



# Financial Assistance and Related Programs

## Are there programs that offer support for children with autism spectrum disorders (ASDs) and their families?

Many children with ASDs 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 the child is eligible. Other public benefits are based on need, such as financial or how serious the disability is. Most children with ASDs, especially those who also have intellectual disability, will qualify for these benefits.

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

## What is Supplemental Security Income (SSI)?

Supplemental Security Income benefits support families who are raising children with disabilities that affect home, school, and community functioning. If a child is eligible based on financial need *and* level of disability, the family will receive funds monthly to support the child's needs. A family that is not low income but has many children or expenses might qualify for this program too. In most states, the child will then also automatically become eligible for Medicaid, publicly funded health insurance.

## What are home and community-based waiver services (HCBWS)?

The most common type of financial support for families is called HCBWS. Home and community-based waiver services funding depends on severity of the child's disability and how it affects the family. Funding may be available to all income levels. However, many states have long waiting lists because

unlike SSI, the family's assets are not part of deciding who is eligible. Parents must call their local HCBWS office as soon as their child is diagnosed with an ASD to get on the waiting list. Once the child receives a funded slot, a case manager works with the family on an annual service plan to choose the supports the family needs. These supports may include respite (in-home, center, or camp-based), medical equipment, home remodeling for safety reasons, and 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 or mental health, or state developmental disabilities organizations. Other sources of local and state information are

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

### What is a special needs will and trust?

Some public supports (such as SSI) depend on the financial status of the family. Monetary gifts to a child may affect continued eligibility for SSI, so it is important to find out how much money your child can have before accepting a gift or an inheritance for him. However, financial resources 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. Not including this statement will result in loss of federal benefits until the inheritance is spent down. In some cases, the person with an ASD may need to repay the government for services provided in the past. Also, siblings' shares of the inherited money may be at risk. Legal help from an experienced lawyer is needed 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 ([www.autismspeaks.org/family-services/tool-kits/transition-tool-kit](http://www.autismspeaks.org/family-services/tool-kits/transition-tool-kit)).

### Resources

American Academy of Pediatrics HealthyChildren.org:

[www.HealthyChildren.org](http://www.HealthyChildren.org)

Social Security Benefits for Children With Disabilities:

[www.ssa.gov/pubs/10026.html](http://www.ssa.gov/pubs/10026.html)

Special Needs Alliance: [www.specialneedsalliance.com](http://www.specialneedsalliance.com)

US Social Security Administration: [www.ssa.gov](http://www.ssa.gov)

The recommendations in this publication do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate. Original document included as part of *Autism: Caring for Children With Autism Spectrum Disorders: A Resource Toolkit for Clinicians*, 2nd Edition. Copyright © 2013 American Academy of Pediatrics. All Rights Reserved. The American Academy of Pediatrics does not review or endorse any modifications made to this document and in no event shall the AAP be liable for any such changes.

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