



Autism Society  
of NORTH CAROLINA



# Accessing Services

Understanding the kinds of services and supports available and how to obtain them

## About the toolkit

The services and supports systems are complex and can be difficult to navigate. This toolkit is designed to help parents and guardians of children and adults on the autism spectrum to understand the kinds of services and supports that may be available to you and your family and how to obtain them.

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## Beyond the toolkit

If this toolkit raises new questions for you, and you want to talk with someone about finding services and supports for your child, ASNC can help. In every NC county, ASNC has Autism Resource Specialists who are experienced parents of children with autism and trained autism educators and advocates. You can find contact information for the Autism Resource Specialist in your community here: <http://bit.ly/AutismResourceSpecialists>. ASNC also offers workshops that might be helpful; you can find the workshop schedule at <http://bit.ly/ASNCWorkshopCalendar>.

If you would like to read more, please refer to the end of the toolkit for additional information sources that are recommended by the ASNC Advocacy, Clinical, and Bookstore staff. To keep updated on the latest books and DVDs, we invite you to connect with the ASNC Bookstore on Facebook, at [www.facebook.com/AutismBookstore](http://www.facebook.com/AutismBookstore), or by emailing staff at [books@autismsociety-nc.org](mailto:books@autismsociety-nc.org) to tell them you would like to join the newsletter mailing list.

ASNC has about 50 local chapters and support groups across North Carolina, and they can be an excellent place to connect with other parents, gain encouragement, and learn from their experiences. Chapters are parent-run and offer support and education on a wide variety of topics. To find one near you at <http://bit.ly/ASNCChapters>.

In addition, ASNC offers an array of services for your loved one. Please visit [www.autismsociety-nc.org](http://www.autismsociety-nc.org) to learn what is available in your area.

# I/DD Services in NC

According to the Autism Society of America, conservative estimates of lifetime care for a person with autism range from \$3.2 million to \$6 million. Given that fact, most families could use some assistance to help them meet the needs of their child or adult family member with Autism Spectrum Disorder (ASD). Individuals with autism may be eligible to receive certain intellectual and/or developmental disability (I/DD) services through the local, state, or federal governments. Navigating the world of I/DD services can be complicated and confusing at times, and parents may need support in accessing the appropriate I/DD services for their loved ones with autism.

## What services and supports are available?

An individual with autism may be eligible for services funded through local, state, and federal governments such as the NC Medicaid Home and Community-Based waiver (formerly called CAP-I/DD or CAP-MR/DD; now called the Innovations waiver), Medicaid-funded services such as B3 Respite, B3 state-funded services such as Developmental Therapies or Respite, state income support programs such as Special Assistance, or federal programs such as SSI benefits. Each program has different income eligibility requirements. For example, the Medicaid Home and Community-Based waiver program does not count or “deem” parental income when determining eligibility for a minor child with an intellectual or developmental disability. Some state-funded programs have co-pays when parental income reaches a certain level or have their own income limits on eligibility. B3 services are based on Medicaid income and level of need eligibility. SSI, however, does deem parental income and assets when determining the eligibility of a minor child with autism who lives at home. When an adult with autism applies for SSI, his own income and assets must fall under the established caps.

Not all individuals with autism will qualify for or receive the above services. However, other programs might offer assistance for your child. Parents of children ages birth to 3 years who have a developmental delay should contact the NC Infant-Toddler Program, which is also referred to as Early Intervention, Birth-3, or ChildFind. (Learn more at [www.bearly.nc.gov](http://www.bearly.nc.gov).) If your child with autism is between the ages of 3 and 22, he may be entitled to special education and related services through your local public school district.

## Does an autism diagnosis automatically make an individual eligible?

No. In North Carolina, there is no entitlement to intellectual and/or developmental disability services, and individuals with disabilities are not guaranteed any support beyond what is federally mandated through the public school system or the federal disability system.

It is also important to understand that eligibility for a particular service does not necessarily mean that the person will receive the service. For instance, a child with autism might be eligible to apply for the NC Medicaid Home and Community-Based waiver, called Innovations and formerly known as the CAP-MR/DD or CAP-I/DD waiver, but because of limited funding and a limited number of slots, the individual probably will be placed on a waiting list even if it is determined that they should receive the waiver.

# NC Medicaid Home & Community-Based Waiver

In North Carolina, children and adults with developmental disabilities such as autism may apply for a slot in a NC Medicaid Home and Community-Based (HCB) waiver. It is called a waiver because many of the traditional regulations of Medicaid health insurance are being “waived,” or not required, to ensure that services are provided specifically for individuals with I/DD and provided in a community setting, rather than in an institution. Under this HCB waiver, only the income and resources of the individual are deemed (counted), not the income and resources of parents or a spouse. What this means for families is that a child with autism whose parents’ income exceeds the guidelines for Medicaid insurance may still be eligible to apply for a Medicaid waiver slot.

## The purpose of the Medicaid HCB waiver

The Medicaid HCB waiver program serves individuals who would otherwise qualify for care in an intermediate care facility for people with intellectual/developmental disabilities (ICF/MR). It allows these individuals the opportunity to be served in the community instead of residing in an institutional or group home setting. The federal government allows states to operate these kinds of waiver programs when states show that community-based care is less expensive than the cost of living in an institution. Local Management Entities/Managed Care Organizations (LME/MCOs) are responsible for management of the HCB waiver operation at the local level. (Note: LME/MCOs were formerly called local Mental Health Centers or local Mental Health Authorities in some communities.) An ASNC Autism Resource Specialist can help you locate your LME/MCO, or you can find a list from the NC Division of Mental Health, Developmental Disabilities and Substance Abuse Services at <http://www.ncdhhs.gov/mhddsas/lmeonblue.htm>.

## Services system changing

North Carolina recently went through several changes to its I/DD system at one time. In addition to changes to the CAP waiver, which is now called Innovations, Local Management Entities (LMEs) have become Managed Care Organizations (MCOs) under another kind of federal waiver called a 1915 b/c managed-care waiver. In this type of waiver, Medicaid’s regulations allowing unlimited choice of provider is “waived,” and states are allowed to limit providers under a managed-care model in which they receive a per-member, per-month set payment to provide services to people in their region, similar to the way an insurance company runs a health maintenance organization (HMO). All this talk of different kinds of waivers can be confusing! If you hear the word “waiver,” make sure you ask to which waiver the person is referring. You can read about managed-care waivers at the NC Division of Mental Health, Developmental Disabilities and Substance Abuse Services website: <http://www.ncdhhs.gov/mhddsas/providers/IDD/index.htm>

State leaders have proposed more reform of the state’s Medicaid system, including additional changes to managed care. The Autism Society of North Carolina is closely following the proposals and the ways they might change how community services are delivered to individuals with autism. To stay informed, please visit the ASNC website regularly, follow us on Facebook at [www.facebook.com/AutismSocietyofNorthCarolina](http://www.facebook.com/AutismSocietyofNorthCarolina) and

Twitter at [twitter.com/AutismSocietyNC](https://twitter.com/AutismSocietyNC), and sign up for ASNC e-updates and e-alerts. Also be sure to visit the ASNC blog at <http://autismsocietyofnc.wordpress.com> regularly for the latest in issues affecting people with autism and their families.

## Key terms in Medicaid

**MCO or Managed Care Organization:** The Local Management Entities (LMEs) are now referred to as MCOs or LME/MCOs. These organizations administer the Medicaid waiver program in each county or region.

**ISP or Individual Support Plan:** This is the new name for what used to be called the PCP (Person-Centered Plan). The ISP details which services and supports the enrollee will be eligible to receive. The Care Coordinator writes the general broad goals for the ISP, and the provider agency will write the detailed benchmarks to address how goals will be met.

**Care Coordinator:** Care Coordinators have replaced individual case managers. Non-waiver services may not have care coordination. Targeted Case Management (TCM) is no longer available under the Innovations waiver. A Care Coordinator is not the same as a case manager. The role of the Care Coordinator is to provide:

- Education about all available MH/SA/DD services and supports, as well as education about all types of Medicaid and state-funded services.
- Linkage to needed psychological, behavioral, educational, and physical evaluations.
- Development of the Individual Support Plan (ISP) in conjunction with the recipient, family, and all service and support providers.
- Monitoring of the ISP and health and safety of the consumer.
- Coordination of Medicaid eligibility and benefits.

Care Coordinators are responsible for administering ISP plans, but they do not provide direct support to individuals.

**Community Guide:** The role of the Community Guide is to help connect Innovations waiver recipients with resources in their community. It is important to understand that the Community Guide is an available service under the Innovations waiver, but it is not guaranteed. Families must request to have the Community Guide service added to their family member's ISP and might need to advocate to show why the service is required.

**Provider:** In North Carolina, service management is separated from service delivery. The LME/MCO manages the provision of services but does not provide services

**ISP TIP:** Parents must advocate for the services their child needs to ensure that the ISP is developed appropriately. Do not sign the ISP signature page at the meeting before receiving and reviewing the final, completed plan. You may schedule a separate meeting with the Care Coordinator to sign the finalized version of the ISP if need be.

**TIP:** A single Care Coordinator may have more than 50 plans in their caseload, so they will not have the time to get to know each person individually or to read their entire file. Caregivers must be proactive and educate the Care Coordinator about their family member's unique needs.

**TIP:** It may be helpful to provide "what if" type scenarios to the MCO during the ISP meeting to justify the need for the Community Guide.

directly to individuals. The LME/MCO contracts with separate, private nonprofit and for-profit organizations that provide services that are available under the Home and Community-Based waiver. Information should be given to individuals about all providers, and individuals should have a choice of providers, but that choice may be limited. Every community has providers that specialize in autism services, and individuals can request autism-specific services and providers.

*Note: There is no traditional "case manager" under Innovations and managed care. Some case-management functions are performed by the LME/MCO Care Coordinator, some by the Community Guide, and some by the provider of services.*

## How to apply for a Medicaid waiver or other LME/MCO services

To apply for the Innovations Medicaid waiver or other LME/MCO services, the first step is to locate the LME/MCO for the North Carolina county in which the individual with autism resides. A map at <http://www.ncdhhs.gov/mhddsas/lme-mcomap4-1-14.pdf> shows which counties are covered by each LME/MCO. Please contact an ASNC Autism Resource Specialist if you need additional assistance finding your LME/MCO.

Once you have located your LME/MCO, contact its access line to speak to its staff. You can find the contact information for your LME/MCO by county at [www.ncdhhs.gov/mhddsas/lmeonblue.htm](http://www.ncdhhs.gov/mhddsas/lmeonblue.htm) or by LME/MCO name at <http://www.ncdhhs.gov/mhddsas/lmeonbluebyname.htm>. Most LME/MCOs also have information on the services they offer and tips on the consumer/family pages of their websites. Here are additional steps to follow:

1. **Contact the Access line** to explain what your child's diagnosis is and what type of services he or she needs. Ask to speak to someone with knowledge of intellectual and/or developmental disabilities or an I/DD specialist. Once you get to a MH/DD/SA Medicaid waiver Coordinator at your LME/MCO, or other appropriate staff, request an application for the Innovations waiver.
2. **Return the completed application** and a copy of the individual's most recent psychological evaluation to the Coordinator. You must include documentation that shows the individual has a developmental disability.
3. **The Coordinator might contact the individual or caregiver** to schedule an appointment to complete the Supports Intensity Scale (SIS), or another tool such as the NC Support Needs Assessment Profile (NC-SNAP), to determine the level of services and supports required by the individual.

*Note: In some cases, because of the length of the waiting list, the person with autism might be placed on a waiting list (known as the Registry of Unmet Needs) for the Innovations waiver without an assessment of the services supports needed. Because needs change over time, the person will be assessed when a slot on the waiver becomes available. (See below for more information.)*

4. If found eligible for an Innovations waiver, **the individual will be placed on the Registry of Unmet Needs** until a waiver slot becomes available for them. A limited number of Innovations waiver slots are available, and individuals may remain on the waiting list for years. Tip: Even though an Innovations waiver slot may not become available for an undetermined length of

**TIP:** Parents have a tendency to want to see the strengths of their child, but when completing the assessment tool, it is important to be honest about the intensity of your child's challenges when they are having their worst day.

time, it is important to apply to have your child with autism added to the Registry of Unmet Needs as soon as possible. LME/MCOs prioritize their waiting list spots by the date of entry, so the sooner your child is on the list, the better.

5. **Ask whether your child is eligible for other comparable services** such as IPRS (Integrated Payment and Reporting System) or state-funded or B3 funds. These vary by LME/MCO and funding sources. If your child is dually diagnosed, he or she may also qualify for mental health services. Be sure you ask the provider if they are familiar with ASD and that is incorporated into your mental health treatment.

Keep in touch with the Innovations waiver Coordinator at your LME/MCO. Inform them if your child's needs intensify, if your address or contact information changes, or if your child is experiencing additional challenges. In some cases, children at high risk for institutionalization may qualify for emergency waiver slots.

## What if my child is denied services or put on a waiting list?

Not every application for an NC Medicaid Home and Community-Based/Innovations waiver will be approved the first time around. Or your child with ASD might be found eligible for an Innovations waiver but be placed on a waiting list to receive services. If you feel that your child with ASD meets the eligibility requirements for a Medicaid Innovations waiver and he is not currently receiving assistance, here are several steps you can take.

- **Provide additional documentation of need:** Review the information that you provided to the agency regarding your child's disability; could you provide additional documentation to make a stronger case that your child needs assistance? Under the new Innovations Medicaid waiver, applicants are assessed using either NC-SNAP or the SIS, which determines their level of need for services and supports. Additional documentation might be useful in showing a greater level of need than was initially determined using the assessment tool.
- **Appeal:** Be sure to file an appeal if you think your child meets the eligibility requirements.
- **Investigate other options:** If your child has been found eligible for a Medicaid Home and Community-Based waiver but was placed on a waiting list, there might be some resources that you can access in the meantime. A limited number of funds may be available through your LME/MCO to assist with developmental therapy (state-funded services) and other supports, sometimes called IPRS (Integrated Payment and Reporting System funds) or B3 funds. Children whose parents meet the income requirements also might be eligible to apply for Medicaid health insurance, which might cover health-care needs such as doctor visits, mental health services, services under Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) and preventive physical care. Income limits for Medicaid are far less stringent when your child is younger than 6. To learn more about Medicaid health insurance, go to [www.ncdhhs.gov/dma/medicaid/families.htm](http://www.ncdhhs.gov/dma/medicaid/families.htm).
- **Contact your state legislators:** Sharing our stories with legislators is one of the most powerful ways to educate them about the need for supports for people with autism and their families. If you are without services, share your struggles and describe how these services would help your family. For tips about contacting your legislator, go to <http://bit.ly/ASNCContactingLegislators>.

# Supplemental Security Income (SSI)

**The SSA defines a “disabled” adult as a person who is 18 years or older and has a medically determinable physical or mental impairment which:**

- Results in the inability to do any substantial gainful activity; AND
- Can be expected to result in death; OR
- Has lasted or can be expected to last for a continuous period of not less than 12 months.

Supplemental Security Income (SSI) benefits are government benefits that may be available to a child younger than 18 who has a documented disability and whose family meets stringent income and asset guidelines. Adults older than 18 with a disability may also apply for SSI benefits. Once the person is an adult, the income and resources of the family are not considered, just the income and resources of the individual. The person’s own income and resources must meet the guidelines established by the Social Security Administration (SSA). Generally, the greater the income, the less the SSI benefit will be. If the family or individual’s countable income is over the allowable limit, they cannot receive SSI benefits. Certain types of income may not count (or be “deemed”) as income for the SSI program.

In North Carolina, individuals who receive SSI are automatically eligible for Medicaid health insurance (not to be confused with the Innovations waiver, which has different income requirements). Individuals who receive SSI do not need to apply separately for Medicaid; even a monthly SSI benefit of \$1 is sufficient to qualify the person to receive Medicaid.

## The definition of disabled for SSI

The Social Security Administration has a specific formula for determining whether an individual is disabled for SSI purposes. The SSA defines a “disabled” adult as a person who is 18 years or older and has a medically determinable physical or mental impairment which:

- Results in the inability to do any substantial gainful activity; AND
- Can be expected to result in death; OR
- Has lasted or can be expected to last for a continuous period of not less than 12 months.

Not all adults with a diagnosis of autism will qualify as having a disability for SSI purposes. It will depend on the degree to which their autism affects their daily living, ability to care for themselves, and ability to hold a job. The SSA considers an impairment to be severe if it significantly limits the person’s physical or mental ability to do basic work activities. Some individuals who qualify for SSI may work as long as they carefully follow certain guidelines regarding income and assets.

The qualifications for disabled children are similar. The evaluation also starts with the question of whether the child under 18 is able to perform substantial gainful activity. If not, the next step is to review the severity of their impairment and how the child is able to perform age-appropriate daily living tasks. From there, the SSA evaluates the child’s functioning in six areas to determine whether he or she meets the criteria for having a disability. The areas are:



- Acquiring and using information
- Attending and completing tasks
- Interacting and relating with others
- Moving about and manipulating objects
- Caring for himself
- Maintaining health and physical well-being

The child must show “marked” limitations in two areas or “extreme” limitations in one domain to be considered potentially eligible to receive SSI benefits.

## The difference between SSI and SSDI

Something that can be confusing is the difference between Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). The SSDI program is financed with Social Security taxes paid by workers, employers, and self-employed people, whereas SSI is financed through general revenues from taxes, meaning benefits are not based on the individual’s prior work history. In a nutshell, SSDI is only available to disabled adults who have been in the workforce for a number of years – usually at least 5 to 10 – and have paid sufficient FICA taxes to the Social Security Administration. Another key difference is that people who receive SSDI are eligible to receive Medicare insurance after two years of receiving disability payments, but those receiving SSI are eligible for Medicaid health insurance immediately.

Children are not eligible to file for SSDI, so they would apply for SSI. For most adults with autism whose impairments are severe enough to meet the SSA definition of disability, SSI will also be the appropriate program for which to apply, given that they are unlikely to meet the FICA tax requirements for SSDI.

## Deeming income and resources to determine eligibility

To receive SSI, an individual must meet very strict income and asset eligibility requirements, which can be found at [www.socialsecurity.gov/ssi/text-income-ussi.htm](http://www.socialsecurity.gov/ssi/text-income-ussi.htm). The Social Security Administration sets the guidelines for the allowable countable income, including earned income, unearned income, in-kind income, and deemed income. The amount of the SSI benefit is based on the individual’s income, and if they exceed the income or asset caps, they will not be eligible for SSI.

**Deemed Income:** When a child younger than 18 applies for SSI, some of the income and assets of their parents (including step-parents who live in the household) will be counted or “deemed” to determine eligibility. When a married adult with a disability applies for SSI, the income of their spouse would be deemed. Parental income is not deemed for adult applicants; therefore, children with autism sometimes become eligible for SSI once they turn 18, even if they were not eligible as minors.

**Tip:** Even a small inheritance can disqualify an adult or child from eligibility for SSI or Medicaid, so all relatives should be asked to refrain from leaving money or assets to your child with autism in their will. Parents can set up a special needs trust (Section 1917(d)(4)(A) of the Social Security Act) to manage the money they wish to leave to their child with ASD. Special needs trusts are extremely complex and must be drafted by an attorney who specializes in estate planning. They also must be administered with great care so as not to affect the child’s eligibility for government benefits.

**Resources:** In addition to falling below the income cap, an SSI applicant must also meet resource requirements, which can be found at [www.socialsecurity.gov/ssi/text-resources-ussi.htm](http://www.socialsecurity.gov/ssi/text-resources-ussi.htm). The SSA counts

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resources as well as income, so in the case of a minor child, their parents must meet the eligibility requirements for allowable assets. When a married adult applies for SSI, their spouse's resources will be counted.

**The SSA considers resources to be the things you own, such as:**

- Cash, bank accounts, stocks, and US savings bonds
- Land
- Life insurance
- Personal property
- Vehicles
- Anything you own that could be converted to cash and used for food or shelter
- Deemed resources owned by parents (for a child under 18) or spouse (for a married adult)

**Certain resources are not counted for SSI:**

- The home you live in and the land it is on
- Household goods and personal effects (example: a wedding ring)
- Burial spaces or burial funds for you and your spouse, each valued at \$1,500 or less
- Life insurance policies with a combined face value of \$1,500 or less
- One vehicle that is used by you or a member of your household for transportation
- Retroactive SSI or Social Security benefits for up to nine months after you receive them (including payments received in installments)
- Grants, scholarships, fellowships, or gifts set aside to pay educational expenses for nine months after receipt

At present time, a child under 18 is limited to \$2,000 in resources. When a child lives with one parent, the first \$2,000 of the parent's resources are not deemed, and when they live with two parents, \$3,000 is not deemed. Any parental assets over those limits will be deemed and counted against the child's \$2,000 resource limit. For example, if a child has no resources, but the parents have over \$5,000 in resources, deeming of parental assets would make the child ineligible for SSI.

Tip: Remember that once your child turns 18, parental income and resources are no longer deemed, so you may wish to revisit the question of eligibility for SSI once your child with ASD reaches the age of majority.

## How to apply for SSI

If you need assistance in completing an SSI application for your child or adult child with autism, an ASNC Autism Resource Specialist might be able to help you. To apply for SSI benefits:

1. Review the SSI Child Disability Starter Kit at [www.socialsecurity.gov/disability/disability\\_starter\\_kits\\_child\\_eng.htm](http://www.socialsecurity.gov/disability/disability_starter_kits_child_eng.htm) or the Adult Disability Starter Kit at [www.socialsecurity.gov/disability/disability\\_starter\\_kits\\_adult\\_eng.htm](http://www.socialsecurity.gov/disability/disability_starter_kits_adult_eng.htm). The starter kits include fact sheets, a checklist for the disability interview, and worksheets with medical and school information for children or medical and job information for adults.
2. Contact Social Security to find out whether the individual's income and resources (including deemed income and resources) fall within the limits.

3. Complete the Child Disability Report at [www.socialsecurity.gov/online/ssa-3820.pdf](http://www.socialsecurity.gov/online/ssa-3820.pdf) or Adult Disability Report at [www.socialsecurity.gov/forms/ssa-3368.pdf](http://www.socialsecurity.gov/forms/ssa-3368.pdf). These reports may also be completed online at [www.socialsecurity.gov/disabilityssi](http://www.socialsecurity.gov/disabilityssi).
4. Complete the SSI application. Adult applicants may complete the application online. The SSI application for a child must be completed in person at your local Social Security office or over the telephone. For a list of offices and their contact information, go to [www.ssa.gov/atlanta/southeast/nc/north\\_carolina.htm](http://www.ssa.gov/atlanta/southeast/nc/north_carolina.htm).
5. SSI claims typically take about 3-5 months to be reviewed. If you change your address or telephone number while waiting to hear about an application, remember to give your updated contact information to the Social Security office.

**TIP:** The Disability Reports ask only for contact information for the applicant's doctor so they can verify the disability. However, to expedite your claim, you can also include copies of all pertinent reports and documents about your child's autism. This will cut down on time waiting for the doctor's office to send paperwork to the Social Security office. Additionally, you might be able to provide additional information from other sources that will strengthen your child's case. Be sure to report how your child's autism affects daily living and functional activities such as self-care, communication, bathing, toileting, eating, community outings, and school.

## Appealing a denied SSI claim

It is not unusual for an SSI claim to be denied the first time around. A denial is not the end of the road; you can appeal the decision. Many claims are approved during an appeal, so it is worth filing an appeal if you believe that your child was incorrectly denied benefits. Keep in mind that the two primary things you will need to show during the appeals process are that your child has a qualifying disability and that your child meets the income and resource requirements.

Appeals must be filed within 60 days of receiving the notice of the decision to deny SSI benefits. The Social Security Administration allows five days for transit, so the true deadline is 65 days after the SSA mailed the letter. You might hear the letter referred to as the Notice of Decision or the Initial Determination.

There are four levels of appeals for SSI benefits, which you can view at <http://www.ssa.gov/ssi/text-appeals-ussi.htm>:

1. The first level is reconsideration, an informal review conducted in the local SSA office where the claim was originally filed. You can even start the appeal online at <https://secure.ssa.gov/apps6z/iAppeals/ap001.jsp>. You will have to complete two forms: the Request for Reconsideration and an Appeal Disability Report. Be prepared to provide additional documentation about the severity of your child's disability to give the SSA a valid reason to reverse its original decision. Reports from authorities such as doctors, schools, or employers are particularly useful. Some families file for reconsideration of their claim without an attorney.
2. If the reconsideration is denied, the next step is to request a hearing before an Administrative Law Judge (ALJ), who conducts an independent review of the case. Most people will have legal representation to go before the ALJ.
3. Appeal to the Social Security National Appeals Council in Washington, DC
4. A lawsuit filed in federal court

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## Managing SSI benefits

If your child receives SSI benefits, it is very important to manage them carefully. Parents may wish to become a representative payee for their child's SSI benefits. (Read more about this here: [www.ssa.gov/ssi/text-repayee-ussi.htm](http://www.ssa.gov/ssi/text-repayee-ussi.htm).) Most children younger than 18 or any legally incompetent adult must have a representative payee assigned to manage their funds. The representative payee is often the individual's parent or legal guardian. (You can learn more about the guardianship process for an adult with autism on the ASNC website: [www.autismsociety-nc.org/images/asnc/gethelp/Guardianship.pdf](http://www.autismsociety-nc.org/images/asnc/gethelp/Guardianship.pdf).)

The representative payee has several responsibilities, which are designated by the SSA. They are required to:

- Use SSI benefits first to meet the individual's basic needs, such as food, clothing, housing, and medical care.
- Save the balance of the funds, preferably in an interest-bearing bank account.
- Submit an annual account reporting how SSI benefits were spent and saved.
- Respond to requests from the SSA on matters such as reviewing ongoing eligibility of disability.
- Report to the SSA any changes that might affect eligibility to receive SSI benefits, such as a change in income, resources, or living arrangements.

**Spending Down Accounts:** The parent, guardian, or representative payee who is responsible for managing SSI funds must keep a careful watch on the assets of the person with autism who receives government benefits. Recipients must continue to meet the limits on income and assets that were part of the initial determination of eligibility. It is essential to monitor the funds in your child's accounts to ensure that they do not exceed the cap on resources; otherwise, they might lose their eligibility to receive SSI. If resources near the limit, it is imperative to spend down accounts on approved needs to keep them under the cap.

# Additional Resources:

## Websites about Medicaid waivers

**NC Innovations Waiver Policy:** <http://www.ncdhhs.gov/dma/mp/8P.pdf>

This is the guidebook for the provision of Innovations waiver services. Although it is a policy used by LME/MCOs and providers, individuals and families will find helpful the explanations of all the parts of the program and how it should operate.

**NCDHHS listing of LME/MCOs:** [www.ncdhhs.gov/mhddsas/lmeonblue.htm](http://www.ncdhhs.gov/mhddsas/lmeonblue.htm)

Here you can find lists of Local Management Entities/Managed Care Organizations by county or name, and a map of counties covered.

**NC Division of MHDDSAS Managed Care Waiver Page:** <http://www.ncdhhs.gov/mhddsas/providers/IDD/index.htm>

This page gives information about all of the 1915 b/c managed-care waiver changes happening in North Carolina.

*Note: LME/MCOs may have a slightly different process for managing their Innovations waiver and other services. See your own LME/MCO for the most accurate information.*

## Contacts and websites for SSI

**Social Security Disability and SSI Hotline:**

800-772-1213 or 919-790-2782

**Social Security Administration website:**

[www.ssa.gov](http://www.ssa.gov)

The Social Security Administration (SSA) oversees SSI benefits.

**SSI website:** [www.socialsecurity.gov/pgm/ssi.htm](http://www.socialsecurity.gov/pgm/ssi.htm)

The homepage for the SSI program includes links to application forms and FAQs.

**Social Security Administration's SSI publication:**

[www.socialsecurity.gov/pubs/11000.html#ao=1](http://www.socialsecurity.gov/pubs/11000.html#ao=1)

An overview of the SSI program; also available as a printable PDF.

**Understanding SSI:**

[www.socialsecurity.gov/ssi/text-understanding-ssi.htm](http://www.socialsecurity.gov/ssi/text-understanding-ssi.htm)

Provides information about eligibility of individuals with a disability for Supplemental Security Income (SSI) benefits, Disabled Adult Child (DAC) benefits, and other benefits to which they may be legally entitled.

**Understanding SSI for Children:**

[www.socialsecurity.gov/ssi/text-child-ussi.htm](http://www.socialsecurity.gov/ssi/text-child-ussi.htm)

**SSI Disability Application for Adults:**

[www.socialsecurity.gov/applyfordisability](http://www.socialsecurity.gov/applyfordisability)

**SSI Disability Application for Children:**

[www.socialsecurity.gov/applyfordisability/child.htm](http://www.socialsecurity.gov/applyfordisability/child.htm)

The Child Disability Report may be completed online, but the rest of the SSI application must be completed in person or over the telephone with your local Social Security Administration office.

**Social Security Administration in North Carolina:**

[www.ssa.gov/atlanta/southeast/nc/north\\_carolina.htm](http://www.ssa.gov/atlanta/southeast/nc/north_carolina.htm)

Find an SSA office in North Carolina to apply for SSI.

**SSI Appeals Process:**

<http://www.ssa.gov/ssi/text-appeals-ussi.htm>

*{Additional Resources continued}*

## NC websites about SSI and Medicaid

**NC Department of Health and Human Services (DHHS):** [www.ncdhhs.gov/index.htm](http://www.ncdhhs.gov/index.htm)

The state agency that oversees programs including Medicaid and SSI in North Carolina.

**NC Division of Social Services (DSS):** [www.ncdhhs.gov/dss/local](http://www.ncdhhs.gov/dss/local)

DSS is a division of DHHS. Services and benefits are delivered to individuals through their local DSS agency. Find the DSS office for your county on this page.

**NC DHHS Medicaid/SSI:** [www.ncdhhs.gov/dma/medicaid/apply.htm#ssi](http://www.ncdhhs.gov/dma/medicaid/apply.htm#ssi)

Explains that individuals who receive SSI in North Carolina are automatically eligible to receive Medicaid as well.

## Additional Information on I/DD Services from ASNC

The Autism Society of North Carolina has a number of informative articles on our website that provide clear explanations of the different social services available in North Carolina. Find them here: <http://bit.ly/ASNCPolicyPapers>

# About Autism

Autism Spectrum Disorder (ASD) refers to a group of developmental disabilities – including classic autism, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), and Asperger’s Syndrome – that affect a person’s ability to understand what they see, hear, and otherwise sense. It is a brain disorder that affects communication, social interaction, and behavior.

Individuals with ASD typically have difficulty understanding verbal and nonverbal communication and learning appropriate ways of relating to other people, objects, and events. No two people with ASD are the same. As its name implies, ASD is a spectrum disorder that affects individuals differently and with varying degrees of severity. Additionally, ASD is often found in combination with other disabilities.

It is estimated that up to 1 out of every 68 children has some form of ASD. Evidence suggests that the prevalence rate in North Carolina is even higher than the national average, at 1 in 58. More than 60,000 individuals live with ASD in North Carolina.

The overall incidence of ASD is consistent around the globe, but it is five times more prevalent in boys than in girls. ASD knows no racial, ethnic, or social boundaries, and family income, lifestyle, and educational levels do not affect the chance of occurrence. While ASD is typically diagnosed in children, it is a lifelong disorder that affects individuals of all ages.

## What Causes ASD?

Although it was first identified in 1943, to this day no one knows exactly what causes ASD. However, research to discover its cause is ongoing. Many researchers believe that there is a strong genetic component. Some research suggests a physical problem that affects the parts of the brain that process language and information; other research points to an imbalance of brain chemicals. A variety of possible external or environmental triggers are also being studied. It is possible that ASD is caused by a combination of several factors.

## Signs and Symptoms

People with ASD may have problems with social, behavioral, and communication skills. They might repeat behaviors and might not understand change in their daily activities. Many people with ASD also have different ways of learning, paying attention, or reacting to things.

### A person with ASD might:

- have severe language deficits or differences
- talk about or show interest in a restricted range of topics
- not point at objects to show interest, such as an airplane flying over
- not look at objects when another person points at them
- have trouble relating to others or not have an interest in other people at all
- avoid eye contact and want to be alone
- have trouble understanding other people’s feelings or talking about their own feelings
- prefer not to be held or cuddled or might cuddle only when they want to
- appear to be unaware when other people talk to them but respond to other sounds
- repeat or echo words or phrases said to them, or repeat words or phrases in place of normal language (echolalia)
- have trouble expressing their needs using typical words or motions
- laugh, cry, or show distress for no apparent reason
- repeat actions over and over again
- have trouble adapting when a routine changes
- have unusual reactions to the way things smell, taste, look, feel, or sound
- be oversensitive or under-sensitive to pain
- lose skills they once had (for instance, stop saying words they were once using)



## Autism Society of NORTH CAROLINA

The Autism Society of North Carolina is the leading statewide resource organization serving people across the autism spectrum throughout their lifespans. We understand the challenges of the autism community because we work with individuals with Autism Spectrum Disorder (ASD) every day.

ASNC works to directly improve the lives of individuals and families affected by autism through advocacy, training and education, and direct services.

**Advocacy:** We are the only autism-specific advocacy organization in North Carolina, and it is the heart of what we do. We find resources for families, assist with school issues, educate families through workshops, help individuals navigate the services system, and host local support groups. We also give those with autism a voice in public policy by maintaining relationships at the state legislature and other policy-making entities.

**Training & Education:** We focus on evidence-based best practices that empower self-advocates, families, and professionals. We also work to increase understanding and acceptance of people with ASD in the community.

**Services:** ASNC is a direct care service provider, and a recipient of the highest level of accreditation by the Council on Quality Leadership for exemplary service provision. Individuals with ASD receive a variety of residential, recreational, vocational, and community-based services that are designed to meet their needs, interests, and strengths.

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