

# Support Programs for Families

## Are there support programs for children with autism spectrum disorders?

Many children with autism spectrum disorders (ASDs) are able to get support from publicly funded programs. Some examples are financial help, education, medical care, job skills training, and residential or living services. Some supports are available to all children, such as a free public education, including special education if the child is eligible. Other public benefits are based on need, such as financial need or how serious the disability is. Most children with ASDs, especially those who also have mental retardation, will qualify for these benefits.

Funding for community-based supports has risen over the past 30 years, but states put different amounts of money into these services. Some states have policies and funding to ensure that all children with disabilities, including ASDs, live in family settings. But many states still give large sums to state facilities, nursing homes, Intermediate Care Facilities for the Mentally Retarded, and other places.

## What is Supplemental Security Income?

Supplemental Security Income (SSI) benefits support families who are raising children with severe disabilities at home. It is mostly for low-income families. If a child is eligible based on financial need *and* the severity of disability, the family will receive funds monthly to support the child's needs. In most states, the child will automatically become eligible for Medicaid.

## What are Home and Community-Based Waiver Services?

The most common type of financial support for families is called Home and Community-Based Waiver Services (HCBWS). HCBWS funding depends on the severity of the child's disability and how it affects the family. HCBWS funding is available to all income levels. However, many states have long waiting lists—on average, 5 to 7 years. This is 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 include respite (in-home, center- or camp-based), medical equipment, home remodeling for safety reasons, and other needed supports. The child usually also becomes eligible for Medicaid (again, without looking at the family income), which in itself is a great support to most families.

## 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, Mental Health, and Mental Retardation or the state developmental disabilities organization. Other sources of local and state information are

- Local parent groups
- Autism Society of America local chapter
- Early intervention administrators
- School district special education coordinators (Call your local school to ask.)

## What is a special needs will and trust?

Some public supports (such as SSI) depend on the financial status of the family. Families risk losing these supports if a well-meaning relative gives the child with ASD money as a gift. However, supports 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 the loss of federal benefits until the inheritance the child receives is spent down. In some cases, the person with autism 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. Ask your doctor for information about them.

## Resources

Special Needs Advocate for Parents (SNAP): [www.snapinfo.org](http://www.snapinfo.org)

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

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