-term planning, guardianship, health insurance, and other financial matters. These processes are often complex, lengthy, and expensive. Take the time to find a reputable source of support and guidance to handle these personal and important matters.
- It is important to speak with your child's pediatrician and special healthcare providers about the transition of his or her adult health care. Informational resources are available online. Take time to research and speak with medical providers who understand and support the needs of the aging child with autism spectrum disorder. Work with the child's pediatrician to develop ways to encourage greater independence in managing health needs such as directing questions directly to the child, when to examine the child without the parent in the room, encouraging the child to prepare for health visits by bringing a list of questions or concerns, etc.



REAL LIFE
Tips
for kids with autism



Safety





Safety at Home

- Common, everyday items in your own home could be dangerous for a child with autism spectrum disorder (ASD). Some children with ASD may throw or break things. Your child may turn lights or stove pilots on and off repetitively. Self-stimulatory behaviors that could be dangerous could involve such things as opening and closing scissors or banging glass items. Work with your school or a behaviorist to help change these potentially dangerous behaviors.
- Ordinary household items like cat litter, detergents, mouth wash, aftershave, and watch batteries are dangerous if swallowed. People with ASD may not understand this danger or may mistaken these items for a similar edible item. Be sure to secure or hide these items as well as medications and ointments. If your child has eaten something and you are not sure if it is safe, you can call the poison control hotline any time to ask for help. If your child has a life-threatening emergency as a result of eating any item, call 911 immediately.
- You can make, print, or purchase visual supports that can be used to identify things that your child should not touch. These signs could be printed with the word “NO” or “STOP” or a picture of the circle-backslash symbol (circle with a diagonal line through it) to indicate when something is prohibited.
- Families could use inexpensive magnetic alarms on doors, cabinets, or windows. These devices will alarm those in the house when a person has opened something that was off-limits. Although some safety devices typically used for toddlers may be helpful, older children with ASD are often too strong and resourceful for these items to protect from dangers. Durable locks and other devices are often better options. Furniture and shelving may need to be bolted to walls or floors. Breakable and sharp items may have to be removed to prevent injuries.
- It is helpful for emergency responders to be aware of safety issues that may add additional challenges when responding to an emergency at your home. Identify the agency that dispatches local 911 calls near your home. Schedule a meeting to speak with a person and ask that a ‘911 identifier’ be associated with your home telephone number. Provide critical information such as when you have additional locks or window bars, where your child may run or hide, triggers for challenging behaviors, and alternate forms of communication used by your child. This information would display on the screen when an emergency call is placed and helps responders be better prepared to protect or rescue your child.
- Children with autism may not recognize fire dangers or comprehend the damage a fire can cause. In addition, a child may not understand fire drills and alarms. In fact, alarms may trigger unpredictable and potentially dangerous behaviors. The child may run to a place where he or she feels comfortable which may be unsafe. Visual tools such as picture cards, social stories, and video modeling can help a child learn fire safety skills and other safety skills in your home. Role playing can also help children practice ways to act safely. Ask your child’s educational team to include some safety goals as part of your child’s IEP. These skills should be practiced at home with different members of the family to increase understanding and to reinforce the skills in multiple environments.
- Before teaching your child to call 911 in an emergency, by sure he or she understands what a true emergency is. Help him or her with the skills needed to provide information and to answer questions during this call. In addition, the child needs to understand instructions and to follow the direction of the emergency dispatcher as well as first responders.
- People with ASD are often attracted to water and may not know how to swim. They may not understand the danger of drowning. If you have a pool, secure it appropriately with fences and locks. Discuss potential water dangers with your neighbors and relatives who have pools so that they are aware of your safety concerns. Work with community recreation providers to coordinate swimming lessons and water-safety skills for your child.
- Discuss your child’s safety challenges with your family, friends, and neighbors. Safety skills learned in your home may not transfer to other locations. It is in your child’s best interest to have as many people as possible understand information related to the safety of your child and the concerns of your family.





Safety in the Community

- Many children with autism spectrum disorder (ASD) have a tendency to run or escape suddenly from an area, unlock or open protected environments, or wander away from a responsible caregiver. These children may find themselves in an unsafe place or situation, involved in unfamiliar social situations, or lost without the ability to seek or ask for help. It is important for children with ASD to carry a form of identification with them at all times.
- If your child has communication challenges, teach him or her ways to answer simple questions like “What is your name?” or “Where do you live?” You can also teach your child to present an identification card when asked these questions. Because a person’s reaching into clothing can be misinterpreted, you can fasten the I.D. card to a retractable keychain and attach it to the outside of clothing so that it remains visible to all. A medical identification bracelet with the person’s name and contact information can also be worn.
- Many regions throughout the country have electronic tracking systems available which serve to help locate a person who is wandering. These tracking devices can be purchased or rented. Once a family is enrolled, they can notify the emergency team when the person is missing. The tracking device is worn on the person’s wrist or ankle and emits a electronic signal so that a Search & Rescue team can find the person sooner.
- Children with ASD are often attracted to water and may not know how to swim. These children may not understand the danger of drowning. Work with community recreation providers to coordinate swimming lessons and water-safety skills for your child.
- Get to know some of your local police officers, firefighters, and rescue workers. Let them meet your child and help them to understand some of his or her challenges. Help your child learn to recognize their uniforms, interact with them, and know that they are “safe people” to go to for help and listen to during an emergency.
- Many states, counties, and towns have established special needs registries which inform emergency responders about the location and needs of people with disabilities in the area. These registries provide vital information for emergency service agencies so that they can prepare necessary resources and respond appropriately. Register your child by providing details about his or her particular challenges and needs before a disaster happens.
- Discuss your child’s safety challenges with your family, friends, and neighbors. Safety skills may not be transferred to other locations or with other people. It is in your child’s best interest to have as many people as possible understand information related to the safety of your child and the concerns of your family.
- As a means of preparation and prevention, purchase or compile a child identification kit containing your child’s fingerprints, current photo, and other means of identifying your child. Your local police department may be able to prepare a kit for your child.
- Using visual tools such as picture cards, social stories, and video modeling can help teach and practice safety skills. Role playing can also help children to practice ways to act safely and interact with people in various situations. Ask your child’s educational team to include some safety goals as part of your child’s IEP. These skills should be practiced at school, at home, and in the community to increase understanding and to reinforce the skills in multiple environments.



REAL LIFE Tips

for kids with autism



Health and Daily Living Skills





Visits to a Doctor or Dentist Office

- Ask other families who have children with autism spectrum disorder (ASD) about the dentists and doctors they prefer. Every child is different, but it is helpful to find reputable healthcare providers who have experience treating children with ASD.
- Ask the healthcare provider if you can schedule a practice visit in order to meet and get to know the office staff and healthcare provider. Discuss the child's method of communication, interests, challenges, and things that calm and motivate him or her. Because many people with autism have various levels of sensitivity to sound, touch, light, and other sensations, it may be helpful for the child to become familiar with equipment that may be used, before the appointment occurs.
- Patience and time are especially important to successful medical appointments for people with ASD. Request an appointment time at the end of the day so that it will not feel rushed and healthcare staff can focus on the needs of the child.
- When going to the appointment, let the child bring his or her favorite toy or video game. This will help him or her feel more comfortable and occupied during the wait and office procedures. Ask the provider to interact with the child before the examination and to permit the child to sit on the floor or on a parent's lap to play with their toy or game rather than sit on an exam table.
- Visual aids can help to familiarize various medical and dental procedures. Social stories and activity schedules can be used to describe and illustrate methods and equipment. It may also be helpful to role play with the child to practice various medical and dental examinations such as using a stethoscope, getting an X-ray, and opening the mouth while sitting in a chair. A template to create social stories, as well as other helpful resources, can be found at www.childrens-specialized.org/KohlsAutismAwareness.
- Ask the healthcare provider to explain a procedure before it happens and to specify each step as it happens. This may help the person with ASD make sense of what is being done.
- When emergency care is needed, it is important to tell the emergency healthcare providers about the child's overall health status, challenges, changes in behavior, and any related diagnoses or "co-morbidities." These may include anxiety, seizure disorders, gastrointestinal disorders, Attention Deficit/Hyperactivity Disorder, and sleep or feeding issues. This information can help prevent misinterpretation of symptoms or suggest additional testing. In addition, let them know if there are any specific triggers that may cause challenging behaviors to occur.
- It may be helpful for school staff to target lessons that prepare the child for healthcare appointments. For example, a procedure can be broken down into small steps by school-based therapists and staff and practiced with family members at home.
- When injections or blood draws are needed, it is common to request additional staff for the procedure. Locate a phlebotomist who is familiar with working with people with ASD and discuss preferred reinforcers and challenges related to the child to help make the procedure successful.
- It may be helpful to work with a behavior therapist to assist in pre-teaching skills related to doctor and dentist visits and procedures. Sometimes arrangements can be made for a therapist to accompany the family to assist in these appointments.





Feeding Challenges

Children with autism spectrum disorder (ASD) often have difficulty with feeding as it relates to rigid behaviors, particularly the inability to change routines and foods. They may exhibit sensory challenges or have gastrointestinal issues, as well.

- In order to help the child ASD be able to sit at a table and participate in mealtime activities, parents and caregivers should develop a consistent mealtime schedule. When children eat little bits “on the go” throughout the day, they are often not hungry at mealtime. Parents should provide structured meals/snacks every one-and-a-half to two hours, offering only water between meals and snacks. This helps to establish a hunger cycle, and increases the likelihood that the child will be more interested in exploring and trying new foods.
- Many times children with ASD want to eat the same foods, in the same way, all the time. To make sure children eat a varied diet, families are encouraged to present foods not in the original containers – in bowls or plates – so that the child doesn’t get used to seeing specific packaging. Use different cups, plates, and utensils so that the child becomes less rigid and more likely to use a variety.
- Present foods even if the child is unlikely to eat it. It may take up to twenty presentations of a new food before a child will accept it. It is encouraged for children with ASD who have difficulties trying new foods to play with various foods. This type of engagement helps to explore the sensory properties of foods – the look, taste, touch, and smell. Touching food is often less challenging than eating it. Place foods on fingers and hands in fun ways, then gradually progress toward the face and mouth. Include other families in these play experiences to reassure the child that eating is pleasurable.
- Sometimes children can have sensory responses to food, such as gagging or vomiting. Try not to over-react to those vomiting behaviors as sometimes it is purposeful as a method to avoid eating. If the food is withdrawn when the child vomits, the child will learn that he or she can get out of the feeding activity and demands by exhibiting that behavior. Gagging is typical for all children as it is a protective way to make sure what is swallowed is safe. Positively reinforce anything that the child does to try a new food. Try to ignore negative behaviors that may be exhibited.
- Parents can seek out comprehensive evaluations for their child who has feeding difficulties. Many hospitals and other healthcare providers have feeding teams who can assess various issues related to feeding problems. These evaluations may include a physician, occupational therapist, speech therapist, nutritionist, and/or mental health professional, in order to assess the whole child and determine if there are medical, sensory, behavioral, nutritional issues affecting the child.
- If the child exhibits frequent episodes of constipation or diarrhea, or you suspect reflux or food allergies, discuss with the child’s pediatrician or a pediatric gastrointestinal specialist who is familiar with children with special needs.

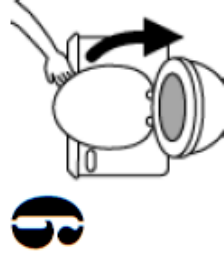
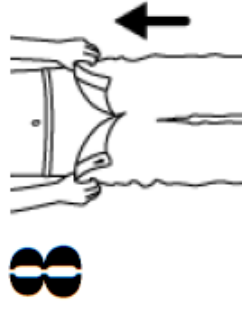
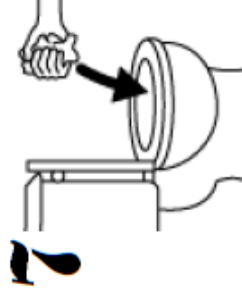
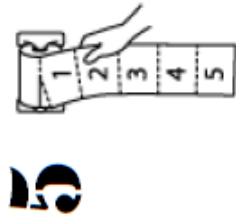
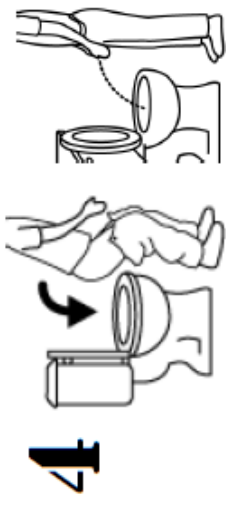
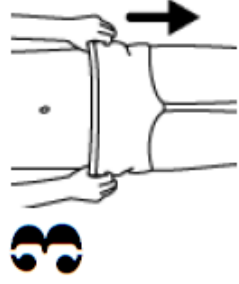
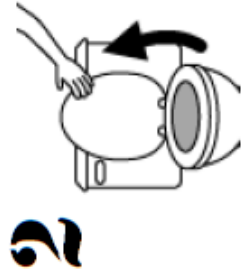
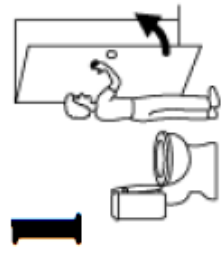




Toileting Skills

- Toileting independently is an important skill that affects quality of life and social acceptance. Not being toilet trained can create social barriers and prevent participation in recreation programs and impact employment opportunities. Work with teachers and therapists to develop toileting skills.
- Teaching this skill can be easier if a person shows readiness signs for toileting. Readiness signs include staying dry for an hour at a time, following one step commands, and understanding cause and effect. Looking uncomfortable when wet or soiled may not be a readiness sign for people with ASD due to reduced body cue sensations.
- Commit to toilet training. It can be challenging, but it is worth it.
- When committing to toilet training, it is important that the person wear underwear instead of diapers or pull-ups. The person needs to begin to recognize the sensation of feeling wet or soiled. Disposable garments prevent a person from that sensation.
- One method is to have the person practice sitting on the toilet for two minutes at a time, with five minute intervals between practice sessions. Choose a time when the person is most likely to need to have to “pee” or “poo.” During these times, provide cues for actions required for toileting.
- Find a reward that is highly motivating for the person and only associated with toilet training. Let this reinforcer be visible in the bathroom, but not accessible – indicating that it will be given as a reward for successful toileting.
- If the person wets or soils himself or herself, have him or her participate in the changing and cleaning processes as much as possible. Be calm and remind the person that the “pee” and “poo” go in the toilet. Have the person assist in undressing, cleaning, and washing hands.
- Once signs of success have been observed, work on ways to encourage the person to self-initiate the toileting skills.
- Visual schedules and charts can be helpful for many people with ASD. A sample schedule is available at www.childrens-specialized.org/KohlsAutismAwareness . Having this type of schedule laminated in the bathroom can serve as a guide during the toilet training process.
- A helpful teaching tool is to model appropriate toileting skills. A trusted family member could bring the person into the bathroom to demonstrate the steps of toileting. If this is not comfortable, there are toilet training videos available to use as visual models.
- It is important to be consistent when teaching toilet training skills. Communicate among all the people involved in the life of the person with ASD, including teachers, therapists, relatives, friends, and other caregivers. It is helpful to have a written plan about how the person currently performs the skills, how often he or she goes to the bathroom, what terminology is used, what rewards are given, and how to handle toilet training accidents.





These and other images are available from Do2Learn <http://www.do2learn.com>







Personal Hygiene

- Personal hygiene is essential for everyone as it affects health, socialization, and employment. When teaching personal hygiene skills to a person with autism spectrum disorder (ASD), it is helpful to know what age-appropriate skills are expected.
- For individuals with ASD, learning hygiene skills can take time to learn and practice. There may be sensory difficulties and anxiety related to completing hygiene tasks. It may be difficult for the person to remember the steps to complete the task. In the beginning, the parent or caregiver, may need to help with some hygiene tasks such as brushing teeth with hand-over-hand assistance. As a skill develops, prompts and support can be faded to promote independence.
- As the person first learns these new skills, it can be helpful to provide meaningful reinforcers to encourage good hygiene practices and motivate continued learning. It can also be helpful to play familiar music in the background that is enjoyable to the person during hygiene activities.
- Visual aids can help the learning process by illustrating and describing methods. These tools can include social stories, activity schedules, charts, and videos. A template to create social stories, as well as other helpful tools, can be found at www.childrens-specialized.org/KohlsAutismAwareness.
- To help make personal hygiene comfortable and to motivate, allow the person to choose personal care items of his or her preference. For instance, he or she can select soaps, toothbrushes, toothpastes, and towels, deodorant which are most tolerable and pleasant and relieve potential sensory issues.
- For individuals who may not be able to practice independent personal care, it is important to provide the choice as to who helps with hygiene and where that occurs. Everyone has a right to privacy, including people who may not be able to care for themselves. Make sure personal hygiene takes place behind bathroom or bedroom doors, maintaining the respect and privacy of the person involved.
- Sometimes it's helpful to pair a song or rhyme with a personal hygiene activity. This can make it easier to recall the steps, keep pace, complete the task, and make it more enjoyable. Timers can also be used to ensure that sufficient time is spent on a hygiene activity. Another helpful tip is to use two baskets or bins. One bin can contain items such as the soap, toothbrush, toothpaste, deodorant, and brush. As each task has been completed, the person can place the item into the "finished" basket on the other side. This method can cue which activities need to be done and which have been completed.
- It is important to help a person with ASD understand puberty as best they can, before it happens, so that he or she knows what to expect as his or her body changes. Puberty changes can be frightening for the child as well as the family. If parents are uncomfortable discussing such topics as penis growth, breast changes, menstruation, and masturbation, they should find someone they can trust to have this conversation. Having important knowledge about their bodies can help decrease fears and anxiety. There are also excellent books and videos available on these topics. Choose those that would be appropriate for the cognitive and maturity level of the child.
- Many personal hygiene skills can be built into a child's IEP. These lessons could be conducted in the classroom or in occupational or speech therapy sessions. Partner with the school to learn their methods of teaching and reinforce these skills at home and in other places the child practices personal care.



When I look in the mirror, how do I look and feel?



Personal hygiene is important!

Personal hygiene is important!

My Personal Hygiene

Check off each step when completed.

_____	<input type="checkbox"/>
_____	<input type="checkbox"/>
_____	<input type="checkbox"/>
_____	<input type="checkbox"/>
_____	<input type="checkbox"/>
_____	<input type="checkbox"/>
_____	<input type="checkbox"/>
_____	<input type="checkbox"/>
_____	<input type="checkbox"/>
_____	<input type="checkbox"/>
_____	<input type="checkbox"/>
_____	<input type="checkbox"/>

I am finished.



REAL LIFE
Tips
for kids with autism



Leisure, Recreation, and Play





Recreation, Leisure, and Play Activities

- Children with autism spectrum disorder (ASD) tend to have fewer recreation and leisure interests than others. In order to help identify preferred play activities, parents, teachers, and therapists can help children explore a variety of activities. Offer choices rather than forcing a child to engage in one activity. Recreation and leisure is about finding an activity that a person enjoys.
- When teaching a recreation skill, it is helpful to break down larger skills into smaller parts so that the child can master them. As smaller skills are mastered, self confidence will grow and the child may be more likely to participate with their peers.
- Music and art activities are great forms of self expression. These activities can be done alone or with peers.
- The park is a great place for a family to recreate, enjoying nature. Visit a local nature center outdoor recreational area to have a supervised scavenger hunt. Partner with the child to search for items with different textures as well as different nature sounds.
- Visit www.childrens-specialized.org/KohlsAutismAwareness to get helpful tips for successful inclusion, ideas for recreation accommodations, tips for adapting recreation programs, as well as other educational resources for recreation and leisure for children with ASD.
- Many families hesitate to let recreation providers know that their child has ASD and his or her specific recreation needs because they don't want to be turned away. It is beneficial to communicate openly with the provider during registration in order to prepare, support, and include the child. The information provided is confidential and can only be shared with those directly involved in supporting the child's recreation programming.
- Parents can arrange for their children to participate in specialized recreation programs. These are excellent ways for children to learn play and social skills and become comfortable in different recreation environments. As a child masters these skills, families and recreation providers can work together to broaden the child's exposure to general recreation and leisure activities.
- The Americans with Disabilities Act (ADA) supports the rights of all individuals, including those with ASD, to participate in recreation programs. The ADA protects the right to receive a needs assessment, participate in integrated recreation programs, receive reasonable accommodations, and use adaptive equipment. When registering a child for a recreation program, in most instances, the recreation provider cannot charge additional fees for reasonable accommodations or for participating in the most integrated setting.





Selecting Toys

- There are so many toys and games available for play. For children with autism spectrum disorder (ASD), it is always important to consider safety first. Many children with ASD may put toys in their mouths, throw, bang, or break them. Consider all physical aspects of the toys before letting a child play with them.
- Look for toys that appeal to the child's senses. Sensory fun can include play with water, beans, rice, clay, sand, or bubbles. There are also books and puzzles with various textures. Initially, touching these items can be uncomfortable for children with ASD. But soon, children can become accustomed to touch and feel of these items and begin to have fun.
- When buying or using commercial toys and games, consider the developmental age of the child, not the actual age range indicated on the package. Less complicated toys may be appropriate for lower functioning children, while toys that provide opportunities for building, discovery, creativity, and social interaction may be enjoyed by higher functioning boys and girls.
- When engaging in play with a children with ASD, it can be helpful to have only a few toys in sight. Too many toys can be overwhelming and distracting for a positive play experience.
- Toys can be a great way to build social skills. Boards games, interactive video games, card games, and sports activities are great ways to engage social interaction. Game rules may need to be simplified in order for the children to enjoy interacting with each other instead of thinking about complex instructions. It may take several times to practice before a child with ASD enjoys a game or activity.
- Some children with ASD prefer physical play while others are more comfortable with less active leisure activities. It is beneficial for the child to be exposed to both types of activities so that he or she has opportunities to experience a full range of play activities.
- Toys can be played with in different ways than initially intended. A child with ASD may enjoy playing with a toy in a different way or play a game with rules of his or her own. Toys, games, and activities can be fun for all, without following official instructions, provided the play is safe.
- Teachers, therapists, and other parents can provide suggestions based on their play experiences with children with ASD. Ask for recommendations based on a child's individual interests and challenges.





Play Dates

- Play dates are opportunities for children with autism spectrum disorder (ASD) to practice social, play, and communication skills in a natural environment. During these experiences, parents can observe their child's strengths and challenges in such skills as sharing and taking turns.
- It can be difficult for children with ASD to understand how to behave in these types of social gatherings. They may not have social skills that are common among their peers. It may be helpful to have a play date with one other child, in order to help prompt and reinforce appropriate interactions.
- When selecting a friend or friends for the play date, it is important for parents to choose children who exhibit behaviors that they would like to have imitated. It is also helpful to select children who have some similar interests with their child, such as video games, puzzles, or dancing to music.
- Initially, play dates should be short. Perhaps a child can only tolerate five or ten minutes. Each time a play date occurs, the child will become more familiar and comfortable with the environment and the friend. Parents may have a sense of how long the child can tolerate a situation. If he or she gets upset after fifteen minutes of play, use that as the measure when coordinating the play date so that a meltdown can be prevented before it starts.
- Initially, supervised and structured activities such as baking cookies or a prearranged art project may work best. Setting up a few organized play stations around the room can help the child recognize the activities before play begins and transition better from one activity to another.
- For the play date, try not to pick toys that the child fixates on, in order to prevent the child from getting upset when a playmate has his or her turn with the toy. Keep these highly preferred toys hidden and out of reach. Include toys, games, and activities that the child is familiar with and is somewhat comfortable sharing.
- Social stories are excellent ways to familiarize children with ASD with the environment and expectations. Photographs of the play area, toys, games, and people can be reviewed before the play date. Include alternative toys and activities within social stories so that the child can be prepared for changes due to such things as bad weather, broken toys, and other unforeseen changes or occurrences. These social stories can describe methods of play, rules, and what behaviors are appropriate during the play date. A blank template for creating social stories is available at www.childrens-specialized.org/KohlsAutismAwareness in order to create them as needed.
- Parents and teachers can role play different types of play interactions. Practicing appropriate behaviors prior to the play date will help the child be more comfortable when he or she is among friends.
- At the beginning, play dates may need to be at home or in an environment that is familiar and comfortable for the child. As he or she becomes more comfortable, play dates can take place in locations of interest such as the park or a zoo. This may take more preparation and support to handle the responsibilities and potential challenges of unexpected meltdowns or wandering.
- Before the play date, parents and teachers can work with the child to establish a body gesture or words as a signal when a situation may be overwhelming or if a break is needed. Over time, the child can learn self-help and self-calming skills to use as needed. The parent or caregiver can also have a signal which can be used when the child is behaving inappropriately – to help remind the child of the skills they practiced.
- It is important to reinforce appropriate behavior as it happens during the play date. Reinforcers could be treats, words, or small tokens of acknowledgment for good behavior.

- Sometimes game rules or play activities need to be changed so that they are more understandable and achievable by the child with autism. Let the playmates know that it is alright to find new ways to play so that everyone has fun.
- When the play date is over, talk with the child about what happened. Let him or her express what went well and any challenges. Emphasize his or her appropriate behaviors and the positive things that happened. Develop tools such as social stories, activity schedules, or rule sheets to help in the areas where support is needed.





Traveling and Vacations

- Traveling to places which are unfamiliar or out of the ordinary routine can be difficult for children with autism spectrum disorder (ASD). Try to select trips and vacation destinations that would be most tolerable for the child. Keep in mind the length of the trip, seasonal weather, crowds, and available activities. Arrange vacation plans during times that there may be less traffic and less crowds. This may help to reduce many challenges and provide for more availability of staff to help at the location.
- Many websites provide background information about the destination. If not, call to speak to a supervisor about accommodations, the location of customer service at the location, bathrooms, and exits. Other questions can include the least crowded times; the intensity of volume, sound, and lights; and a schedule of activities or events. It can be helpful to use travel agencies that are familiar with travelers having special needs.
- Before the trip, review pictures, videos, and maps together. This can help familiarize the child with the destination, see different options, and build excitement.
- Role play different situations to practice things like waiting in lines, going through security at an airport, remaining in the vehicle, and wearing safety belts. Videos, social stories, and other visual aids help to prepare for the trip, understand appropriate behavior, and can help to reduce anxiety.
- When going on a trip, bring along favorite snacks, toys, and other items that can help make him or her feel more comfortable. Video games and other electronic devices with headphones can help distract from increased sensory challenges and help ease lengthy trips. Save a couple of highly preferred items in case something unexpected happens along the way.
- It is important to have the child carry identification when traveling. The identification should also include the child's method of communication and any challenges that are important to know in case he or she gets separated from parents or caregivers.
- Bad weather, broken rides, closed areas, detours, and other obstacles may change or cancel intended plans. When talking about schedules, routes and activities, use expressions such as "we might visit," "if it's available," and "we'll try to." Let the child know there may be an alternative in case something may not go as planned.
- During the vacation, transitioning from one activity or location to another may be difficult for someone with ASD. Use toys, snacks, or other enjoyable items to help with these changes. Visual aids, activity schedules, or timers may also help ease the transitions.
- It is helpful to reveal the child's challenges to people who can be helpful to the child and those with him or her. Airport representatives, flight attendants, hotel staff, customer service representatives, and others in the travel and hospitality industry rely on parents and caregivers for ways to help make the experience enjoyable and comfortable for everyone involved. Honest communication may result in such things as alternate access, private waiting areas, or extra time allowances.
- Other travelers may have their own perceptions of the child's behaviors. If someone shows or expresses difficulty with the child's behaviors, honestly communicating what's going on. Most times people are sensitive and will be more accommodating once they understand the situation.
- Many hotel rooms have suites where families can prepare meals in the room or call for room service. This might be a helpful option if a difficulty occurs at a public eating area.

- Many hotel rooms have suites where families can prepare meals in the room or call for room service. This might be a helpful option if a difficulty occurs at a public eating area.
- When traveling by airplane, call the Transportation Security Commission (TSA Cares) toll free at 1-855-787-2227 72 hours prior to traveling with questions about screening policies, procedures and what to expect at the security checkpoint. TSA Cares serves as an additional, dedicated resource specifically for passengers with disabilities, medical conditions or other circumstances or their loved ones who want to prepare for the screening process prior to flying. Public transportation providers cannot refuse to transport a person solely because involuntary behavior offends, annoys, or inconveniences employees or other passengers unless the behaviors are unsafe or injurious. The e-mail address for TSA Cares is TSA-ContactCenter@dhs.gov