NC InCK NC INTEGRATED CARE FOR KIDS

Children and Youth with Special Health Care Needs

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1.0 Purpose of This Guide

The Children and Youth with Special Health Care Needs (CYSHCN) Guide is designed for Family Navigators and other professionals serving families of children with complex medical needs, intellectual disabilities, and/or traumatic brain injuries. This guide contains information to help Family Navigators and others connect CYSHCN to the services/supports they need to thrive.

CYSHCN's daily care needs can be overwhelming to their parents and caregivers. CYSHCN may require assistance with activities of daily living, such as bathing, dressing, and feeding. Some children also have difficulty with walking, talking, and learning. In addition to these unique challenges, families of CYSHCN must also cope with the daily responsibilities of life and ensure they have food, housing, medical care, and transportation, just like other families. Meeting these everyday needs becomes much more challenging when there is a special needs child in the family.

Families are often not aware of the services and resources available to their children. Family Navigators serve as a critical source of support, information, and referrals to these programs.

2.0 Identifying Children and Youth with Special Health Care Needs (CYSHCN)

NC Department of Health and Human Services (NC DHHS) defines Children and Youth with Special Health Care needs as children who "have or are at risk for chronic physical, developmental, behavioral or emotional conditions and need health-related services beyond those generally required by children."

A list of common diagnoses for CYSHCN can be found here. Often, children with these diagnoses experience some kind of medical complexity such as diabetes, tracheotomy, or a gastrostomy tube and their development may be delayed by issues like an intellectual disability or concurrent mental health diagnosis.

3.0 Supporting Families of Children and Youth with Special Health Care Needs

Care managers can help families of CYSHCN understand their child's condition and needs, navigate complex systems, and connect to diagnosis and treatment resources. Below are some ways that care managers support families of CYSHCN.

3.1 Obtaining a CYSHCN Diagnosis

Many children and youth with special health care needs are undiagnosed or under-diagnosed. Their families may benefit from obtaining and understanding the child's diagnosis and associated treatment recommendations.

3.1.1 Supporting a Family in Obtaining a CYSHCN Diagnosis

Children need evaluation and diagnosis from a medical provider to access Medicaid-funded treatment services for CYSHCN. An intellectual/developmental disability (I/DD) diagnosis must be made by either a licensed psychologist or a medical professional (acceptable credentials include PhD or PsyD (LP), LPA,

MD, DO). School or psychoeducational evaluations do not provide diagnoses. A child's primary care provider (PCP) is a great starting point for the diagnostic process if the family suspects medical or developmental concerns. Here's how you can help:

1. Encourage the family to discuss developmental or medical concerns with their PCP and identify follow-up options for further assessment and diagnosis.
2. Assist the family with following up on referrals or recommendations from their PCP. Common referral destinations by age include:
    a. Age 0-3: the local Children's Developmental Service Agency (CDSA) Infant-Toddler Program can help set up formal assessment
    b. Age 3-5: if not yet in kindergarten, the child can receive screening and evaluation for developmental concerns through the Exceptional Children's Preschool programs at their local school districts
    c. Age 5+: older children can be evaluated at school, or families can work with their PCP or care manager to arrange psychological testing
3. Help families access the treatment option recommended in their evaluation (e.g. occupational therapy, physical therapy, and speech therapy)

3.1.2 Obtaining Psychological Testing

If there is a suspected developmental concern or mental health issue, psychological testing may be recommended. Family Navigators can assist with connecting families to psychological testing by contacting the member's insurance plan for a full list of contracted providers or, if the member has a Medicaid Direct Tailored Plan, by contacting the member's Local Management Entity/Managed Care Organization (LME/MCO) to be referred for an evaluation. Review page 12 of the NC InCK Behavioral Health Guide to learn more about psychological testing and evaluation.

3.1.3 Additional Resources for Developmental Screening and Diagnosis:

- Developmental Monitoring and Screening | CDC
- CDC's Developmental Milestones | CDC
  Learn More About Your Child's Development: Developmental Monitoring and Screening English & Spanish | CDC
- Birth to 5: Watch Me Thrive! Screening Guides | U.S. Department of Education

3.2 Accessing Treatment and Care Management Services

Once an official diagnosis is received, CYSHCN may benefit from a referral to specialized care management services and additional treatments to support their needs.

3.2.1 Care Management Models for Children and Youth with Special Health Care Needs

CYSHCN are often eligible for and can benefit from specialized care management programs. Family Navigators can support families of CYSHCN by understanding and connecting families to these supports. Some key care management programs for CYSHCN are described below.

Table 1. CYSHCN Care Management Programs

Program	Overview/Eligibility	How to Access
Early Intervention Services (age 0-3): Children's Developmental Services Agency (CDSA)	CDSA is the lead agency for the NC Infant Toddler Program (NITP), which provides supports to children who have a developmental delay OR specific diagnosed physical or mental conditions that have a high probability of resulting in developmental delay. The goal of NITP services is to facilitate Kindergarten Readiness.	Family Navigators can refer a child directly to a CDSA, encourage a family to contact a CDSA, or communicate with a child's health care provider about a referral to a local CDSA. Children in Durham, Granville, Orange, and Vance Counties can be referred to the Durham CSDA by contacting: Portia Pope, Director portia.pope@dhhs.nc.gov, Phone: 919-560-5600 Children in Alamance County can be referred to the Greensboro CDSA by contacting: Debbi Kennerson debbi.kennerson@dhhs.nc.gov, Phone: 336-334-5601
Early Intervention Services (age 3 to 5): NC Exceptional Children Preschool Services	Children who are 3-5 years of age and not yet in kindergarten can receive screening and evaluation for developmental concerns through the local school districts and their Exceptional Children Preschool Programs. Referring children from ages 3 to 5 to these programs can help to put services into place that facilitate Kindergarten Readiness. Children may benefit from a referral for screening and evaluation if they: Have a developmental delay OR Received services previously through a local CDSA	Family Navigators can contact School District Preschool Coordinators directly or encourage families to do so.
Care Management for At Risk Children (CMARC)	CMARC is a statewide care management model run through local health departments that is available	For additional information about CMARC and the referral process see individual county information:

	to children ages 0-5 who may benefit from additional support due to special health care, developmental or behavioral health needs. Services include parenting support, referrals to medical care and connections to community resources for families in need of support with housing, food and other areas.	Orange County: Care Coordination for Children (CC4C) | Orange County, NC (orangecountync.gov) Granville/Vance: Care Management for At-Risk Children (CMARC) – Granville Vance Public Health (gvph.org) Alamance County: Case Management for At-Risk Children (CMARC) – Alamance County Health (alamance-nc.com) Durham: Care Management for At Risk Children (CMARC) | Durham County - NC - Public Health (dcopublichealth.org) Referral application for all counties: CC4C Screening and Referral Form (orangecountync.gov)
Community Alternative Program for Children (CAP-C)	CAP-C provides an alternative to institutionalization for Medicaid beneficiaries who are medically fragile and at risk for institutionalization if the home and community-based services approved in the CAP/C waiver were not available. These services allow the beneficiary to remain in or return to a home and community-based setting. Some services include care management with private community-based agencies, attendant nurse care, home	Encourage families who are interested in CAP-C services for their child to talk to their PCP about a referral, a case management entity, social worker or by contacting NCLITSS Customer Support Center. For additional information about CAP-C services and the referral process: Community Alternatives Program for Children (CAP/C) | NC Medicaid (ncdhhs.gov) How to make a referral: Community Alternative Program Referral Process

	accessibility adaption, nutritional services and non-medical transportation.	
Community Alternative Program for Disabled Adults (CAP-DA)	The CAP/DA program provides an alternative to institutionalization for Medicaid beneficiaries ages 18 and older who are medically fragile and at risk for institutionalization. These services allow the beneficiary to remain in or return to a home and community-based setting. Some services include case management with local Department of Social Services, adult day health, equipment, modification and technology, specialized medical supplies and community transition.	Encourage families who are interested in CAP-DA services for their young adult to talk to their PCP about a referral, a case management entity, social worker or by contacting NCLITSS Customer Support Center. For additional information on CAP-DA eligibility and referral: Community Alternatives Program for Disabled Adults (CAP/DA) | NC Medicaid (ncdhhs.gov) How to make a referral: Community Alternatives Program Referral Process
Tailored Care Management (TCM)	TCM is a care management service available to individuals who are Tailored Plan-eligible. The Tailored Plan is a type of NC Medicaid plan that will provide the same healthcare services as Standard Plans plus additional behavioral health and I/DD services not covered by Standard Plans. Tailored Plans are expected to launch in 2024.	Tailored Plan-eligible individuals or their guardians can contact the member services line at their designated LME/MCO to be connected to TCM. Vaya Health (Alamance, Granville, and Vance Counties) 1-800-962-9003 (Mon. – Sat., 7 a.m. to 6 p.m.) Alliance Health (Durham and Orange Counties) 800-510-9132

3.2.2 Tailored Plans and the Innovations Waiver Program

Family Navigators supporting children with mental health diagnoses and/or I/DD may want to talk with families about transitioning from Medicaid Standard Plans to Tailored Plan services if the youth is unable to access recommended treatment through Medicaid Standard Plans.

Tailored Plans (TP) are a type of NC Medicaid plan that will provide the same healthcare services as Standard Plans plus additional services not covered by Standard Plans. These additional services include enhanced behavioral health services, services for a mental health disorder, substance use disorder, intellectual/developmental disability (I/DD) or traumatic brain injury (TBI), pharmacy services, long-term services and support, and services to address social determinants of health. Tailored Plans are expected to launch in 2024.

Family Navigator Tip: Care managers can help individuals transfer to Tailored Plan coverage. Visit NCDHHS in the "Request to move to NC Medicaid Direct or LME/MCO" section for additional information.

Tailored Plans also operate a Medicaid waiver program called the Innovations Waiver. The Innovations Waiver is designed to meet the needs of individuals with intellectual or developmental Disabilities (I/DD) who prefer to get long-term care services and supports in their home or community, rather than in an institutional setting. Tailored Plans facilitate I/DD services and oversee a network of community-based service providers. Individuals who receive waiver funding work with a team to develop a Person-Centered Plan of Care and request the services and supports they need.

Tailored Plans manage Innovations Waiver eligibility and the waitlist for Innovation services which is called the Registry of Unmet Needs (RUN). Eligible individuals often wait as long as 7-10 years for Innovation services due to funding levels for Innovations Waiver slots. An individual does not need to be enrolled in a Tailored Plan to be placed on the RUN.

To be considered for eligibility for the Registry of Unmet Needs, an individual must meet the following criteria:

- A documented diagnosis of a developmental disability or related condition that was manifested prior to the age of 22 and is likely to continue indefinitely.
- Substantial functional limitations in self-care, understanding and use of language, learning, mobility, self-direction, and/or the capacity for independent living, AND
- Would benefit from services and supports to promote the acquisition of skills and to decrease or prevent regression.

If an individual is deemed eligible, they are placed on the Registry of Unmet Needs. Individuals often wait 7-10 years for an Innovations Waiver "slot" to open for them. There are some I/DD services available to individuals on the Registry of Unmet Needs which can be accessed through the Tailored Plans.

To learn more about the Innovations Waiver and applying for the Registry of Unmet Needs:

Members in Alamance, Granville and Vance Counties: Visit the Vaya Health Innovations Waiver page or contact member services at 1-800-962-9003.

Members in Durham and Orange Counties: Visit the Alliance Health Innovations Waiver page or contact member services at 800-510-9132.

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Family Navigator Tip: If you are working with a child that has an I/DD diagnosis, please tell them about Innovations Waiver Services and explore a referral to the Registry of Unmet Needs. Despite the long waitlist, this can be a very important resource for individuals with an I/DD diagnosis especially as they transition to adulthood and child-focused supports are reduced.

3.2.3 Additional Outpatient Services Often Recommended for CYSHCN:

CYSHCN may also be referred to support services such as occupational therapy, physical therapy, speech therapy, or applied behavior analysis. A physician's order will be needed to engage in these programs. Family Navigators can support families of CYSHCN by identifying providers that are contracted with their health plan and sending referrals as needed.

Table 2. Common Additional Support Services

Service	Definition	Eligibility
Occupational therapy (OT):	Allows individuals to participate fully in activities of by building motor skills, physical skills, and self-esteem	Child has difficulty completing age-appropriate activities of daily living
Physical Therapy (PT):	Allows individuals to improve their range of motion, strength, flexibility and movement patterns	Child has difficulty completing age-appropriate tasks or displays unusual movement patterns
Speech Therapy (ST):	Allows individuals to improve communication skills like gesturing, talking, listening, and understanding	Child has communication disorder or swallowing disorder or concerns of delay in communication
Applied Behavior Analysis (ABA)	Service for individuals who have been diagnosed with autism spectrum disorder (ASD) who are under the age of 21.	Child has confirmed ASD diagnosis

3.3 Accessing School and Community Resources

3.3.1 Navigating the School System for CYSHCN

Children and Youth with Special Health Care Needs are often eligible for accommodations in school to support their educational needs. Parents and guardians may benefit from Family Navigator support with understanding their child's educational rights, accessing resources, and advocating for in-school accommodations.

It is important to educate families of CYSHCN about special education services that may be available to their children (e.g. Individualized Family Service Plan, Individualized Education Plan, 504 plan; see the NC InCK School Guide for more details). Here's how you can help families navigate the school system:

- Assist in making the initial referral to the school system
    - Age 3-4: Transitioning from Early Intervention to Exceptional Children's preschool
    - Age 4-5: Transitioning from Exceptional Children's preschool to kindergarten
- Assist family in understanding Individualized Educational Plan development process, 504 Plan eligibility, and in-school accommodations and modifications for students with disabilities

3.3.2 Social Security Income and the CYSHCN Population

Social Security Income (SSI) can be an important resource for families of CYSHCN. If a child is approved for SSI, the child is automatically approved for Medicaid, even if the child has private insurance. The private insurance will be the primary payor, while Medicaid will be the secondary payor. All co-payments, deductibles, and co-insurance are paid by Medicaid. Parents and caregivers should not have any out-of-pocket costs for medical care or prescriptions.

The SSI/SSDI application process can be done online or through a phone appointment with Social Security. Details of the application process can be found here; additional information about the SSI process for children specifically is available here.

If families need support applying for SSI/SSDI benefits and/or appealing a denied application, see links below.

- Legal Aid: Help Applying for SSI/SSDI benefits
- Legal Aid: Benefits: Have you been Denied SSD or SSI Benefits?
- Disability Rights NC: Medicaid, SSI or Disability Benefits

3.3.3 Guardianship

Family Navigators may assist members who receive guardianship services. Guardianship is a legal relationship awarded by the court to an individual person or agency when an identified individual is unable to make independent decisions about their personal and financial affairs.

Guardianship typically occurs when the identified individual is over 18 years old. In some cases, guardianship can be petitioned at 17 ½ years old depending on the need.

For an individual person or agency to be awarded guardianship, they will be required to present medical records, psychological evaluations, and other evaluations to justify the need for guardianship.

The legal guardian will make decisions about the identified individual's living arrangements, finances, and medical treatment.

To reach out to an individual who receives guardianship services, Family Navigators will have to coordinate with the legal guardian. For example, if an 18-year-old is in a residential facility and has a legal guardian, the Family Navigator will need to contact the legal guardian and obtain a release of information form that allows the individual and facility to communicate.

3.3.4 Additional Resources to Support CYSHCN and Their Families:

Table 3. Identification Resources

Resource	Overview/Eligibility	How to Access
Disability placard	Applicant must be deemed disabled or handicapped	https://www.ncdot.gov/dmv/title-registration/license-plates/Pages/disability-placards-plates.aspx **Application:**MVR-37A (ncdot.gov)
No-fee ID	North Carolina residents diagnosed with a developmental disability	Official NCDMV: State IDs (ncdot.gov) **Application:**DL-232.pdf (ncdot.gov)
Homebound Customer Requests for ID card	Residents who want to obtain an ID card but are unable to appear at an NCDMV driver license office because of a severe disability may request homebound assistance. Must present a letter from a physician certifying that the resident is homebound due to severe disability, provide proof of age and identity, a valid Social Security number and proof of citizenship and residency.	• NC DOT Homebound Information • Completing the Homebound Service Request form • Contacting NCDMV online • Calling Central Issuance at (919) 861-3030 • Sending a fax to (919) 615-7289 Requesting by mail from the Central Issuance Unit, 3176 Mail Service Center, Raleigh, NC 27697-3176

Table 4. Transportation Resources

Resource	Overview/Eligibility	How to Access
Medicaid Transportation	Family Navigators can refer members to the member services line with their Prepaid Health Plan to gather additional information.	Medicaid Transportation | NC Medicaid (ncdhhs.gov) Non-Emergency Transportation for NC Medicaid Managed Care | NC Medicaid (ncdhhs.gov)
Public transportation	Tips when using public transportation	Accessible Public Transportation: FAQ - DRNC (disabilityrightsnc.org)
Transportation if a member has an	Tips on school transportation if a member has an IEP	School Transportation - DRNC (disabilityrightsnc.org)

Individualized Education Plan (IEP)		
Free public transit passes by area:		
Go Triangle Pass	Youth between the ages of 13 to 18 can use a Youth GoPass to ride GoTriangle, GoRaleigh, GoCary or GoDurham buses free!	https://gotriangle.org/youthgopass
Chapel Hill	Chapel hill provides various bus riding options for members with disabilities.	Transit | Town of Chapel Hill, NC
Durham County	Bus riders with disabilities are eligible to ride all GoDurham buses at half price. Bus rider must present the appropriate ID card.	GoDurham Fares & Passes | GoDurham (godurhamtransit.org)
Granville County	Granville offers a county shuttle. Individual with disability can contact Granville County Senior Center for assistance.	Oxford Loop Shuttle - Granville County
Vance County	The Around Town shuttle is a public deviated fixed-route shuttle from Monday through Saturday.	Around Town Shuttle | KartsNC
Orange County	Orange County Public Transportation for individuals with a disability.	Americans with Disabilities Act | Orange County, NC (orangecountync.gov)

Table 5. Educational Resources

Educational Resources	Overview/Eligibility	How to Access
Infant Toddler Program Step-by-Step Guide	Information on Infant Toddler Program	Step-by-Step Guide
IEP Road Map	Information on how to complete an IEP	IEP-Road-Map-for-Families.pdf (ecac-parentcenter.org)
504 Plan Fact Sheet	Information on 504 Plans and eligibility	504 Plan Fact Sheet
Sample School Accommodations	Accommodations to help a family consider on the IEP or 504 Plan	Sample-Accommodations.pdf (ecac-parentcenter.org)
Accommodations while in college	Tips on requesting accommodations while in college	Sample College Accommodation Request - DRNC (disabilityrightsnc.org)p

Beyond Academic Program	Program for students with intellectual disabilities who are interested in furthering their education beyond high school.	https://beyondacademics.uncg.edu/ Phone: 336-334-3905
The Pre-ETS STAR Program	Virtual training program for students with disabilities.	Pre-ETS STAR Virtual Training for Students with Disabilities – Disability:IN North Carolina (di-nc.org) Email: beth@di-nc.org
UP Western Carolina	Two-year, on-campus living and learning experience for college-aged persons with intellectual disability	https://www.wcu.edu/learn/departments-schools-colleges/ceap/stl/special-education-programs/university-participant-up-program/index.aspx Phone: 828-227-3297
Vocational Rehabilitation Services (VR)	Help people with disabilities achieve their goals for employment and independence.	https://www.ncdhhs.gov/documents/files/value-realized-partners-path-your-career/open County office contacts: https://www.ncdhhs.gov/divisions/vocational-rehabilitation-services/vocational-rehabilitation-local-offices

3.3.5 Specific State and County Resources

Table 6. State and County Resources

Program	Overview/ Eligibility	How to Access
North Carolina Children and Youth with Special Health Care Needs Help Line	Information and referral help line for children and youth at risk for chronic physical, developmental, behavioral or	Email: CYSHCN.Helpline@dhhs.nc.gov Phone: 800-737-3028

	emotional conditions and the need for health services.	
First in Families	Offer support to families, who meet financial eligibility requirements, and have a member with a developmental disability or delay, or at risk or a traumatic brain injury.	First In Families of North Carolina (fifnc.org) Phone: 919-251-8368
ARC of NC	Promotes and protects the human rights of people with intellectual and developmental disabilities.	The Arc of NC | Advocacy & Services For People Disabilities (arcnc.org) Phone: 919-782-4632
Triangle Disability & Autism Services	Supports children and adults with intellectual and/or developmental disabilities and autism to achieve personal goals.	Home - Triangle Disability & Autism Services (arctriangle.org) Phone: 919-942-5119
Autism Society of NC	Improves the lives of individuals with autism, while providing support and community education.	Autism Society of North Carolina | Find Help (autismsociety-nc.org) Phone: 800-442-2762
Exceptional Children's Assistance Center	Helps improve the lives and education of all children, specifically, children with disabilities and special healthcare needs.	Discover ECAC - Exceptional Children's Assistance Center (ECAC) (ecac-parentcenter.org) Phone: 800-962-6817
Disability Rights of North Carolina	Legal advocacy agency that supports the rights of people with disabilities in North Carolina.	Disability Rights North Carolina (DRNC) - DRNC (disabilityrightsnc.org) Phone: 919-856-2195