

ACCESSING SERVICES TOOLKIT

About the toolkit

The services and supports systems for individuals on the autism spectrum are complex and can be difficult to navigate. This Autism Society of North Carolina (ASNC) toolkit is designed to help parents and guardians of children and adults on the autism spectrum to understand the services and supports that may be available and how to obtain them.

If this toolkit raises new questions for you, and you want to talk with someone about finding services and supports for you or your child, the Autism Society of North Carolina (ASNC) offers an array of services for you and your loved one. Here are some of the ways ASNC can help:

- **Autism Resource Specialists:** In every North Carolina County, ASNC has Autism Resource Specialists who are experienced parents of children with autism and trained autism educators and resource specialists. You can find contact information for the Autism Resource Specialist in your community here: <http://bit.ly/AutismResourceSpecialists>.
- **Workshops and webinars:** ASNC offers a variety of workshops and recorded webinars that may be helpful to you and your family. You can find more information on the [Workshop Calendar page](#) or [Autism Webinars page](#).
- **Local Support Groups:** ASNC has local support groups across the state, and they can be an excellent way for parents to connect with other parents, gain encouragement, and learn from others' experiences. Support Groups are parent-run and offer support and education on a wide variety of topics. To find one near you visit the [ASNC Support Group page](#)

Please visit www.autismsociety-nc.org to learn more about what is available in your area. Additional resources recommended by ASNC Advocacy and Clinical staff are also available at the end of this toolkit.

Table of Contents:

	Pages
Intellectual and/or developmental disability (I/DD) services in North Carolina	2 - 4
<ul style="list-style-type: none">• What services and supports are available?• Does an autism diagnosis automatically make an individual eligible?	
NC Medicaid Home and Community-Based (HCBS) Waiver	4 - 11
<ul style="list-style-type: none">• The purpose of the Medicaid HCBS Waiver• Services system changing• Key Medicaid terms• How to apply for a Medicaid Waiver or other LME/MCO services• What if my child is denied services or put on a waiting list?	
Supplemental Security Income (SSI)	11 - 21
<ul style="list-style-type: none">• The definition of “disabled” for SSI• The difference between SSI and SSDI• Deeming income and resources to determine eligibility• How to apply for SSI• Appealing a denied SSI claim• Managing SSI benefits• Additional Resources• About Autism	

Intellectual and/or Developmental Disabilities (I/DD) Services in North Carolina

It can take a lot of resources to raise and support someone on the autism spectrum and most people would benefit from some assistance to help meet those needs. Individuals with autism may be eligible to receive certain intellectual and/or developmental disability (I/DD) services through the local, state, or federal governments. Here is information to help you navigate and access the appropriate I/DD services for yourself or your loved ones with autism.

What supports are available?

An individual with autism may be eligible for:

- NC Medicaid Home and Community-Based (HCBS) Waiver, known as the Innovations Waiver.
- 1915i services (for Medicaid-eligible individuals) including Respite, Supported Employment, Community Living and Supports, Community Transition, allied health treatment (OT/PT/ST), outpatient and other therapies as well as evidence-based behavior therapies like Research Based-Behavioral Health Treatment (RB-BHT).
- State and local funded services under IPRS funding.
- State income support programs such as Special Assistance.
- Federal programs such as SSI benefits.

Each program has different eligibility requirements based on income and/or disability. For example, the Medicaid Home and Community-Based Waiver (Innovations) program does not consider (or “deem”) parental income when determining eligibility for a minor child with an intellectual and/or developmental disability if other criteria for the program is met.

Some state-funded programs may have income limits on eligibility or have co-pays when parental income reaches a certain level. In North Carolina, parental income and assets are considered when determining the eligibility of a minor child with autism who lives at home: North Carolina does not have what is known as a TEFRA or Katie Beckett waiver that only looks at a minor child’s income for Medicaid eligibility. When an adult with autism applies for SSI, their 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 you or your child. Parents of children aged birth to three years who have a developmental delay should contact the NC Infant-Toddler Program, which is also referred to as Early Intervention, Birth-3, or Child Find. Learn more at www.ncdhhs.gov/itp-bearly. If your child with autism is between the ages of three and 22, they 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 (I/DD) services based on diagnosis alone. In addition, individuals with disabilities are not guaranteed any support beyond what is federally mandated through the public school system or the federal disability system. Individuals who are Medicaid eligible have some entitlement to I/DD services, but not all individuals on the spectrum will be Medicaid eligible. To find out if you or your family member is Medicaid eligible you or they must apply through the local Department of Social Services or start the application process online at the NC Department of Health and Human Services – Division of Health Benefits.

It is also important to understand that eligibility for a particular service does not necessarily mean 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, (Innovations), but because of limited funding and a limited number of slots, the individual will likely be placed on a waiting list even if it is determined that they should receive the waiver.

NC Medicaid Home and 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 Services (HCBS) Waiver. It is called a waiver because many of the traditional Medicaid health insurance regulations are being “waived,” or not required, to ensure that services are provided specifically for individuals with I/DD in a community setting, rather than in an institution.

Under the HCBS Waiver, only the income and resources of the individual are deemed (or counted), not the income and resources of the individual’s parent(s) or a spouse/partner. What this means for families is that a person on the autism spectrum with a parent(s) or spouse/partner whose income exceeds the guidelines for Medicaid insurance may still be eligible to apply for a Medicaid waiver slot.

Other individuals may be eligible for Medicaid and Medicaid Waivers based on the amount of health care costs they have and can factor in the cost of health care and disability supports to their income, and “spend that money down” to qualify.

The purpose of the Medicaid HCBS Waiver

The Medicaid HCBS Waiver program serves individuals who would otherwise qualify for care in an intermediate care facility for people with intellectual/developmental disabilities (I/DD). It allows these individuals to be served in the community instead of residing in an institutional setting.

The federal government allows states to operate these kinds of waiver programs when a state can show that community-based care is less expensive than institutional care. Local Management Entities / Managed Care Organizations (LME/MCOs) are responsible for managing HCBS Waiver operations at the local level. (Note: LME/MCOs were formerly called local Mental Health Centers or local Mental Health Authorities in some communities and may now also be referred to as “Tailored Plans.”) 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 systems change

North Carolina recently made changes to its Medicaid system. Most Medicaid beneficiaries have been *or soon will be* placed into one of two types of managed-care plans under a state 1115 Medicaid waiver. People are enrolled in either Standard Plans or Tailored Plans, depending on their diagnosis and level of need; most people with I/DD who are eligible for Medicaid will be in a Tailored Plan.

Managed care means that insurance plans and regional health management organizations in NC receive a per-member, per-month set payment to provide physical health, behavioral health, and/or developmental disability services to people in their region—like the way an insurance company runs a health maintenance organization (HMO).

All this talk of different kinds of waivers can be confusing! In short, if you hear the word “waiver,” make sure you ask to which waiver the person is referring. North Carolina has many different waivers. You can read about Medicaid Transformation at the NC DHHS website [here](#).

North Carolina has made a lot of changes to its health and disability services systems in the last decade. The Autism Society of North Carolina closely follows public policy changes and provides input to policy makers. To stay informed, please visit the [ASNC website](#) regularly, follow us on [Facebook](#) and [Twitter](#), and sign up for ASNC e-updates and e-alerts. Also be sure to visit the [ASNC Blog page](#) at regularly for the latest in issues affecting people with autism and their families.

Key Medicaid terms

MCO or Managed Care Organization: Standard and Tailored Plans may be managed by insurance companies, provider-led health plans, or quasi-governmental authorities called Local Management Entities (LMEs).

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.

Your Tailored Care Manager or Care Coordinator is responsible for writing the general broad goals for the ISP, and the provider agency will write the detailed benchmarks to address how goals will be met.

Tailored Care Management: The role of care management organizations is to provide:

- Education about all available MH/SUD/IDD services and supports, as well as education about all types of Medicaid and state-funded services.
- Linkage to needed psychological, behavioral, educational, adaptive, 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 service providers as well as Medicaid eligibility and benefits.

Provider: In North Carolina, service management is separated from service delivery. Standard and Tailored Plan companies and/or the LME/MCO manage the provision of services but does not provide services.

TIP: *Everyone eligible for Tailored Plans has a choice of Care Management. Ask any potential care management agency about their familiarity with autism spectrum disorder before selecting a care manager.*

TIP-ISP: *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 Manager or Care Coordinator to sign the finalized version of the ISP if need be.*

TIP: *A single Care Manager or Care Coordinator may know about autism, but they have many people on their caseload, so caregivers must be proactive and educate the Care Manager/Coordinator about their family member's unique needs.*

TIP: *It may be helpful to provide "what if" scenarios during the ISP meeting to justify the need for certain types of services. The Standard and Tailored Plan companies and/or the LME MCO contract with separate, private nonprofit and for-profit organizations that provide services available under Medicaid, including the Home and Community-Based waiver, 1915i services, health care, behavioral health services, pharmacy benefits, and other state and local funded services. Information about all providers should be given to individuals, and individuals should have a choice of providers; however, choice of I/DD, mental health, or substance use providers may be limited under the Tailored Plan model. Every community has providers that specialize in autism services, and individuals can request autism-specific services and providers. Individuals also have a choice of care manager providers and can ask for a care management organization that is familiar with autism and other I/DDs.*

How to apply for a Medicaid Waiver or other Tailored Plan services

To apply for the Innovations Medicaid Waiver (aka HCBS Waiver) or other Tailored Plan services, the first step is to locate the LME/MCO, aka the Tailored Plan manager, for the North Carolina County in which the individual with autism resides. [This map](#) shows which counties are covered by each LME/MCO Tailored Plan. 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. Find the contact information for your county's LME/MCO here: 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:

- **Contact the Access line** to explain what your child's diagnosis is and what type of services they need. 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/SUD Medicaid waiver Coordinator at your LME/MCO, or other appropriate staff, request information about the benefit package/services you or your family member is entitled to, including an application for the Innovations Waiver.
- **Return the completed application** and a copy of the individual's most recent psychological evaluation to the Coordinator. You must include documentation showing the individual has a developmental disability.
- **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), and/or the 1915i services assessment, to determine the level of services and supports required by the individual. *Note: Because the number of people needing services exceeds the funding available, 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.)

- 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 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.*

Tip: *Parents tend 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.*

- Ask whether your child is eligible for other comparable services such as 1915i services for I/DD, Early Periodic Screening Diagnosis and Treatment (EPSDT services), or IPRS (Integrated Payment and Reporting System) or state-funded services. These vary depending on your eligibility for Medicaid or other local funding sources. If your child has other diagnoses, they may also qualify for behavioral health services. Be sure you ask the provider if they are familiar with ASD and that strategies for people on the autism spectrum are incorporated into any behavioral health treatment.

Keep in touch with the Innovations Waiver Coordinator at your LME/MCO as well as your Care Manager if you are eligible for one. 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, though emergency slots are very limited so not all at risk will qualify.

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 they are not currently receiving assistance, here are several steps you can take:

- **Provide additional documentation of need:** Review the information 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? Different assessment tools are used for different types of services: Additional documentation might be useful in showing a greater level of need than was initially determined using the assessment tool(s).
- **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 (Innovations) Waiver but was placed on a waiting list, there might be some resources you can access in the meantime including IPRS state and local services funds, and/or if your child is between the ages of 0-3, services from the local Child Developmental Services Agency (CDSA). Individuals with ASD and children whose parents meet the income requirements also might be eligible to apply for Medicaid health insurance, which may cover 1915i services like Respite, Supported Employment, Community Living and Supports, and Community Transition as well as health care and behavioral health needs like doctor visits, preventative physical care, behavioral health services, services under Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) including RB-BHT (evidence-based behavior therapies). Income limits for Medicaid are far less stringent when your child is younger than six years of age. To learn more about Medicaid health insurance, go to: <https://medicaid.ncdhhs.gov/>
- **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 [here](#).

Supplemental Security Income (SSI)

Supplemental Security Income (SSI) benefits are government benefits that may be available to a child younger than 18 or an adult who has a documented Disability. For a child under the age of 18, they must have a disability that results in marked and severe functional limitations; 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 and whose family also 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). The adult must have a documented disability that 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. 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 (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 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 will 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 they meet 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 five to 10 years) 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, whereas 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. In some cases, a child may be eligible for SSI on a parent's social security record if the parent is an insured worker who is deceased, retired, and collecting benefits, or disabled and collecting SSDI, plus other criteria that the child and family must meet. These situations are complex. We recommend contacting your local social security office for more information on children of adults who are collecting social security.

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: <https://www.ssa.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. If they exceed the income or asset caps they will not be eligible for SSI.

Deemed Income: When a child younger than 18 years of age applies for SSI, some of the income and assets of their parents (including stepparents 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. However, some help from others for living expenses and other “in-kind” support may be counted and may reduce the amount of SSI one receives. Please see <https://www.ssa.gov/ssi/text-living-ussi.htm> for more information.

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 [here](#). The SSA counts 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.
- Life insurance.
- Personal property.
- 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; 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:

- Review the [SSI Child Disability Starter Kit](#) or the [Adult Disability Starter Kit](#). 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.
- Contact Social Security to find out whether the individual's income and resources (including deemed income and resources) fall within the limits.
- Complete the [Child Disability Report](#) or [Adult Disability Report](#). These reports may also be completed online at www.socialsecurity.gov/disabilityssi.
- Complete the SSI application. Applicants may complete the application online. For a list of offices and their contact information, go to www.ssa.gov/atlanta/southeast/nc/north_carolina.htm.

- 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 selfcare, 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 you or your child was incorrectly denied benefits.

Keep in mind the two primary things you will need to show during the appeals process are: (1) you or your child has a qualifying disability; and (2) you or 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 here](#). The following is a general review of those levels.

(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 [here](#). 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 you or 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 people file for reconsideration of their claim using an attorney, but many people file without enlisting the help of an attorney.

(2) If the reconsideration is denied, the next step is to request a hearing before an Administrative Law Judge (ALJ), who will conduct 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, D.C.

(4) A lawsuit filed in federal court.

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: <https://www.ssa.gov/payee/>)

Most children younger than 18 or any person under guardianship who is deemed a 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 with the ASNC [Guardianship Toolkit](#) on the Autism Society of North Carolina website.)

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, 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 receiving 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 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

Below are some additional resources to assist you in accessing services for your child or yourself. This toolkit is not intended to cover all the available resources or possible funding streams due to the individualized nuances of the supports potentially available. We recommend completing the form on our [Talk with a Specialist page](#) to connect with one of our Autism Resource Specialists.

Websites about Medicaid waivers and services

- **[NCDHHS Waiver Services](#):** This provides more detailed information about Innovations Waiver services. Although it is a policy used by LME/MCOs and providers, individuals and families will find helpful explanations for all parts of the program and how it should operate.
- **[NCDHHS listing of LME-MCO/Tailored Plans](#):** Here you can find lists of Local Management Entities/Managed Care Organizations by county or name, and a map of counties covered.
- **[NC Medicaid EPSDT Services for Children under the age of 21](#)**
- **[1915i Transition](#)**
- **[NC Division of MHDDSAS Managed Care Waiver Page](#):** This page has information about all the 1915(b)/(c) managed-care waiver changes available 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:** The Social Security Administration (SSA) oversees SSI benefits.
- **Supplemental Security Income (SSI) website:** The homepage for the SSI program includes links to application forms and FAQs.
- **Social Security Administration's SSI publication:** An overview of the SSI program; also available as a printable PDF.
- **Understanding SSI:** 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**
- **SSI Disability Application for Adults**
- **SSI Disability Application for Children:** 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:** Find an SSA office in North Carolina to apply for SSI.
- **SSI Appeals Process**

NC websites about SSI and Medicaid

- **U.S. Social Security Administration:** The federal agency that oversees SSI and applications for social security benefits.
- **NC Department of Health and Human Services (DHHS):** The state agency that oversees programs including Medicaid in North Carolina.
- **Apply for Medicaid**
- **NC Division of Health Benefits (DHB) – NC Medicaid:** NC DHB is a Division of NC DHHS. This page includes links for all Medicaid resources including information on getting Medicaid, working with an Enrollment broker to learn about healthcare options, about the Medicaid Ombudsman, and other helpful information about changes to Medicaid.
- **NC Division of Social Services (DSS):** DSS is a division of NC DHHS. Your local DSS agency will determine eligibility for programs like Medicaid, food

and nutrition services, energy assistance, etc. Find links to the DSS office for your county on [this page](#).

Additional Information on I/DD Services from ASNC

The Autism Society of North Carolina has several informative articles on our website that provide clear explanations for the different social services available in North Carolina. Find them [here](#).

About Autism

Autism Spectrum Disorders (ASD) affects a person's ability to understand what they see, hear, and otherwise sense. It is a brain disorder that affects communication, processing, social interaction, and behavior.

Individuals on the autism spectrum/autistic adults may have difficulty understanding verbal and nonverbal communication and learning appropriate ways of relating to other people, objects, and events. No two people on the spectrum 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 36 children has some form of ASD. In North Carolina, more than 75,000 individuals live with ASD. The overall incidence of ASD is consistent around the globe; however, it appears to be five times more prevalent in boys than in girls. Because of this disparity, girls may be underrepresented in these statistics and may be diagnosed at a later age. 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.

About Autism Society of North Carolina

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 policymaking entities.

Training and Education: We focus on evidence-based best practices that empower autistic adults, 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 designed to meet their needs, interests, and strengths.

Autism Society of North Carolina

5121 Kingdom Way, Suite 100

Raleigh, NC 27607

800-442-2762

info@autismsociety-nc.org

www.autismsociety-nc.org

Connect with us on social media:

- [com/AutismSocietyofNorthCarolina](https://www.facebook.com/AutismSocietyofNorthCarolina)
- [com/AutismSocietyNC](https://www.instagram.com/AutismSocietyNC)
- [com/AutismSocietyNC](https://www.linkedin.com/company/AutismSocietyNC)
- [com/autismsocietync](https://www.youtube.com/channel/UC...)