As a parent, you know your child better than anyone else. If your child is not meeting the milestones for his or her age, or if you think there could be a problem with the way your child plays, learns, speaks, acts and moves, talk to your doctor and share your concerns. Don’t wait. Acting early can make a real difference.

BASIC INFORMATION

Call to make an appointment with your child’s doctor, and be sure to tell the doctor’s staff that you’re calling because you have concerns about your child’s development.

Before the appointment, complete the CDC’s Developmental Milestones Checklist and write down your questions or concerns to take with you to the doctor’s appointment.

During the doctor’s appointment, show the completed milestones checklist to the doctor. If your child is missing milestones, point them out and share any other concerns you may have. If your child is not missing any milestones, but you still have concerns, tell the doctor about them.

Ask the doctor if your child needs further developmental evaluation. If so, ask for a referral and call right away. If you have difficulty getting an appointment, let the doctor know.

IMPORTANT FACTS

If your child’s doctor has told you to “wait and see,” but you feel uneasy about that advice, talk with another doctor to get a second opinion and call the number below for a free evaluation to find out if you can get free or low-cost services that can help.

If your child is under age 3, call BabyNet at 866-512-8881 or make your referral online here: babynet.scdhhs.gov/prebabynet.

If your child is age 3 or older, call the local public elementary school (even if your child does not attend school there) to inquire about an evaluation. You do not need a doctor’s referral to have your child evaluated for services. You can say, “I have concerns about my child’s development and I would like to have my child evaluated through the school system for preschool special education services.” If the person who answers the phone is unfamiliar with preschool special education services, ask to speak with the Special Education Director.

The South Carolina Department of Disabilities and Special Needs (DDSN) is the state agency that provides services to children and adults with severe lifelong disabilities. To see if you child meets the criteria for services, apply by phone at 800-289-7012.

Resources You May Find Helpful

cdc.gov/ActEarly
msp.scdhhs.gov/babynet
msp.scdhhs.gov/babynet/site_page/refer-child-babynet
ddsn.sc.gov/services/applying-services
ed.sc.gov/districts-schools/special-education-services
familyconnections.sc.org/education/early-learners
usc.m.ed.sc.edu/cdrhome/Roadmap.pdf
The South Carolina Department of Disabilities & Special Needs (SCDDSN) provides services to children from birth to three years of age through a contract with South Carolina First Steps. First Steps in the state’s lead agency for Part C services under the Individuals with Disabilities Education Act (IDEA), the law that governs how states and public agencies provide early intervention, special education, and related services. Infants and toddlers, birth to age 3, with disabilities and their families receive early intervention services under IDEA Part C. Services can include speech-language therapy, occupational therapy, physical therapy, assistive technology, health services and more. The SC/EI will work with your family to create an Individualized Family Service Plan (IFSP) to lay out the supports and services your child will need.

If ever unsatisfied with your current SC/EI and would like help finding another one, contact ddsn.sc.gov/contact.

BASIC INFORMATION

For children eligible for IDEA/Part C, the Intake Coordinator will document your child’s eligibility, provide your family with a copy of the evaluation results. You will then be asked to provide the Intake Coordinator with your top three choices for service coordination/early intervention providers.

The Service Coordinator/Early Interventionist (SC/EI) is the person who works in partnership with your family to coordinate needed services. They will ensure that your family will have access to a full array of services including medical, social, educational, or other needed services through 4 key components: Assessment, Care Planning, Referral and Linkage and Monitoring and Follow Up.

The SC/EI will partner with your family to help empower you to learn to eventually be able to make decisions and coordinate your own care and services.

IMPORTANT FACTS

The South Carolina Department of Disabilities & Special Needs (SCDDSN), provides services to children from birth to three years of age through a contract with South Carolina First Steps. First Steps in the state’s lead agency for Part C services under the Individuals with Disabilities Education Act (IDEA), the law that governs how states and public agencies provide early intervention, special education, and related services. Infants and toddlers, birth to age 3, with disabilities and their families receive early intervention services under IDEA Part C. Services can include speech-language therapy, occupational therapy, physical therapy, assistive technology, health services and more. The SC/EI will work with your family to create an Individualized Family Service Plan (IFSP) to lay out the supports and services your child will need.

If ever unsatisfied with your current SC/EI and would like help finding another one, contact ddsn.sc.gov/contact.

Resources You May Find Helpful

scdhec.gov/health/finding-healthcare/getting-help-people-disabilities
ssa.gov/disability/disability_starter_kits_child_factsheet.htm
scdhs.gov/eligibility-groups/disabled-children
uscm.edu.libguides.com/cdr

When you learn that your child has a disability, it’s important to realize that you’re not alone. It’s now time to get prepared as possible to be able to negotiate the challenges that await your family. Collect as much information as you can about your child’s disability, about the services that are available, and about the things you can do to help your child develop to the fullest extent possible.
Your child has been diagnosed with an intellectual and/or developmental delay or disability (IDD).

(AGES 3 AND UP)

WHAT'S NEXT?

Now that your child has received a diagnosis, it’s important to take one step at a time. You will need to learn about the systems of supports available, what to do next, and connect with the services your child needs. You are your child’s greatest advocate so be sure to let your voice be heard. Prepare to actively participate in your child’s care, services and school.

BASIC INFORMATION

There will be many agencies and organizations to contact for help once your child receives a diagnosis. Be sure to call the South Carolina Department of Disabilities and Special Needs (SCDDSN). It’s the agency that plans, develops, oversees and funds services for South Carolinians with severe, lifelong disabilities such as autism, traumatic brain injury, spinal cord injury and conditions related to each of these 4 disabilities. To request eligibility, call 800-289-7012, Monday–Friday, 8:30 a.m. to 5:00 p.m. Be sure to have the following information available: your child’s full name, date of birth, social security number, Medicaid number (if Medicaid eligible), home address, phone number, and email address (if available). You will be asked several questions and will need to select 3 Intake Service Providers from a list of available providers in South Carolina. The Intake Provider will help you through the eligibility process at no cost to you. DDSN will contact the Intake Service Provider(s) you choose and you will be notified in writing of eligibility status.

IMPORTANT FACTS

The South Carolina Department of Disabilities & Special Needs (SCDDSN) provides an array of services that you can read more about here. If your child is age 3–6, a Service Coordinator /Early Interventionist (SC/EI) will coordinate services with a person-centered planning approach, which is built upon the vision of what the individual would like to do in the future.

The most important services to meet an individual’s lifelong needs are obtained through entrance into a Medicaid service program. Be sure to have your SC/EI discuss with you the different Medicaid programs, how to apply, and the waivers available to help individuals remain in their own home. If your income prohibits eligibility, apply for the Katie Becket Waiver, which allows for Medicaid coverage, regardless of parents’ income.

Be sure to contact the South Carolina Department of Education’s Office of Special Education Services to begin the special education assessment process.

Resources You May Find Helpful

scdhec.gov/health/finding-healthcare/getting-help-people-disabilities
ed.sc.gov/districts-schools/special-education-services
ed.sc.gov/districts-schools/special-education-services/parent-resources/disability-resources
Transitioning from Early Intervention Services to Case Management Services.  
(AGES 6 AND UP)

WHAT TO EXPECT

In South Carolina, Early Intervention Services last from birth until 6 years of age. Once a child turns 6, they will need to transition from Early Intervention Services to Case Management Services. Case Management Services are intended to ensure that individuals who are eligible for DDSN services have access to a full array of necessary services that will enable them to **live in community settings** (i.e., their home, a group home, etc.) rather than in institutional settings.

### BASIC INFORMATION

**Case Management Services** are provided by trained professionals, called Case Managers, who have knowledge of the medical, social, educational, and other services that are available. Case Managers learn about each individual's specific needs. Case Managers assure that services are appropriate, effective and, as needed, make referrals and/or link people to appropriate service providers.

Case Managers are employed by Disability and Special Needs (DSN) Boards and contracted service provider agencies that have been qualified by DDSN as providers of Case Management.

Those who will receive Case Management Services must choose a service provider from among those available. You can find a Service Provider here. Learn more about a Case Management provider here.

If ever unsatisfied with your current Case Manager and would like help finding another one, contact ddsn.sc.gov/contact.

### IMPORTANT FACTS

Case Managers assist families by identifying and addressing needs and concerns, coordinating resources, providing information and support, creating and developing opportunities, monitoring and evaluating services, constructing lifelong plans, assuring plan achievement, and educating the community.

Some tips for working with your child’s Case Manager (CM) include:

- Provide as much information as possible to the CM. If you don’t understand something, let your CM know.
- Always ask about anything that is not clear to you. They will explain any topics or issues to you.
- CMs provide lots of information and resources. It helps to use a folder to keep all the information organized and in one place. Make a note of questions to ask and put them in the folder.

Good communication is key to ensuring that your questions and concerns are resolved.

### Resources You May Find Helpful

ddsn.sc.gov/about-us/divisions/intellectual-disability-and-related-disabilities/case-management
app.ddsn.sc.gov/public/directory/landing.do
app.ddsn.sc.gov/public/ratings/listing.do?serviceId=6&countyId=
[ddsn.sc.gov/contact](ddsn.sc.gov/contact)
If a student has an IEP, school districts must provide transition services to prepare students with disabilities to move from school to post-school life. The activities must be based on the student’s needs, preferences, and interests, and are used to help students get ready for college, technical school, work, adult education, adult services, independent living, and participating in their community. Transition services start when the student turns 13, but planning must begin before their birthday. The IEP must include these transition services.

**BASIC INFORMATION**

Transition planning works best when students are actively involved. Family members and other adults also play important roles in this long-term planning. Teachers, administrators, and support agencies work with the student and family to reach their goals.

**IDEA** has been an important law for students receiving special education and related services. As a parent, you can do much to help your child with a disability move through their transition years. You can become familiar with the federal regulations and the procedures used in South Carolina and your child’s school district.

Appropriate transition services will enable your student to develop the skills needed for independent living. With knowledge of IDEA, you and your child can become stronger self-advocates, and you can help your young adult develop skills needed for the future.

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**IMPORTANT FACTS**

The outside adult service agencies that should be involved in transition planning could include the following:

- SC Vocational Rehabilitation
- SC Department of Mental Health
- SC Department of Disabilities & Special Needs

Other agency representatives who could be involved may include:

- Rehabilitation Counselor
- Social Worker/Case Manager
- Employment Agency Staff
- Independent Living Center Staff
- Disability Support Staff from a Postsecondary School
- Person knowledgeable about Assistive Technology
- Person knowledgeable about Social Security Income (SSI) and Medicaid
- Personal Care or Health Care Providers
- An advocate from an Advocacy Organization
- Anyone you feel might be beneficial to the planning process

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**Resources You May Find Helpful**

- sites.ed.gov/districts-schools/special-education-services/oversight-and-assistance-o-a/indicator-13-module
- wrightslaw.com/info/trans.faqs.htm
- sites.ed.gov/osers/2020/10/pathways-to-partnerships
- transitionalliancesc.org
As the parent of a child with special needs, you face many challenges that other families do not. For example, when your child turns 18, he or she may still be enrolled in school for several more years while their peers are starting college or working. When your child with a disability turns 18, they become an adult who is legally responsible for their choices and actions and parents can lose the ability to make decisions for their adult child. Don’t wait until your child with special needs turns 18 to begin planning—start early!

**WHAT TO EXPECT**

If your child has not been enrolled in Medicaid, it’s time to **apply now**. Be sure to enroll in a **Medicaid Waiver Program** and/or get on the waiting list as soon as possible.

If your child has not been involved with the SC Department of Disabilities & Special Needs, it’s now **time to get involved**.

If your child does not already have one, **apply for an Identification card**.

Investigate **ABLE Accounts**. It’s an investment account available to eligible individuals with disabilities.

At age 18, a person is presumed eligible to vote. Your child can **register to vote here**.

Find information on **Registering for Selective Service**.

Learn about **The Arc and the Center for Future Planning**.

Learn about **The Arc’s Free Financial Planning Resources**.

**BASIC INFORMATION**

It is a milestone in every parent’s life when a child turns 18. The child is now an adult, and while many responsibilities now shift from the parent to the child, parents still want to be involved in helping their young adult make decisions. There are many legal issues that a parent and child should consider before the child turns 18. For parents of special needs children, parental involvement can be critical and, depending on the disability, necessary for continuation of care.

The following is a partial list of resources and information for you to consider when you have a child who is about to turn 18. Please click the links to learn more.

There are **Alternatives to Guardianship & Supported Decision Making**.

Youth Who Receive SSI Benefits as Children **must reapply for adult SSI benefits** at Age 18. If your child hasn’t been receiving SSI, they can **apply now**.

**Resources You May Find Helpful**

[able-sc.org/get-support/supported-decision-making](able-sc.org/get-support/supported-decision-making)

[www.ssa.gov/disability](www.ssa.gov/disability)

[healthcare.gov/people-with-disabilities/coverage-options](healthcare.gov/people-with-disabilities/coverage-options)

[apply.scdhhs.gov/CitizenPortal/application.do](apply.scdhhs.gov/CitizenPortal/application.do)
As parents, we hope for our children to grow up and, as difficult as it may be for us emotionally, fly the coop to live on their own as full-fledged, independent adults. However, if you have a child with special needs, these concerns run much deeper, and that goal may seem out of reach. This is why parents should start to consider what happens to their children with special needs, no matter how young they may be, well before they turn 21.

**BASIC INFORMATION**

Life is full of transitions, and one of the more remarkable ones occurs when our kids are ready to leave high school and go out into the world as young adults.

One of the first things to consider is what will your child with special needs do after completing high school.

- Will your child continue their education?
- Will they live on their own?
- What about getting a job?
- Will your child need integrated and/or supported employment?
- Will your child need to continue working on increasing independence to whatever extent is possible?
- How will he or she participate in the community?
- What happens if you are no longer able to care for your child?

You may find the following links to resources helpful as you plan for your child's future after high school.

**Learn about Special Needs College Programs in South Carolina.**

**Research Residential Habilitation Services.**

**Look into Vocational Rehabilitation Services and other employment programs.**

**Find information about Job Seeker Resources from Hire Me SC.**

**Learn about Independent Living for All from Able SC.**

**Research Day Services in South Carolina.**

**Look into getting a break from caregiving by visiting the South Carolina Respite Coalition.**

**Learn about Kinship Caregiving.**

**Download Your Legacy of Care:** Providing for Your Special Needs Child Today, Tomorrow & Always – by Donald Bailey with J. William G. Chettle.

**Visit The Arc’s Center for Future Planning.**

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**Resources You May Find Helpful**

- homeschoolingsc.org/special-needs-college-programs-sc
- scvrd.net
- able-sc.org/get-support/employment-programs
- hiremesc.org