Pediatric Patient Education™
Expert advice from the American Academy of Pediatrics

ASD—Family Support and Support in School

Families of children with autism spectrum disorder (ASD) may experience stress before, during, and after a diagnosis. Here is information from the American Academy of Pediatrics about support available for families of children with ASD.

Family Support

Families of children with ASD may experience stress before, during, and after diagnosis. Parents often consider family support a vital part of an overall supports and services plan. Many families feel they do not get enough help from the professionals involved with their children, like learning how to obtain services for their children and family members.

Family-centered planning helps address the unique needs of each family member and is an essential part of the pediatric medical home. Studies show that parents with more support from other parents and community organizations have less stress. Families of children with ASD can assist each other with finding help in their communities.

As soon as a diagnosis of ASD is made, families should be referred for parent support groups in their communities. Family group meetings provide parents with a chance to meet other families with children with ASD and may be a major source of information and comfort. At first, some families may prefer not to share their feelings with others. Support groups give information about resources and provide excellent opportunities for networking.

There are many different types of support groups, including

- National organizations with local chapters. Some families help other children with ASD and their families by getting involved with autism-specific organizations. Families can help advance efforts for research about ASD through these organizations and get information about local resources.
- Local organizations such as local and state parent groups.
- Special interest support groups such as families who have specific therapy interests (like ABA or special diets), siblings of children with disabilities, and teens and adults with ASD. Members of these support groups, many of whom were once helped by others, can informally help parents and people with ASD.
- Online support groups.

To successfully address the stressors related to the behaviors of ASD and advocate for services and related issues, parents of children with ASD need to support each other. All adult caregivers of a child with ASD should work together to address behavioral concerns and support one another.

Similarly, extended family members, such as grandparents, may play an important role in supporting the decisions and behavioral limit setting of parents, as well as being able to help out with the care of children with ASD.

Respite Services

When extended family or friends are not available to care for a child with ASD, respite services (child care provided by trained individuals) can help parents by allowing them to attend to other family needs. Although agencies that specialize in respite services for children with disabilities are usually available in most large cities, they may not be in smaller communities or rural areas.

If parents need help paying for respite care, support may be available through state agencies serving people with intellectual disabilities, ASD, or other mental health disorders. Funding may be available through family support services (FSS) programs, and those eligible for Medicaid, often through a home and community-based services waiver program, may also qualify for respite care. The Medicaid Home and Community-Based Services Waiver Program might simply be referred to as a “waiver” program because it allows states to waive certain Medicaid requirements to provide services to people who would otherwise reside in an institution, a nursing home, or a hospital.

Waivers vary from state to state, with different eligibility criteria, services, and amounts of funding. Waivers often have long waiting lists, so, as soon as a diagnosis of ASD is made, it is important to learn what is available in your state, who is eligible, and how and when to apply. If outlined in the waiver plan, the child may be eligible for recreational activities such as summer camps. Depending on family income or other state eligibility requirements, the child may also be eligible for Medicaid coverage, independent of a waiver.

Support in School

IDEA governs how children with disabilities, including autism, are supported in school. The federally regulated process starts with determining whether the child has an identified disability in one of 14 categories. The child is evaluated through standardized assessments to determine whether they require specially designed instruction through an IEP. Parents can request an evaluation if they are concerned about how their child is performing at school. It is recommended to request this in writing. While each child is treated as an individual, there are some core concepts outlined in IDEA that are helpful for caregivers to understand. IDEA states that children with disabilities should be educated in inclusive environments with typically developing children to as great of an extent as possible (in other words, the federal law principle of least restrictive environment). However, such placement should not negatively affect the child’s progress or minimize the services that should be provided as outlined by an IEP. Simply put, the child should be provided with all needed support to be successful in the regular classroom or supported in an alternative placement when additional supports are necessary.

Visit HealthyChildren.org for more information.

Adapted from the American Academy of Pediatrics patient education booklet, *Understanding Autism Spectrum Disorder (ASD)*.

The American Academy of Pediatrics (AAP) is an organization of 67,000 primary care pediatricians, pediatric medical subspecialists, and pediatric surgical specialists dedicated to the health, safety, and well-being of all infants, children, adolescents, and young adults.

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN®

healthychildren.org
Powered by pediatricians. Trusted by parents.
from the American Academy of Pediatrics