



Financial Assistance

Are there programs that offer support for children with autism spectrum disorder and their families?

Many children with autism spectrum disorder (ASD) are able to get support from programs funded through their state or county. Some examples are financial help, education support, medical care, job skills training, and residential or living services. Some supports are available to all children because of federal laws, such as a free public education, including special education if needed. Other public benefits are based on need, such as financial or how serious the disability is. Most children with ASD, especially those who also have intellectual disability, will qualify for these benefits.

Funding for community-based supports has gone up over the past 30 years, but states put different amounts of money into these services. Some states have policies and funding to be sure that most children with disabilities, including ASD, live in family settings. Others fund state facilities, community-based homes, and other places where people with ASD might live away from their families.

Many states require that insurance covers applied behavioral assessment (ABA) therapy. Health insurance may cover “related services” such as transportation costs. Also, the Department of Motor Vehicles can give disability parking permits for the transportation of children and adults with disabilities.

What is Supplemental Security Income?

Supplemental Security Income (SSI) benefits support families who are raising children with disabilities that affect home, school, and community functioning. A child is eligible because of financial need and level of disability. Eligible families will receive money monthly to support the child’s needs. A family who does not have low income but has many children or costs might qualify for this program too. In most states, the child will then also automatically become eligible for Medicaid, publicly funded health insurance.

What is a Home- and Community-Based Services (HCBS) waiver program?

The most common type of financial support for families is known as a Home- and Community-Based Services (HCBS) waiver

program. Funding from an HCBS waiver depends on the level of the child’s disability and how it affects the family. Funding may be available at any income. For a child or teen younger than 18, income means the family’s income. For a young adult 18 or older, income means the young adult’s income. However, many states have long waiting lists. Parents must call their local HCBS office as soon as their child is diagnosed as having ASD to get onto the waiting list. Once the child receives a spot, a case manager begins working with the family. Together, they work on a yearly service plan to choose the supports the family needs. These supports may include respite services so parents can take a break (in-home, at a center, or at camp), medical equipment, home remodeling for safety reasons, or other needed supports.

Children who qualify for waiver services might also qualify for medical assistance or another public insurance.

What is available in my state?

Because each state has different services, families must call their state or county offices of the departments of health and human services and mental health or their state developmental disabilities organizations. Other sources of local and state information are

- **Autism Society** (www.autism-society.org) local or state chapters
- **Autism Speaks** (www.autismspeaks.org) local or state chapters
- Early intervention programs (Go to the **National Early Childhood Technical Assistance Center** [www.nectac.org] to find early intervention programs in each state.)
- **Easterseals** disability services (www.easterseals.com) (Services for children and adults who have ASD are available in >20 states.)
- Local parent groups (eg, **Family Voices**) (www.familyvoices.org), which has state pages and contacts on its site
- School district special education coordinators (Call your child’s school to ask for further information.)
- Title V agencies in each state (**Guide** is available at www.amchp.org/AboutTitleV/Documents/UnderstandingTitleV.pdf; a few states provide some services for children who have ASD.)



What is a special needs will and trust?

Some public supports (such as SSI) depend on the family finances. If you give money to a child it may affect eligibility for SSI, so it is important to find out how much money your child can have before accepting a gift or an inheritance. However, money can be protected with a special needs will and trust.

A very important part of the will is a statement that says the money a child inherits is to be used only for items and services not covered by Medicaid, SSI, or other federal funding. If you leave out this statement you could lose federal benefits until the inheritance is spent down. In some cases, the person with ASD may need to repay the government for services provided in the past. Also, siblings' shares of inherited money may be at risk. You should get help from an experienced lawyer when developing a special needs will and trust. Various nonprofit and for-profit groups can help parents. Information about special needs trusts is included in the Autism Speaks *Transition Tool Kit: For Families on the Journey from Adolescence to Adulthood* (www.autismspeaks.org/family-services/tool-kits/transition-tool-kit).

Resources

ABLE National Resource Center: <http://ablenrc.org>

American Academy of Pediatrics HealthyChildren.org:
www.HealthyChildren.org

Benefits for Children With Disabilities. Woodlawn, MD: US Social Security Administration; 2019. <https://www.ssa.gov/pubs/10026.html>. SSA publication 05-10026. Accessed May 21, 2019

Special Needs Alliance: www.specialneedsalliance.com

US Social Security Administration: www.ssa.gov

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