Innovative Approaches Initiative

Children and Youth with Special Health Care Needs

A Guide For Health Care Financing Resources

The Innovative Approaches Initiative

An initiative facilitated by Cabarrus Health Alliance.

Updated 8.17.19

Children and Youth with Special Health Care Needs

A Guide for Health Care Financing Resources

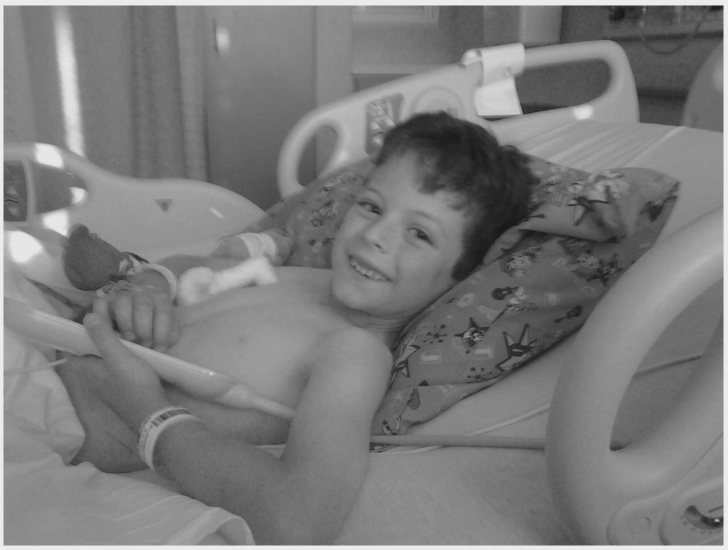
Introduction

Approximately 20% of children under age 18 in the United States have a special health care need. The Maternal and Child Health Bureau defines children and youth with special health care needs (CYSHCN) as those who "have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally."

CYSHCN often need services from multiple systems—health care, public health, education, mental health and social services. They may require multiple specialists including medical specialists, physical, speech, or occupational therapists, and mental health or home health providers.

Families raising children and youth with special healthcare needs (CYSHCN) or disabilities often experience financial hardships as a result of inadequate health insurance coverage. 49% of families have reported having difficulty paying their bills due to high costs of medical care for their child.

While most families have health insurance through Medicaid or private insurance, not every service or support that CYSHCN require is covered. As a result, families often have to pay large amounts out of pocket, creating financial hardship and medical debt.



Navigating the complicated mix of private and public health programs can be challenging. *A Guide for Health Care Financing Resources* was developed through the Innovative Approaches Initiative to help families of CYSHCN navigate the health care system and to find financial resources to cover therapies, equipment, and other health necessities for their child.

A glossary has been added to help you manage the technical terms found in the world of health care and health financing. The information in this guide can change frequently. For most up-to-date information, go to: www.resourcecafe.org

Innovative Approaches Initiative

The Innovative Approaches Initiative works in partnership with medical providers, community agencies and parents to improve the services systems for children and youth with special healthcare needs. Innovative Approaches Initiative is supported through the NC Division of Public Health, Children and Youth Branch.

Getting Organized

Organize Your Child's Health Information

Keeping all your paperwork related to your finances and child's disability in one place is one of the most important things you can do. Having the right information at your fingertips saves time, helps with decision making and reduces caregiver stress.

A Care Notebook is a great recordkeeping tool to organize your child's health information, insurance paperwork, prepare for appointments, track changes in medicines or treatments, and to file information about your child's health history.

Begin with a large 3-ring binder, tabs for the binder to divide the binder into sections, and a three-hole punch. The binder should be big enough and sturdy enough to hold all your child's pertinent medical information for several years.

A template for Care Notebook pages may be downloaded and printed from the Exceptional Children's Assistance Center (ECAC) website at:
https://www.ecac-parentcenter.org/family-to-family-health-center/care-notebook/

The downloaded pages includes steps on organizing and using the Care Notebook.
Other recordkeeping supplies you may want to consider are:

- A calendar with room for writing notes
- A spiral notebook for recording phone conversations and meetings with professionals
- A place to file papers such as a filing cabinet or file box with a lid
- Hanging file folders with plastic tabs
- File folders and labels
- Highlighters (for drawing attention to important information)

Establish a Medical Home

Every child and youth deserves a medical home.

The American Academy of Pediatrics (AAP) developed the medical home as a model of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective to every child and adolescent. A pediatric medical home is a family-centered partnership within a community-based system that provides uninterrupted care with appropriate payment to support and sustain optimal health outcomes. Medical homes address preventative, acute, and chronic care from birth through transition to adulthood. A medical home facilitates an integrated health system with an interdisciplinary team of patients and families, primary care physicians, specialists and subspecialists, hospitals and healthcare facilities, public health and the community.

From AAP Agenda for Children: Medical Home

In other words, a Medical Home is the one place you take your child for **all** their health care needs:

- Check-ups
- Sick visits
- Accidents
- Special health needs
- Immunizations (shots)

A Medical Home is a doctor's office, a community clinic, or a local health department. The staff there knows you, your child and your child's health history.

You want to take your child to someone you know and trust. A Medical Home offers the very best care to make sure your child gets check-ups, screenings, and shots to stay well. They work with you in planning your child's care. They help you find the right community programs, resources and specialists.

Accessing Medicaid

NC Medicaid and Health Choice/CHIP

Medicaid is a program that provides financial assistance for children, elderly and medically needy families and individuals. The cost is shared by the federal and state governments. The federal government establishes general guidelines and minimum benefits for eligibility.

One of the federal requirements is that Medicaid for children must provide a very comprehensive package of benefits called **EPSDT (Early Periodic Screening, Diagnosis, and Treatment).**

EPSDT covers regular screening services (check-ups) for infants, children and adolescents. These screenings are designed to identify health and developmental issues as early as possible. If your child has Medicaid and is not able to access needed procedures or services, please refer to the EPSDT Coverage Guide at the link below:

https://www.medicaid.gov/medicaid/benefits/downloads/epsdt_coverage_guide.pdf

Administered through the North Carolina Department of Health and Human Services, **NC Medicaid** and **NC Health Choice or CHIP (Children's Health Insurance Program)** offer ways to cover some or all of the cost of health care for your child or youth with special heath care needs. Medicaid and Health Choice are both income based. To apply or see if your child is eligible for either of these programs, please contact the Department of Social/Human Services in your county or go online to:

https://dma.ncdhhs.gov/medicaid/get-started/eligibility-medicaid-or-health-choice

If your family income is too much to qualify for Medicaid but too little to afford private insurance, your child may qualify for **NC Health Choice**. If your monthly income is more than 159% of the poverty level, a small enrollment fee of $50 and co-pays on medical visits and prescription drugs are required. If your monthly income is below 159% of the poverty level, there are no enrollment fees or co-pays.

If your child is denied either Medicaid or Health Choice, it is your right to appeal. To learn more about the appeal process, please go to:
https://dma.ncdhhs.gov/medicaid/your-rights

Services Covered by Health Choice/CHIP

- Case Management and care coordination services (coordinator helps families access health insurance, medical care, and services)
- Dental services
- Durable medical equipment (such as wheelchairs, oxygen, insulin pumps, etc. prescribed by a doctor)
- Disposable medical supplies (such as incontinence supplies for children over 3 years old, underpads, catheters, ostomy supplies, nutritional supplements, etc.)
- Emergency services
- Family planning services
- Hospice care for children in their last phase of life
- Home health care—medically necessary skilled nursing services, specialized therapy (such as physical therapy, speech-language pathology and occupational therapy), home health aide services and medical supplies.
- Immunizations (shots)
- Laboratory and radiological services
- Mental health services (inpatient and outpatient)
- Physician and clinic services (well-child and sick visits)
- Physical therapy
- Occupational therapy
- Therapy for children with speech, hearing and language disorders
- Prescription drugs
- Substance abuse services
- Surgical services

Reference: NC Department of Health and Human Services

IMPORTANT! Transformation to NC Medicaid Managed Care

The Division of Health Benefits (formerly, DMA) launches changes to begin in November 2019. For the most recent information, go to https://www.ncdhhs.gov/divisions/medicaid-transformation

Revised 8/19

Accessing Medicaid

Social Security Income (SSI)

SSI is a federal program under Social Security that provides monthly cash benefits to individuals (including children) with disabilities who have limited income and resources. If your child qualifies for SSI, they will also be eligible for Medicaid.

Your child may qualify for SSI payments if he or she is younger than age 18, has a physical or mental condition, or combination of conditions that meets Social Security's definition of disability for children, and if his or her income and resources fall within the eligibility limits. Income and resources of family members living in the child's household is considered for eligibility.

When you apply for SSI benefits for your child, you will be asked for name, address and phone number for every doctor, therapist or provider that your child has seen over the last year, medical records, and a list of medications. Other information may be needed as well such as names and addresses of schools, teachers, psychologists, IEP, original or certified copy of your child's birth certificate, proof of income of all family members living in the household and proof of any resources such as bank accounts, stocks, life insurance policies, etc.

Once your child/young adult turns 18 years old, only his or her income and resources are considered for eligibility.

To apply for SSI benefits for your child, please contact the Social Security Office in your county or go online to:

https://www.ssa.gov/disability/disability_starter_kits_child_eng.htm

Reference:https://www.ssa.gov/ssi/text-child-ussi.htm

Medicaid and Special Education

If a child is eligible for Medicaid, Medicaid pays for health and related services provided in schools when the services are provided through a child's Individualized Family Service Plan (IFSP) (for children birth to 3 years old), or Individualized Education Plan (IEP) (for children 3 to 21 years old). Under the Individuals with Disabilities Education Act (IDEA), children with disabilities are eligible to receive educational and related services that will help them achieve their educational goals. These goals will be documented in the child's IEP or toddler's Individualized Family Service Plan (IFSP). These services must be provided in the school, although children may receive similar services outside the school setting. Covered services may include, but are not limited to, physical therapy, occupational therapy, speech pathology or therapy services, psychological counseling, nursing, and transportation service.

It is important to note that, except under waivers, Medicaid can only pay for ***rehabilitation services*** that restore functional losses. For children with developmental disabilities, ***habilitation services*** to develop (as opposed to restore) functional abilities are very important. Schools play a very important role in providing both these skills but can only bill Medicaid for rehabilitation service, not habilitation services unless the child is covered by a waiver.

If a child is not Medicaid-eligible, educational and related services are covered by the school.

Reference: https://ec.ncpublicschools.gov/finance-grants/medicaid-in-education

Appealing a Denial

Medicaid/Health Choice: If your child has been denied Medicaid or Health Choice benefits and you disagree, you may file an appeal. If a Medicaid health service is denied (or if it is reduced, terminated, or suspended), you will receive a letter that describes the decision and why it was made. The letter has instructions for how to appeal. Please sign the required forms to accept delivery of the letter. The letter will come from the Division of Health Benefits (NC Medicaid) or one of its vendors. For questions about appeals, contact The Appeals Unit, NC Medicaid at:

919-855-4260

SSI: If your child has been denied SSI benefits, you may request an appeal. Generally, you have 60 days after you receive the notice of denial. There are 4 ways to appeal: Reconsideration (which can be appealed online), Hearing by an Administrative Law Judge, Request for Review by the Appeals Council, or Federal Court Review. For more information on appealing an SSI denial, go to:

https://www.ssa.gov/benefits/disability/appeal.html

or call **800-772-1213**

Reference: *https://www.ssa.gov/ssi/text-appeals-ussi.htm*

Accessing Medicaid for your child in North Carolina

<table>
<tr><th>Program</th><th>Eligibility (as of January 2019)</th></tr>
<tr><td>Medicaid for low-income blind, seniors and people with disabilities</td><td>Monthly Income Limits for Aged, Blind and Disabled
<table><tr><td>Family Size</td><td></td></tr><tr><td>1</td><td>$1,041</td></tr><tr><td>2</td><td>$1,410</td></tr></table></td></tr>
<tr><td>Medicaid for Infants and Children</td><td>Monthly Income Limits: Medicaid for Infants and Children
<table><tr><td>Family Size</td><td>Age 0-5</td><td>Age 6-18</td></tr><tr><td>1</td><td>$2,186</td><td>$1,385</td></tr><tr><td>2</td><td>$2,960</td><td>$1,875</td></tr><tr><td>3</td><td>$3,733</td><td>$2,365</td></tr><tr><td>4</td><td>$4,507</td><td>$2,854</td></tr></table></td></tr>
<tr><td>NC Health Choice or CHIP</td><td>Annual Income Limits: Health Choice
<table><tr><td>Family Size</td><td>133% (a)</td><td>211% (b)</td></tr><tr><td></td><td>Annual Income</td><td>Annual Income</td></tr><tr><td>1</td><td>$16,152</td><td>$25,620</td></tr><tr><td>2</td><td>$21,900</td><td>$34,740</td></tr><tr><td>3</td><td>$27,648</td><td>$43,848</td></tr><tr><td>4</td><td>$33,384</td><td>$52,968</td></tr></table>Enrollment Fees:
If your family monthly income is above 159% of the federal poverty level, there is an enrollment fee of $50 for one child or $100 for two or more children. The enrollment fee must be paid for each 12-month continuous enrollment period. If your family monthly income is at or below the 159% poverty level, there is no enrollment fee.

Copayments:
If your monthly income is above 159% of the federal poverty level, copayments are:
• $25 for non-emergency emergency room use
• $5 per physician visit
Prescription drugs: $1 for a generic drug, $1 for a brand drug for which no generic is available, and $10 for brand drug for which there is a generic available

If your family monthly income is less than or equal to 159% of the federal poverty level, copayments are:
• $0 per physician visit
• $10 for non-emergency emergency room use
Prescription drugs: $1 for a generic drug, $1 for a brand drug for which no generic is available, and $3 for brand drug for which there is a generic available</td></tr>
</table>

Reference: https://files.nc.gov/ncdma/documents/files/Basic-Medicaid-Eligibility-Chart-2019_0.pdf *Revised 4/19*

Program	Eligibility
CAP-C (Community Alternatives for Children)	• CAP/C is available to any child from birth through 20 years of age who meets both the Medicaid eligibility criteria and the CAP/C eligibility criteria: • Lives in a private residence • Be able to be cared for safely at home • Require the same level of care as a child in a nursing home or hospital • Have a family willing to participate in the care and in the care planning for their child *Reference: https://medicaid.ncdhhs.gov/medicaid/get-started/find-programs-and-services/community-alternatives-program-for-children*
CAP-DA	• CAP/DA) is for adults age 18 and older with disabilities • They remain in their primary private residences rather than nursing home placement. *Reference: https://medicaid.ncdhhs.gov/providers/programs-services/long-term-care/community-alternatives-program-for-disabled-adults*
NC Innovations Waiver	• Children or adults that have an IDD diagnosis. • Have limitations in three of six major activity areas (*self-care, receptive and expressive language, capacity for independent living, learning, mobility, and self-direction and economic self-sufficiency*). • Need waiver services in order to keep living at home or to move out of an ICF/IDD group home/center. • Be eligible for Medicaid. • Live in a private living arrangement or a small facility (*with no more than six residents*). *Reference: https://medicaid.ncdhhs.gov/nc-innovations-waiver*

Do you or does someone in your family get Medicaid or NC Health Choice?

7 Things You Need to Know About NC's Move to NC Medicaid Managed Care

North Carolina Medicaid and NC Health Choice are moving to "Medicaid Managed Care" in November 2019. This means that you will get to choose from more than on Medicaid health plan, and that health plan will be run by an insurance company. Your benefits and your share of the cost (such as copayments) will stay the same. You will receive information about how to choose and enroll in a health plan that best fits your needs. Here is what you need to know:

1. **MEDICAID MANAGED CARE IS COMING IN 2019.** Managed care for Medicaid and NC Health Choice programs will begin in November 2019. Most people who get Medicaid will move to NC Medicaid Managed Care and will get to choose a prepaid health plan. Some people will begin later, but no one will begin earlier than November 2019. Until then, keep using Medicaid and NC Health Choice as you do today.
2. **YOU WILL HAVE ALL THE INFORMATION YOU NEED TO MOVE TO MEDICAID MANAGED CARE.** As the start of Medicaid Managed Care gets closer, you will get updates with more details. You can also get your questions answered online, on the phone, and in person.
3. **THE ONLY THING TO DO NOW IS UPDATE YOUR INFORMATION AND KEEP IT UP TO DATE.** Your address and phone number will be used to send you more information about Medicaid Managed Care. If you need to update this information, please call or go to your county Department of Social Services. Here is a list of Social Services offices and phone numbers. www.ncdhhs.gov/divisions/dss/local-county-social-service-offices
4. **HELP WILL BE AVAILABLE TO CHOOSE A HEALTH PLAN AND ENROLL.** The state has hired a company to give you information on the health plans in your area that will help you choose the best health plan for you.
5. **MANY THINGS WILL STAY THE SAME.** NC Health Choice benefits are staying the same. Only ***how*** you get your care and services will change. Eligibility rules for Medicaid are the same. The same health services, treatment, and supplies will continue to be covered. You will still receive high quality care from a doctor near you and help with transportation to the doctor if you need it. Your share of Medicaid costs, if you have any, will stay the same as long as your household income stays the same.
6. **YOUR RIGHTS WILL BE PROTECTED.** You will have rights to make sure you can fix issues with your health plan quickly and with little hassle. You will have the right to file grievances and appeals if necessary. There will be a new "ombudsman program" dedicated to help you get information and fix issues, whether you are in Medicaid managed Care or have yet to move to Medicaid Managed Care.
7. **HOW TO GET MORE INFORMATION.** If you have questions about NC Medicaid Managed Care or what it will mean for you and your family, please visit our website at www.ncdhhs.gov/medicaid-transformation

HERE IS WHAT TO EXPECT:

- **AUGUST 2018:** The state chose the company that will help you choose and enroll in the health plan of your choice.
- **FEBRUARY 2019:** The state announced which health plans will be available in Medicaid Managed Care.
- **SUMMER 2019:** You will get information on the health plans in your area, including how to find out which health plans have your doctor, and a phone number you can call to get help to understand your choices.
- **JULY-SEPTEMBER 2019:** Medicaid Managed care will start by dividing the state into two phases. This is when you will choose a health plan if you live in the Phase 1 regions of the state.
- **NOVEMBER 2019:** Medicaid managed Care will start in the Phase 1 regions.
- **OCTOBER –DECEMBER 2019:** If you live in the Phase 2 regions, this is when you will choose a health plan.
- **FEBRUARY 2020:** Medicaid Managed Care will start in the Phase 2 regions. Medicaid Managed Care now will be available throughout the state.

Accessing Medicaid Waiver Services

A waiver is a provision in Medicaid law which allows the federal government to waive rules that usually apply to the Medicaid program. This helps the state to accomplish certain goals, such as reducing costs, expanding coverage or improving care for certain target groups such as children with special healthcare needs or disabilities. Medicaid waivers are not considered an entitlement, which means some children may spend several years on a waiting list before they receive services.

NC Innovations Waiver

The NC Innovations waiver allows children and adults living with intellectual and/or developmental disabilities (IDD) get extended coverage through Medicaid. Parent's income is waived so only the child or adult with IDD's income is counted. Services may include assistive technology equipment and supplies, community navigator, community living and support, home modifications, residential supports, respite, supported living and supported employment.

The regional Managed Care Organization (MCO), Cardinal Innovations Healthcare, manages the NC Innovations waiver. To apply for the waiver, please call:

704-939-7980 or 800-939-5911

What to expect when you call:
The coordinator for waiver services will ask questions about your child. You will be asked to fill out an application for the waiver. You will need your child's most recent psychological report or you may need to schedule an appointment for a psychological evaluation. You will need to sign release forms for your provider to share information with Cardinal.

If your child is found eligible for the NC Innovations waiver, their name will go on a waiting list called the "Registry of Unmet Needs." Because families often wait several years for their child to receive the NC Innovations waiver services, it is **IMPORTANT to apply for the waiver when your child is young.**

If your child has Medicaid and is waiting for the waiver services, you may be able to access limited services such as respite and a community guide.

If you need assistance navigating this process, please call 800-939-5911 and ask to speak with someone in Member Engagement.

For more information, please go to the link below:

https://www.cardinalinnovations.org/Members/How-Coverage-Works/Medicaid-funded-coverage?tab=1

(b)(3) Services

(b)(3) services are additional supports for individuals who have Medicaid. Your child may be able to access these services while on the Registry of Unmet Needs if they have Medicaid. (b)(3) services may include respite, in-home skill building, or supported employment. Your child does not have to be on the Registry of Unmet Needs to access (b)(3) services if they have Medicaid.

Cardinal Innovations Healthcare manages (b)(3) services. For more information, please call:

800-939-5911

State-funded Services

If your child with IDD or mental health issues and is not eligible for Medicaid, they may be eligible for State-funded Services. In some cases you may be subject to a sliding-scale fee, which means you will be responsible for some of the cost.

To be eligible for state-funded services, you must:

- Not have Medicaid or adequate private health insurance
- Need a service that is not covered by Medicaid
- Meet specific income requirements

Cardinal Innovations Healthcare manages state-funded services. For more information, please call:

800-939-5911

Reference: www.cardinalinnovations.org

Accessing Medicaid Waiver Services

CAP-C (Community Alternative Program for Children)

Also called the Katie Beckett waiver, this program is a way to grant Medicaid to children, birth through age 20, who are medically fragile, even if the family income is higher than allowed for Medicaid. Parent income and resources are **not** counted toward eligibility. The determination is based on the degree of the individual child's functional limitations and his or her need for specialized care and services.

Services include in-home aide, home and vehicle modifications, assistive technology, training, respite care, diapers, therapies, specialized medical equipment and a case manager.

To apply, please call one of the CAP-C providers in your county:

Cabarrus
Quality Health Care Services (888) 640-5960
RHA Health Services (800) 207-7828
Walkers Home Care (252) 432-6308
Footprints (704) 412-2144

Rowan
RHA Health Services (888) 207-7828
RBS Case Management (910) 206-7974
Footprints (704) 412-2144
Quality Health Care Services (888) 640-5960

Union
Quality Health Care Services (888) 640-5960
RHA Health Services (888) 207-7828
Walkers Home Care (252) 432-6308

Gaston
RHA Health Services (888)207-7828
Walkers Home Care (252) 432-6308
Footprints (704) 412-2144

For all other counties, please go to:
Find your CAP-C Providers

For more information on CAP-C, please go to:
https://medicaid.ncdhhs.gov/medicaid/get-started/find-programs-and-services/community-alternatives-program-for-children

CAP-DA (Community Alternative Program for Disabled Adults)

The Community Alternatives Program for Disabled Adults (CAP/DA) is for adults age 18 and older with disabilities who prefer to remain in their primary private residences rather than nursing home placement. Services include personal aide, home accessibility, meal preparation, respite, specialized medical equipment and supplies, case management, and financial management services.

For more information on CAP-DA, please go to:

https://medicaid.ncdhhs.gov/medicaid/get-started/find-programs-and-services/community-alternatives-program-for-disabled-adults

Reference: NC Department of Health and Human Services

Other Insurance Options

Private Insurance

Affordable Care Act/Health Insurance Marketplace

When the ACA became law, it created a new way for people who are unemployed, employed part-time or who work for small businesses to get health insurance and to lower the cost of health care. Health insurance is a good way to help you manage your health care costs. You pay health care companies a premium (a set amount of money each month) and you get benefits to pay for eligible health care expenses, including regular doctor visits, injuries or long-term illnesses. Each year the Marketplace has a period of time called Open Enrollment for individuals to sign-up. The Marketplace offers tax credits and other savings based on your income.

To learn more about the ACA, Health Insurance Marketplace and Open Enrollment, go to:

www.healthcare.gov

Need someone in your community to help you with enrollment? Go to https://localhelp.healthcare.gov/#/ and enter your city and state or Zip code in the box under: Find Local Help. You will find a list of Health Care Navigators that can help.

Self Pay Private Insurance

In some limited cases insurance companies sell private health plans outside the Marketplace and outside of the Open Enrollment time frame. If you buy a plan outside the Marketplace, you do not get premium tax credits or other savings on your income.

Health Insurance Through Your Employer

Many companies offer insurance to their employees as a benefit. Larger companies may be required to offer health care insurance to employees. Smaller businesses may be able to get a tax credit when purchasing insurance through a partner like www.ehealthinsurance.com or the www.healthcare.gov.

North Carolina Association of Free and Charitable Clinics

NCAFCC is a nonprofit organization made up of a network of clinics that provide quality care for those uninsured and underinsured in NC. To find a free clinic near you, go to:

www.ncafcc.org

NC HIPP
(Health Insurance Premium Payment Program)

NC HIPP pays the private health insurance premium for those dually covered by Medicaid and private health insurance through an employer. If your family is at risk of losing or cannot use your private health insurance because your child has a high-risk illness, you may qualify to have the premium paid for under NC HIPP.

In other words, if your family has private insurance through an employer and any family member has Medicaid, if you qualify, NC HIPP will reimburse your family for your portion of the monthly premium.

For more information or to apply, go to the link below:

https://medicaid.ncdhhs.gov/medicaid/get-started/find-programs-and-services/health-insurance-premium-payment-program

Transition to Adult Insurance

In North Carolina, a young adult may stay on their parents' or guardians' health insurance plan until they turn 26 years old. If the parent or guardian is getting insurance through the Marketplace, the young adult can remain covered through December 31 of the year they turn 26. Once a young adult is no longer covered by their parent's insurance, if they do not qualify for Medicaid based on their income, and they can't get coverage through their job, they may need to purchase health insurance through the Marketplace at www.healthcare.gov

TIP: If you are not getting a driver's license, you may apply for an identification card through the NC Division of Motor Vehicles before age 18. This will help when you apply for health care insurance. There is no fee for an identification card for individuals who are blind or have a developmental disability. The application and more information can be found at:

Www.ncdot.gov/dmv/license-id/identification

Dental

Find a Dentist

Finding a dentist for your child with special health care needs or disability can be challenging. Insure Kids Now website can help you locate a dentist in your area that accepts Medicaid or CHIP. The dental list also indicates whether or not the practice can accommodate children with special needs.

https://www.insurekidsnow.gov/coverage/find-a-dentist/index.html

Safety Net Dental Clinics

Safety Net Dental Clinics are non-profit dental facilities where low income families or individuals can go for dental care. Most clinics accept Medicaid and NC Health Choice for Children. Many of these clinics also provide sliding-fee scale to low income patients who have no dental insurance.

Eligibility varies from clinic to clinic. To find your closest Safety Net Dental Clinic, go to:

https://publichealth.nc.gov/oralhealth/services/safetynetclinics.htm

The Grottoes of North America

The Grottoes of North America Humanitarian Foundation is a 501 (c) (3) nonprofit organization that brings "Special Smiles" to children with special needs by providing them much-needed dental care. The program helps cover the costs of dental treatment, excluding hospital and hospital anesthesia costs, for children with cerebral palsy, muscular dystrophy and related neuromuscular disorders, those with intellectual disabilities, including Downs Syndrome, and dental treatment for organ transplant recipients.

To find your closest Grotto program in NC, contact volunteer - Stephen White, PM at **704-485-2891**

Health Departments

Cabarrus Health Alliance

To make affordable and high-quality dental care easily accessible, Cabarrus Health Alliance has two offices, one in Concord and one in Kannapolis, in addition to a traveling mobile unit. Dental services are available for any child or adult, regardless of residency. Cabarrus Health Alliance accepts most major private insurance policies. CHA also accepts Medicaid and NC Health Choice. Both Medicaid and NC Health Choice cover dental services for children under the age of 18. CHA provides a sliding fee scale for Cabarrus County residents who do not have dental insurance. This means that patients pay a rate for dental care that is based on their income. Patients must bring in proof of income (such as a pay stub), in order for staff to determine their eligibility. Patients will pay either 40%, 60%, 80%, or the full cost of service, depending on their income level. If you are interested in learning more about your payment options and projected cost of treatment, call 704-920-1070. For more information, see the link below:

http://www.cabarrushealth.org/103/Dental-Services

Rowan Smile Center for Children

The Smile Center is a dental clinic for children of Rowan County that provides compassionate and quality dental care for children up to 18 years old. They accept Medicaid, Health Choice, private insurance and self-pay. If you are not eligible for Medicaid or Health Choice, services may be provided on a sliding-fee scale based on family size and income. To make an appointment, please call 704-216-8796. For more information, please go to:

https://www.rowancountync.gov/325/Smile-Center

Union County Dental Clinic

Located at the Department of Human Services, The Union County Dental Clinic provides dental services at discounted rates to adults and children 1 year old and up. Accepts Medicaid/NC Health Choice , private insurance and self-pay. Appointments are required and can be made by calling **704-296-4829.**

Gaston Family Health Services General Dentistry

Complete dental care for children, adolescents and adults. Services include exams, cleanings, extractions, fillings, infant/toddler screenings, sealants, and dental varnish (fluoride). To make an appointment, call 704-853-5191. For more information, please go to:

https://gfhs.info/gfhs-dental-clinic/

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Advocating with Policymakers for Health Coverage

You are your child's best advocate! In order to make changes at policy level around health coverage, parents must advocate with those who make the policies.

According to NC Child, parents must first know the "lay of the land."

- Find out who represents you, where to vote, and all about the voting rules in North Carolina. Go to www.ncvoter.org
- Know your legislative delegation. Find out more about them at www.ncleg.net
- Know what committees are important to your issues. List of committees and members can be found at www.ncleg.net
- Know your US Congress people
- Know important local and state administrative agencies and commissions

Tips on Sharing Your Story

When something impacts your life, it is important to be able to share your story in order to make policy changes. Whether you are sharing your story with policymakers, in the media such as Facebook or Twitter, or a letter to the editor, your key messages have to be succinct and actionable. You should aim to have all the messaging elements—problem, solution, action in 4—5 sentences. Keep it brief!

- Know your audience.
- Speak with confidence. You have a story to tell.
- Work with other advocates and agree on a common message or solution.
- Understand that sharing your story in the media will draw more attention to your family.
- Practice, practice, practice.

Tips for Meeting with Elected Officials

- Arrange the meeting.
- Recruit the right mix of people to the meeting. (Find other people with whom you have common ground and shared values.)
- Hold a pre-meeting.
- Prepare your strategy.
- During the meeting, it's ok to say "I Don't Know."
- Follow-up. (Send a brief thank you note or email.)

For more information on advocating with policymakers and to access the NC Child Advocacy Toolkit, please go to **www.ncchild.org**

Reference: NC Child 8/2019

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FINANCIAL HARDSHIP IN FAMILIES RAISING CYSHCN

Inadequate insurance coverage and financing results in significant financial hardship for many families raising children and youth with special health care needs[1] (CYSHCN).

CYSHCN

Most CYSHCN have insurance, but having health insurance does not necessarily mean the coverage is adequate or affordable. Being insured is only part of the story. Many families make difficult sacrifices to help ensure adequate care for their CYSHCN.

FAMILIES

Inadequate health care coverage is a serious problem for a large percentage of families raising CYSHCN. Not every service or support CYSHCN need is paid for by insurance and as a result, families often incur large out-of-pocket (OOP) costs, resulting in financial hardship and medical debt.[2]

PAYERS & POLICYMAKERS

Adequacy is a problem for both publicly and privately insured CYSHCN. Implementing financing strategies aimed at covering more services and reducing families' OOP expenses could help address higher costs later as the result of absent or delayed care.

PROVIDERS

Adequacy is composed of three elements: benefits (what a child needs is covered), access (children can get the services they need by being able to see appropriate providers) and affordability (OOP expenses are reasonable).

CATALYST CENTER RESOURCES

Breaking the Link Between Special Health Care Needs and Financial Hardship

This report examines the impact that health care financing and coverage gaps have on the lives of families and highlights innovative policy solutions that can improve care for CYSHCN.

http://cahpp.org/resources/breaking-the-link-between-special-health-care-needs-and-financial-hardship/

Information for Families

This directory provides links to a range of national and state-based direct service organizations and to information related to Title V Maternal and Child Health programs.

http://cahpp.org/projects/the-catalyst-center/info/

Family Stories

These personal stories help illustrate the challenges families face raising CYSHCN and demonstrate what is possible when additional financing and services are available.

http://cahpp.org/projects/the-catalyst-center/stories/

State Financing Strategies

This page links to examples of the innovative strategies states are using to improve and finance care for CYSHCN, like relief funds, benefits counseling, and more.

http://cahpp.org/projects/the-catalyst-center/financing-strategies/

DEFINING CYSHCN: According to the federal Maternal and Child Health Bureau, CYSHCN are those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions, and who also require health and related services of a type or amount beyond that required by children generally.[1]

CITATIONS

1. McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P., Perrin, J., Shonkoff, J., & Strickland, B. (1998). A new definition of children with special health care needs. *Pediatrics*, 102(1):137–140.

2. Dworetzky, B., Wilson, K., Koppelman, E., Comeau, M., Charmchi, P., Ablavsky, E., ... Bachman, S. (2017). *Breaking the link between special health care needs and financial hardship (2nd ed.)*. Boston. Retrieved from http://cahpp.org/wp-content/uploads/2017/04/Catalyst_Center_Breaking_The_Link-2nd-ed.pdf

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Appendix A: Glossary

Activities of Daily Living (ADLs): Often the criteria to qualify for certain services, these include bathing, dressing, eating, mobility, transferring, toileting and grooming.

Affordable Care Act (ACA): The Patient Protection and Affordable Care Act (PPACA) or Affordable Care Act is the federal health reform legislation signed into law in March 2010. Extends coverage to many uninsured Americans, attempts to lower health care costs and improve efficiency, and eliminates industry practices that contribute to denial of coverage.

Allowed Charge: The amount an insurer will allow the provider to charge for each service.

Annual Limit: The total amount the insurer will pay over the course of a plan year.

Annual Out-of-Pocket Maximum: The most an insured person will have to pay in any given year for all services received under an insurance policy. This amount includes co-payments and deductibles.

Balance Billing: The portion of charges the insured person is billed after the insurance company pays the usual and customary or allowed charges it deems appropriate for the services received, after the insured pays co-payments or coinsurance. For example, if the provider's charge is $100 and the allowed amount is $70, the provider may bill you for the remaining $30. A preferred provider **may** not balance bill you for covered services.

Beneficiary: The person enrolled in a health insurance plan who receives insurance benefits.

Carrier: The insurance company or HMO offering a health plan.

Case Management: A system of review and coordination to ensure that individuals receive appropriate, reasonable health care services.

Children with Special Health Care Needs (CSHCN or CYSHCN): Defined by the Maternal and Child Health Bureau as children from birth to age 21 who have, or are at risk for, chronic physical, developmental, behavioral, or emotional conditions and need health and related services of a type or amount beyond that required by children generally.

Children's Health Insurance Program (CHIP): Provides coverage to low- and moderate-income children. Like Medicaid, it is jointly funded and administered by the states and the federal government. It was originally called the State Children's Health Insurance Program (SCHIP).

COBRA: This law (Consolidated Omnibus Budget Reconciliation Act) allows employees and their dependents who previously had health insurance through their employer to purchase and continue coverage for a limited time period.

Coinsurance: An insured person's share of the health care provider's charge, usually a percentage of the charge. Coinsurance is often split 80%-20%.

Coordination of Benefits (COB): A provision in a health insurance policy that applies when a person is covered under more than one medical program to eliminate over-insurance and duplication. COB provisions determine which insurer pays first and the amount each pays.

Co-payment (or Co-pay): The set dollar amount (often $10 or $20)which a patient must pay when visiting a health care provider. Insurance pays the rest of the fee.

Cost-sharing: Health care provider charges for which a patient is responsible under the terms of a health plan. Cost-sharing includes deductibles, coinsurance and co-payments. Balance-billed charges from out-of-network physicians are not considered cost-sharing.

Deductible: A dollar amount that a patient must pay for health care services each year before the insurer will begin paying claims under a policy. A policy may contain a deductible that applies to each covered member and a limit on the total amount of deductible a family will pay.

Dependent: An individual (usually a child or a spouse) who relies on another person for support and who obtains health coverage through that person.

Exchange: Federal health care reform calls for the creation of health benefit exchanges in each state to assist individuals and small businesses in comparing and purchasing qualified health insurance plans. Each exchange will determine who qualifies for subsidies and make subsidy payments to insurers on behalf of the individuals receiving them. Exchanges will also accept applications for other health coverage programs such as Medicaid and CHIP.

Exclusions: Specific conditions or circumstances listed in an insurance policy that eliminate coverage for certain types of health condition or situations.

Explanation of Benefits (EOB): The insurance company's written explanation of a claim that shows what they paid and what the client must pay. The EOB is sometimes accompanied by a benefits check. The EOB shows the services provided, the amount billed, the insurance company payment made, and the insured person's out-of-pocket responsibility (deductible, coinsurance and/or co-payments) or an explanation of the denial of benefits.

Formulary: The list of drugs covered fully or in part by a health plan.

Generic Drug: Once a company's patent on a brand-name prescription drug has expired, other drug companies are allowed to sell the same drug under its' chemical name or functional description. Generic drugs are less expensive and most prescription and health plans reward clients for choosing generic drugs.

Group Health Insurance: Coverage through an employer or employee organization (like a union) that that provides medical care for all participants in the group and/or their dependents. Coverage can be direct, though insurance, by reimbursement, or in other ways.

Health Maintenance Organization (HMO): A type of managed care organization (health plan) that provides health care coverage through a network of hospitals, doctors and other health care providers. Most services are provided by physicians who are employed by, or under contract with, the HMO. The monthly fees remain the same, regardless of types or levels of services provided.

Health Savings Account (HAS): A tax-exempt trust or custodial savings account set up to pay for qualified medical expenses for beneficiaries covered under a high deductible health plan. HSAs are individually owned and portable, like an IRA.

HIPAA: This federal law (Health Insurance Portability and Accountability Act of 1996) made it easier for individuals to move from job to job without losing insurance or coverage. It also mandated standards for the electronic exchange of health care data; the use of national identification systems for patients, providers, payors, and employers (or sponsors), and required measures to protect the security and privacy of patients.

Home and Community Based Waiver: A Medicaid waiver that permits a state to offer a wide array of services that an individual may need to avoid more costly institutional care.

In-Network Provider: A health care provider (such as a hospital or doctor) that has contracted to be part of the network for a managed care organization or insurance plan, usually for discounted payment. The provider agrees to the rules and fee schedules in order to be part of the network and agrees not to balance bill patients for amounts beyond the agreed upon fee.

Lifetime Benefit Maximum (or Lifetime Limit or Maximum Lifetime Benefit): The maximum amount a health plan will pay over the course of an individual's life. Federal health care reform now prohibits lifetime limits on benefits.

Managed Care: A system that manages care delivery to control costs and coordinate services. The system often requires members to choose a primary care provider, to obtain the primary care provider's permission to see a specialist, and to use providers within the plan's network.

Mandated Benefits: Benefits that health insurance plans are required by state or federal law to provide to policyholders and eligible dependents.

Medicaid: A jointly funded state and federal program, administered by the states, that provides health insurance to certain eligible people. Eligibility for Medicaid is based on income, disability, and/or other criteria.

Medicare: A federally funded health insurance program, administered by the federal government, for people 65 years of age and older, certain younger people with disabilities, and people with end stage renal disease.

Network: The group of physicians, hospitals and other providers who contract with an insurance company to provide services to members.

Out-of-Network: Provider Any provider, hospital, pharmacy or other facility that has not contracted with the health insurance plan to provide services to the plan's members. An individual may not be covered at all, or may be required to pay a higher portion of the total costs, if he or she seeks care from an out-of-network provider.

Out-of-Pocket Limit: An annual limitation on all cost-sharing for which patients are responsible under a health insurance plan. This limit does not apply to premiums, balance-billed charges from out of network health care providers, or services that are not covered by the plan.

Pre-Existing Condition: Exclusion A contractual limitation or exclusion of benefits for an illness, medical condition, or injury that was recognized, diagnosed, or treated before buying a new health care policy. The ACA prohibits pre-existing condition exclusions for all plans beginning January 2014.

Preferred Provider Organizations (PPO): A type of managed care organization or plan that provides health care coverage through a network of providers. The PPO usually requires the policyholder to pay higher costs when care is provided by an out-of-network provider.

Premium: The amount paid to an insurance company in exchange for providing coverage for a specified period of time under a contract. Premiums are usually paid monthly, but can be charged on an annual or quarterly basis.

Preventative Benefits: Covered services that are intended to prevent disease or to identify disease while it is more easily treatable. The ACA requires insurers to provide coverage for preventative benefits without deductibles, co-payments, or coinsurance.

Primary Care Provider (PCP): The health care provider a managed care plan's member is required to contact first when he or she needs health care services, usually a physician specializing in primary care services. The PCP is responsible for knowing the member's complete medical history, performing routine health care, referring the member to a specialist when necessary.

Prior Authorization: A requirement that an insured obtain the plan's approval for certain services before the service can be received and paid for by the company.

Provider: The term used for health professionals such as doctors, hospitals, nurse practitioners, chiropractors, physical therapists, and others offering health care services.

Referral: An authorization given by a provider, usually a primary care provider, allowing a managed care plan member to seek care from a specialist.

Self-Insured (Self-Funded) Plan: A health insurance plan provided by an employer who assumes all of the financial risk of providing health insurance benefits to employees. I n some cases the employer will hire an independent manager or insurance company to handle claim processing and other administrative duties. Employers that elect to self-insure or partially insure their group health plan are not state regulated. Self-insured plans are governed by ERISA (Employee Retirement Income Security Act) and ERISA has no mandate to provide some services. For example, ABA is excluded by many self-funded plans, leaving employees without access to necessary therapy for their children.

Subscriber: The person responsible for payment of premiums or whose employment is the basis for eligibility for membership in a health plan.