

Who Can I Contact Now?

A general tip-sheet with resources for when your child is first diagnosed with a special health care need

NC Children and Youth With Special Health Care Needs HELP LINE



- The Help Line is an information and referral Help Line for those living with, caring for and concerned about a child with special health care needs. You can learn about health care programs and funding resources available to North Carolina residents.
- Topics most often discussed with help line callers include:
 - Information and services available under government and community programs.
 - Resources to help pay for medications, medical equipment/supplies, adaptive devices, visits to the doctor, utilities or food.
 - How to find health care and dental providers.
 - How and where to apply for disability income for a child.
 - How to find services when relocating to and within North Carolina.
- For more information call 1-800-737-3028 or email CYSHCN.Helpline@dhhs.nc.gov

Exceptional Children's Assistance Center (ECAC)

- ECAC is a North Carolina parent organization committed to improving the lives and education of ALL children with disabilities and/or special healthcare needs ages 0 to 26.
- ECAC offers free workshops, online learning, leadership trainings, newsletters, and other tools.
- For more information call 1 800-962-6817 or visit <https://www.ecac-parentcenter.org/>



NC 2-1-1

- NC 2-1-1 is an information and referral service that you can call to get free and confidential information on health resources within your community. Dialing 2-1-1 is free, available 24 hours every day, and available in most languages.
- NC 2-1-1 has information on thousands of programs and services in North Carolina. They refer you to organizations in your community that can address your needs including food, shelter, energy assistance, housing, parenting resources, healthcare, substance abuse, as well as specific resources for older adults and persons with disabilities, and much more. When you call NC 2-1-1, someone will help you find resources and information.
- For more information call 2-1-1 or visit <https://www.nc211.org/>



Trillium

- Trillium Health Resources is an agency that manages mental health, substance use, and intellectual/developmental disability services in eastern North Carolina. Their goal is to connect you to the help you need. Services are for those with Medicaid, are uninsured, or cannot afford services.
- Trillium does not provide direct care, but works with local non-profits, government agencies, medical providers, therapist, hospitals, and other agencies to offer services you may need.
- Call or 1-877-685-2415 visit <https://www.trilliumhealthresources.org/> for more information



Local Special Needs Registry

- The Special Needs Registry is a list of medically needy, and/or disabled individuals who would require assistance in the event of an emergency.
- This registry alerts emergency responders your address and gives them the vital information they need to meet your child's needs. Participation in the registry is voluntary and all information is strictly confidential, used only for emergency purposes.
- For more information on this service, contact the Pasquotank-Camden Emergency management at (252) 335-4444 or the Perquimans Emergency Management at (252) 426-7029

Do I have a way to organize my child's medical, developmental, educational and service information so that it is easy to use when needed?

If not, obtain a **Care Notebook** from the **Exceptional Children's Assistance Center (ECAC)** to help organize important information,

A Care Notebook can be obtained free of charge from the ECAC by calling 1-800-962-6817 or by visiting the following website: <http://www.ecacparentcenter.org>

**Do I know what an Individualized Education Plan (IEP) is?
Have I started thinking about goals for my child's education?**

An IEP is a plan that spells out the specific types of help your child will get. It is a map that lays out the program of special education instruction, supports and services kids need to make progress and succeed in school.

For additional information contact ECAC by calling 1-800-962-6817 or by visiting the following website: <http://www.ecacparentcenter.org>

Questions to ask your doctor about transitioning to adult healthcare

- When does my child start to meet with you on their own for part of the visit to more independent when it comes to their own health and health care?
- What does my child need to learn to get ready for adult health care? Do you have a checklist of self-care skills that my child needs to learn?
- Can I work with you to prepare a Medical Summary and Emergency Care Plan for my child?
- Before my child turns 18 and becomes a legal adult, what information about consent do we need to learn about? If my child needs help with decisions, where can I get information about this?
- At what age does my child need to change to a new doctor for adult health care?
- Do you have any suggestions of adult doctors for my child to transfer to?



Financial Resources

- Does my child qualify for Supplemental Security Income (SSI) (income supplement program for those meeting eligibility requirements)?
If yes, please contact:
U.S. Social Security Administration
Phone: 1 (800) 772-1213
Website: <http://www.ssa.gov/pgm/ssi.htm>
- Does my child qualify for Medicaid or Health Choice (health coverage program for those meeting eligibility requirements)?
If yes, please contact your local Department of Social Services

Community Services

- Does my child have an Intellectual/ Developmental Disability (ID/DD)? For more information please contact:
Trillium Health Services
1-877-685-2415
<https://www.trilliumhealthresources.org/>
- Does my child qualify for Respite services (short-term, temporary relief for caregivers)? For more information please contact:
North Carolina Department of Health and Human Services
Children and Youth with Special Health Care Needs (CYSHCN) Helpline at 1 (800) 737-3028 or email CYSHCN.Helpline@dhhs.nc.gov
- Does my child qualify for the Community Alternatives Program for Children (CAP-C) (eligibility based program providing home and community based services)?
For more information on the CAP-C programs, please visit:
<https://www.ncdhhs.gov/assistance/childrens-services/community-alternatives-program-for-children>
- Does my child qualify for the Community Alternatives Program for Intellectual or Developmental Disability (CAP-IDD) or Disabled Adults (CAP-DA) (eligibility based program providing home and community based services)?
For more information on the CAP-C programs, please visit:
<https://www.ncdhhs.gov/providers/provider-info/mental-health/idd-systems-of-services> or
<https://medicaid.ncdhhs.gov/providers/programs-services/long-term-care/community-alternatives-program-for-disabled-adults>

Transitioning into Adulthood (ages 13+)

Information for Youth with Special Health Care Needs

Preparing for LIFE after High School

Questions to consider:

1. What will their day be like when they no longer attend school?
2. What kind of support does your child need to be successful?
3. What about independent transportation—is it possible, can your child successfully use the bus system or obtain a driver's license?
4. Can your child answer the question “what do you want to do when you are done with school?”
5. Do you know what your child is interested in? Does your child know?
6. Are you familiar with post-secondary educational opportunities? Are you familiar with Disability Services at 2 and 4-year universities?

National Secondary Transition Technical Assistance Center
www.nsttac.org/content/students-families

North Carolina Postsecondary Education Alliance
www.cidd.unc.edu/psea/

Think College! College options for people with disabilities
www.thinkcollege.net/
7. Are you familiar with guardianship? Do you need full or partial guardianship?

Student Age Action Needed

12-14 Years:

- Actively participate in your child's IEP/504 meeting at school- include as needed social skills, communication, functional math and reading, self-help and self-advocacy skill on the IEP to help increase independence

By 14 Years

- Begin transition planning
- Identify job interests and abilities
- Identify community services that provide job training and placement opportunities
- Explore guardianship before age 18
- Begin application to adult service agencies
- Consider summer employment or participate in volunteer experiences

16-18 Years:

- Contact adult services programs: Colleges, Vocational or Technical Schools
- Social Security Administration (apply for SSI or Disability benefits)
- Residential or Independent Living Services
- Vocational Rehabilitation (252) 331-4768
- Identify Recreational/Leisure Activity Groups
- Begin Medical Transition process

17-18 Years

- Begin to consider and research Guardianship
- Continue to review and update Transition Plan
- Take ACT or SAT tests if needed for educational plans
- Visit colleges and their Disability Services Office
- Register with Disability Service Office of your preferred school by end of senior year

18+ Years

- If still enrolled in high school, continue to review and update Transition plan
- Establish needed Health Benefits
- Develop long term financial support plan
- Participate with community based support services
- Residential living

Infant Toddler Years (ages 0-3)

Things to Consider



Do I know what an Individualized Family Service Plan (IFSP) is, and have I started thinking about goals for my child's development?

The IFSP is a written treatment plan that maps out the early intervention services your child will receive, as well as how and when these services will be carried out. It details your child's current levels of functioning, specific needs and goals for treatment.

For additional information contact: Children's Developmental Services Agency (CDSA) by calling (252) 338-4044 or by visiting the following website: <http://www.bearly.nc.gov>

Child Care/Early Intervention Services

Options to consider include:

Child Care Aid

Local Department of Social Services

- **Pasquotank**
(252) 338-2126
<http://www.pasquotankcountync.org>
- **Perquimans**
(252) 426-1806
<https://www.ncdhhs.gov/divisions/social-services/perquimans-county-department-social-services>
- **Camden**
(252) 331-4787
<http://www.camdencountync.gov/departments/planning-zoning/9-departments>

Care Coordinator for Children (CC4C)

Albemarle Regional Health Services

(252) 338-4423

<https://www.communitycarenc.org/what-we-do/clinical-programs/care-coordination-children-cc4c>

Albemarle Alliance for Children & Families

(252) 333-1233

<http://www.albemarleacf.org>

Chowan Perquimans Smart Start

409 Old Hertford Road, Edenton, NC 27932

(252) 482-3035

<http://www.cp-smartstart.org/>



Nutritional Concerns

- Does my child need nutrition supplements or special formulas?
For health concerns, contact your local pediatrician.
- Does my child qualify for Women Infants and Children (WIC) Supplemental Nutrition Program services?
For the most current information on WIC program income limits please visit:
<http://www.fns.usda.gov/wic/>
- To apply for WIC, please contact the local health department
 - Pasquotank (252) 338-4400
 - Perquimans (252) 426-2100
 - Camden (252) 338-4460Or visit <http://arhs-nc.org/>



Financial



- Does my child qualify for **Supplemental Security Income (SSI)** (income supplement program for those meeting eligibility requirements)?
If yes, please contact:
U.S. Social Security Administration
1 (800) 772-1213
Website: <http://www.ssa.gov/pgm/ssi.htm>
- Does my child qualify for **Medicaid or Health Choice** (health coverage program for those meeting eligibility requirements)?
If yes, please contact your local Department of Social Services

Community Services

- Does my child qualify for **respite services** (short-term, temporary relief for caregivers)?
For more information please contact:
North Carolina Department of Health and Human Services
Children and Youth with Special Health Care Needs (CYSHCN) Helpline at
1 (800) 737-3028 or email CYSHCN.Helpline@dhhs.nc.gov
- Does my child qualify for the Community Alternatives Program for children (CAP-C) (eligibility based program providing home and community based services)?
For more information on the CAP programs, please visit:
<https://www.ncdhhs.gov/assistance/childrens-services/community-alternatives-program-for-children>
- Does my child qualify for **services after age 3**? A Transition Planning Conference should be scheduled by age two and a half to discuss the transition out of Early Intervention Services (CDSA) and eligibility for Preschool Services through the Public Schools. Consult with your Early Intervention Service Coordinator (CDSA) for more information on the Transition Planning Conference.



Supplies

- Does my child need any **specialized equipment**, and if so, who do I contact?
For questions related to specialized equipment at home contact your Medicaid Case Manager or CAP-C Case Manager. For questions related to specialized equipment at school (if applicable) contact your child's teacher.
- Does my child need **assistive technology (AT)** to support their ability to participate actively in the home, childcare program, community or other natural environment? If so, consult with your Early Intervention Service Coordinator (CDSA)

Preschool Years (ages 3-5)

Things to Consider



Do I know what an Individualized Education Plan (IEP) is?
Have I started thinking about goals for my child's education?

An IEP is a plan that spells out the specific types of help your child will get. It is a map that lays out the program of special education instruction, supports and services kids need to make progress and succeed in school. For additional information contact ECAC by calling 1-800-962-6817 or by visiting the following website:
<http://www.ecacparentcenter.org>

Child Care/Exceptional Children's Preschool Services

Options to consider include:

Child Care Aid

Local Department of Social Services

- Pasquotank
(252) 338-2126
<http://www.pasquotankcountync.org>
- Perquimans
(252) 426-1806
<https://www.ncdhhs.gov/divisions/social-services/perquimans-county-department-social-services>
- Camden
(252) 331-4787
<http://www.camdencountync.gov/departments/planning-zoning/9-departments>

North Carolina Pre-Kindergarten

NC Northeast Region Pre-K Program Policy
Consultant

(919) 604-7626
<https://ncchildcare.ncdhhs.gov/Home/DCDEE-Sections/North-Carolina-Pre-Kindergarten-NC-Pre-K>

Care Coordinator for Children (CC4C)

Albemarle Regional Health Services

(252) 338-4423
<https://www.communitycarenc.org/what-we-do/clinical-programs/care-coordination-children-cc4c>

Albemarle Alliance for Children and Families

(252) 333-1233
<http://www.albemarleacf.org>

Chowan Perquimans Smart Start

409 Old Hertford Road, Edenton, NC 27932
(252) 482-3035
<http://www.cp-smartstart.org/>

Head Start

712 Virginia Rd, Edenton, NC 27932
(252) 482-4495
<http://www.eiccaa.org/head-start.html>

For additional information and services, contact your local school system,
private school, or home school association.

Nutritional Concerns

- Does my child need nutrition supplements or special formulas?
For health concerns, contact your local pediatrician.
- Does my child qualify for Women Infants and Children (WIC) Supplemental Nutrition Program services?
For the most current information on WIC program income limits please visit:
<http://www.fns.usda.gov/wic/>

To apply for WIC, please contact the local health department

- Pasquotank (252) 338-4400
- Perquimans (252) 426-2100
- Camden (252) 338-4460

Or visit <http://arhs-nc.org/>



Financial



- Does my child qualify for Supplemental Security Income (SSI) (income supplement program for those meeting eligibility requirements)?
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Website: <http://www.ssa.gov/pgm/ssi.htm>
- Does my child qualify for Medicaid or Health Choice (health coverage program for those meeting eligibility requirements)?
If yes, please contact your local Department of Social Service

Community Services

- Does my child have an Intellectual/ Developmental Disability (ID/DD)? For more information please contact:
Trillium Health Services
1-877-685-2415
<https://www.trilliumhealthresources.org/>
- Does my child qualify for Respite services (short-term, temporary relief for caregivers)? For more information please contact:
NC Department of Health and Human Services Children and Youth with Special Health Care Needs (CYSHCN) Helpline at 1 (800) 737-3028 or email CYSHCN.Helpline@dhhs.nc.gov
- Does my child qualify for the Community Alternatives Program for Children (CAP-C) (eligibility based program providing home and community based services)?
For more information on the CAP-C programs, please visit:
<https://www.ncdhhs.gov/assistance/childrens-services/community-alternatives-program-for-children>

Supplies



Is my child potty trained? If not, will they need any incontinent supplies?
Does my child need any specialized equipment, and if so, who do I contact?
For questions related to specialized equipment at home contact your Medicaid Case Manager or CAP-C Case Manager. For questions related to specialized equipment at school (if applicable), contact your child's teacher.

Grade School Years (ages 6-13)

Things to Consider



Do I know what an Individualized Education Plan (IEP) is?
Have I started thinking about goals for my child's education?

An IEP is a plan that spells out the specific types of help your child will get. It is a map that lays out the program of special education instruction, supports and services kids need to make progress and succeed in school.

For additional information, contact ECAC by calling 1-800-962-6817 or by visiting the following website:

<http://www.ecacparentcenter.org>

Preparing for the Transition

- Know your child's IEP/504 team
- Participate in the development of the IEP/504 goals and objectives for your child
- Share information regarding IEP/504 goals, services and accommodations with those who are working with your child to ensure coordination and collaboration among service providers
- Share your insights regarding your child - how he/she learns best, what motivates or frustrates him/her, etc.

Socialization and Safety Tips

- Provide opportunities for social interactions to help your child develop social skills
- If available, consider a "Lunch buddy" or Peer Helper" program to provide additional social support
- Monitor interactions with others for signs of bullying or teasing
- Help your child with knowing how to respond when bullying or teasing
- Engage the assistance of the school guidance counselor if assistance is needed regarding interactions with peers
- Expect changes in your child's behavior as he/she goes through puberty, and provide information regarding these changes based on his/her level of understanding

Personal Development Tips

- Encourage your child to become more independent based on their individual abilities
- Work on organizational skills with your child to help him/her handle the increased demands in school
- Check out available resources for tutoring or skill development

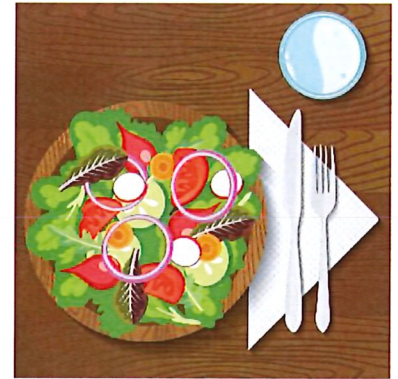
Did you know?

- The Special Needs Registry is a voluntary registry of individuals who would require assistance in the event of an emergency.
- This registry alerts emergency responders as to a resident's address and gives them the vital information they need to better meet the resident's needs.
- Participation in the registry is voluntary and all information is strictly confidential, used only for emergency purposes
- Children and youth are eligible to register with the Special Needs Registry if they are medically needy, and/or disabled.
- For more information on this service, contact the Pasquotank-Camden Emergency management at (252) 335-4444 or the Perquimans Emergency Management at (252) 426-7029

Nutritional Concerns

- Does my child need nutrition supplements?
For health concerns, contact your local pediatrician.
- Does my child qualify for free or reduced lunch?
For the more information on program requirements please contact your local public school

- Pasquotank (252) 335-2981 <https://www.ecpps.k12.nc.us/>
- Perquimans (252) 426-5741 <http://www.pqschools.org/>
- Camden (252) 335-0831 <https://ccsnc.org/>



Financial Resources



- Does my child qualify for Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) (income supplement program for those meeting eligibility requirements)?
If yes, please contact:
U.S. Social Security Administration
Phone: 1 (800) 772-1213
Website: <http://www.ssa.gov/pgm/ssi.htm>
- Does my child qualify for Medicaid or Health Choice (health coverage program for those meeting eligibility requirements)?
If yes, please contact your local Department of Social Service

Community Services

- Does my child have an Intellectual/ Developmental Disability (ID/DD)? For more information please contact:
Trillium Health Services
1-877-685-2415
<https://www.trilliumhealthresources.org/>
- Does my child qualify for Respite services (short-term, temporary relief for caregivers)? For more information please contact:
NC Department of Health and Human Services Children and Youth with Special Health Care Needs (CYSHCN) Helpline at 1 (800) 737-3028 or email CYSHCN.Helpline@dhhs.nc.gov
- Does my child qualify for the Community Alternatives Program for Children (CAP-C) (eligibility based program providing home and community based services)?
For more information on the CAP-C programs, please visit:
<https://www.ncdhhs.gov/assistance/childrens-services/community-alternatives-program-for-children>



Supplies

- Does my child need any specialized equipment/ incontinent supplies, and if so, who do I contact?
For questions related to specialized equipment at home, contact your Medicaid Case Manager or CAP-C Case Manager. For questions related to specialized equipment at school (if applicable), contact your child's teacher.