



The Registry of Unmet Needs: The waiting list for the NC Innovations Waiver

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of North Carolina

What is the Registry of Unmet Needs (RUN)?

“Innovations waitlist”

“Registry of Unmet Needs”

“on the RUN”

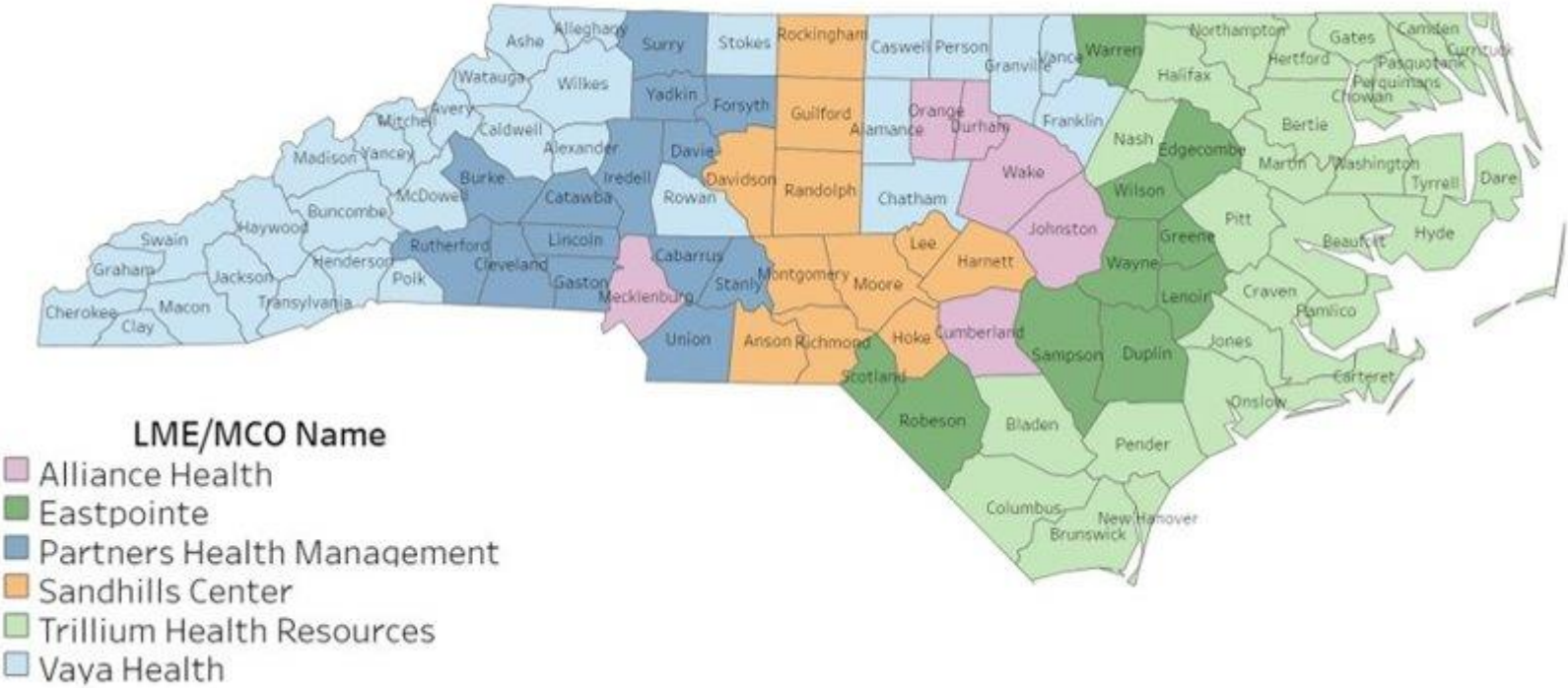
“IDD Eligibility”

“Waiver waitlist”

Why is the RUN important?

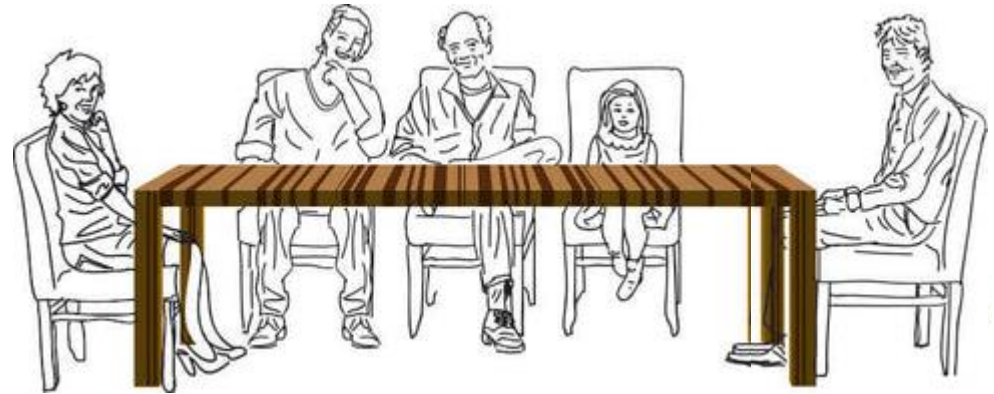
- It is how you get an NC Innovations Waiver slot
- The process also allows you to get “IDD services” while you wait for an NC Innovations Waiver slot
- It ensures the LME-MCO is aware of you and your needs
- It provides data to the people at the State making decisions

How is the RUN managed?



How is the RUN managed?

Slot-based



Time waiting, county specific

| | A | B | C | D | E |
|---|----------|---------|------------|--------|-----------------------------|
| 1 | Date | Time | Name | County | Diagnoses |
| 2 | 5/1/2007 | 3:12pm | Jane Smith | Orange | Autism, Depressive Disorder |
| 3 | 5/1/2007 | 4:30pm | Bob Green | Durham | Cerebral Palsy |
| 4 | 5/2/2007 | 10:21am | Jim Black | Durham | Down Syndrome |
| 5 | 5/3/2007 | 11:46am | Amy Young | Wake | Moderate ID |
| 6 | | | | | |
| 7 | | | | | |

Why is the RUN important?

12,500 receive Innovations

15,000 are on the RUN, waiting

10,000 eligible but not on RUN

Average wait = 9.5 years

What specifically does my LME-MCO require to get on the RUN? What is the process?

It depends!

COMING SOON: Webinar 2 – How to get on the RUN at each LME-MCO

Determining Eligibility for Services for People with Intellectual and Developmental Disabilities

You are receiving this notice as requested information. Managed Care (MCO) need behavioral health services for service



At any time, you can register. The first step in development:

Regi

BACKGROUND

Name _____

Date of birth _____

Mailing Address _____

City _____

County _____

Telephone Number _____ Gender _____

Primary Language English American Sign Language Spanish Other: _____

1. You will be asked to complete an assessment (approximately one hour and a half (90 minutes). This assessment is required by the Waiver to be placed on the Registry.
2. You will be asked to send documentation (see examples

VAYAHEALTH

Search [Q]

Am I eligible for Innovations?

To be eligible for **Innovations**, you must first have a psychological evaluation that documents an intellectual/developmental disability that impairs functioning, other than mental illness, and be at risk of placement in a developmental center.

Participation in the N.C. Innovations Waiver is based on eligibility criteria and availability.

Phone Number: [Input Field]

et Needs

UNMET NEEDS?

is a waiting list for individuals who are on the list. Through the Waiver process, people are placed on when they are notified. North Carolina can keep track of more slots. Individuals are notified when more slots are available.

ian of an individual who will contact Sandhills Center at 1-800-256-2452. Our staff can provide more information about eligibility. You also can learn more about what other services may be available while on the waitlist.

How long will I be on the waitlist/RUN? When will I get a slot?

Impossible to estimate!

- Each county will have a differing amount of movement in slots
 - Slots are vacated due to choice, death, institutionalization, moving out of the state
 - People moving into your county may have older date than you
- Some people on the waitlist may be difficult to reach – the LME-MCOs may move on to the next person waiting after several attempts
- Some people on the waitlist may not be eligible for NC Innovations once they go through the process
- “Right sizing” the allocation among counties may mean your county doesn’t get a slot or gets fewer

Debunking some myths:

- You do NOT need to have Medicaid in order to apply!
- You do NOT need to be deemed “disabled” by Social Security to apply or receive services!
- You can live independently and still qualify for the RUN!
- A child can be placed on the RUN as soon as the qualifying diagnosis is obtained – there are not age limits!

What specifically does my LME-MCO require to get on the RUN? What is the process?

You need to ensure you have the following basic info in a Psychological Evaluation or across medical documents:

1. Qualifying IDD Diagnosis (clearly listed and began before age 22)
2. Psychological/medical assessment measures confirming diagnosis
3. Adaptive Function assessment

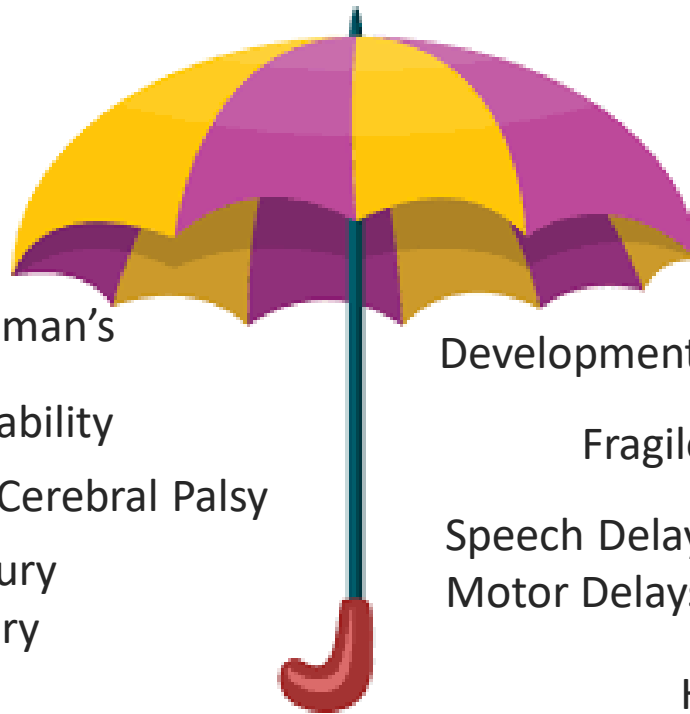
What is a Psychological Evaluation?

A trained and licensed psychologist

- Gathers developmental, medical, behavioral, and psychiatric history
- Uses tests, questionnaires, assessment tools, direct observations, and interactions
- Assesses an individual's behavior and needs
- Determines a diagnosis
- Provides recommendations

What is a Qualifying IDD Diagnosis?

IDD is an umbrella



- Rett Syndrome
- Autism
- Intellectual Disability
- Vision Impairment
- Traumatic Brain Injury
- Acquired Brain Injury
- Chromosomal duplications and deletions
- Angelman's
- Cerebral Palsy
- Developmental Delay
- Fragile X
- Speech Delays
- Motor Delays
- Muscular Dystrophy
- Down Syndrome
- Tourette Syndrome
- Seizure Disorder
- Hearing Loss

Why does the diagnosis need to be present prior to age 22?

The NC Innovations Waiver aims to provide people with specific developmental disorders an array of services. By definition, “developmental years” are when you are below age 22.

Some people do not have this documentation for various reasons:

- No records from childhood
- Diagnosed as an adult

NOTE: That's okay! More and more adults are seeking diagnoses. Many psychologists are skilled at obtaining information from “early reporters” to determine diagnosis.

What does it mean to be “clearly listed?”

THIS

| | |
|-----------|--|
| Diagnosis | 299.00 Autism Spectrum Disorder 314.01 ADHD 309.9 Adjustment Disorder, Unspecified |
|-----------|--|

The *Childhood Autism Rating Scale, Second Edition, High Functioning Version (CARS-2-HF)* rates children and adults on 15 areas of behavior and was developed to assist in identifying individuals with autism spectrum disorders (ASDs) and distinguishing them from individuals with other diagnoses. The CARS-2-HF was scored based on direct observation during this evaluation, parent report, school records and observations by school personnel. [REDACTED] received a total score of 39.0 which falls in the Severe Symptoms of an ASD.

RECOMMENDATIONS

It is recommended that the educational team, including parents/guardians, review the results of this evaluation, alongside any other relevant data, in order to determine whether [REDACTED] meets requirements for special education and related services under special education eligibility law. Eligibility for Exceptional Children services is a team decision and it is to be determined by the IEP team at the evaluation meeting. Specific suggestions for [REDACTED] include:

NOT
THIS

Psychological/Medical Assessment confirming diagnosis

The assessment needed is generally based on the type of IDD

| Examples: Diagnosis | Measure |
|-------------------------|---|
| Fragile X | Medical confirmation (genetics) |
| Autism | Autism Eval (ADOS, CARS, GARS) |
| Intellectual Disability | IQ test |
| Fetal Alcohol Spectrum | Neuropsych, medical confirmation, mother's medical record |
| Spina Bifida | Neuropsych, medical |

What do all LME-MCOs require for placement on the waitlist/RUN?

Adaptive Function Assessment with scores indicating severity

Vineland Adaptive Behavior Scale (VABS-3)
Adaptive Behavior Assessment Scale (ABAS)
Diagnostic Adaptive Behavior Scale (DABS)
Scales of Independent Behavior-Revised (SIB-R)

What is adaptive functioning? How is it assessed?

Adaptive functioning is your ability to complete everyday activities and function within your community.



How do I get a Psychological Evaluation?

Private Insurance

- Call your insurance company to determine providers in-network and close to your home/work
- Be sure to ask what your co-pay might be
- Before attending the appointment, confirm the provider accepts your insurance!

Medicaid

- Call your LME-MCO and request a list of providers

What if my insurance does not cover psychological evaluations?

Be cautious! Many psychology practices have stopped accepting insurance which means they are asking you to pay out-of-pocket for the service.

The cost can be anywhere from several hundred to several thousand dollars.

Before you sign up to pay this much, please reach out to one of the resources at the end of this presentation to see if there are lower cost alternatives, or financial assistance programs that can help.

What should I do while I'm on the waitlist?

While waiting for your name to get to the top of the NC Innovations Waiver waiting list in your county:

- Ask “**What IDD services are available while I wait?**”
 - Services available vary by LME-MCO
 - Generally funded by Medicaid or state funding (IPRS)
 - Subject to available providers and available staff



What should I do while I'm on the waitlist?

You should **call at least yearly to verify you are on the waitlist** with the correct date and that all of your information is correct.

You should **keep the LME-MCO up to date on your needs** – if your needs increase, let them know!

- Why is this important? LME-MCOs may have flexible funding or programs that can benefit you. They may also have limited “Emergency Innovations Waiver Slots” for individuals who cannot wait until their name comes to the top of the list. There are not many of these slots.
- Every call to the LME-MCOs is documented, so when you provide updates, they will remain in your file for any future review.

What if I can't wait any longer?

- Call your LME-MCO to discuss your needs
- Request an Emergency Innovations Waiver Slot
- Determine if you qualify for Tailored Care Management (Medicaid Tailored Plan) that can help you meet some of your needs
- Utilize crisis resources as needed for urgent/emergency situations
- Reach out for additional help from other agencies

What happens if my LME-MCO merged with another?



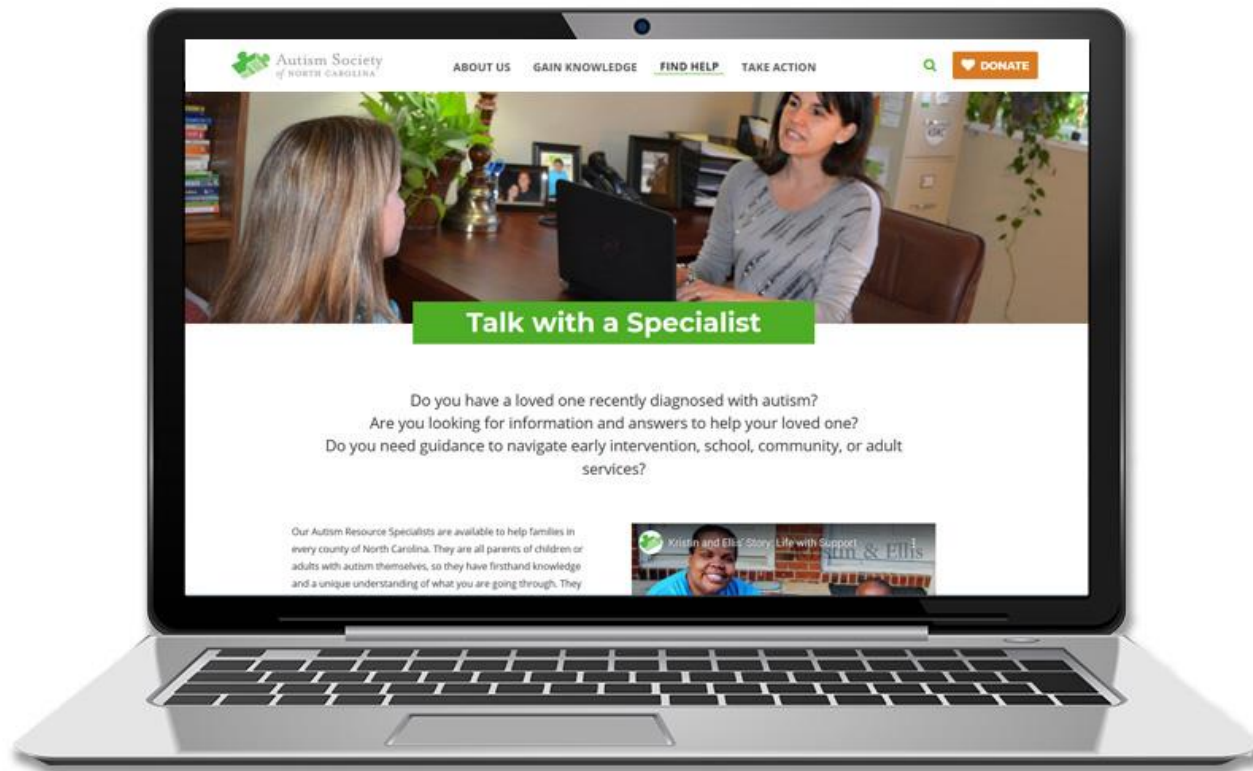
The date and time you were added to the RUN **should transfer and be honored** by the new LME-MCO.



You should **call and verify**. Look for any documentation or paperwork you received confirming your date/time on the RUN. This can include voicemails, emails, and letters.

Resources

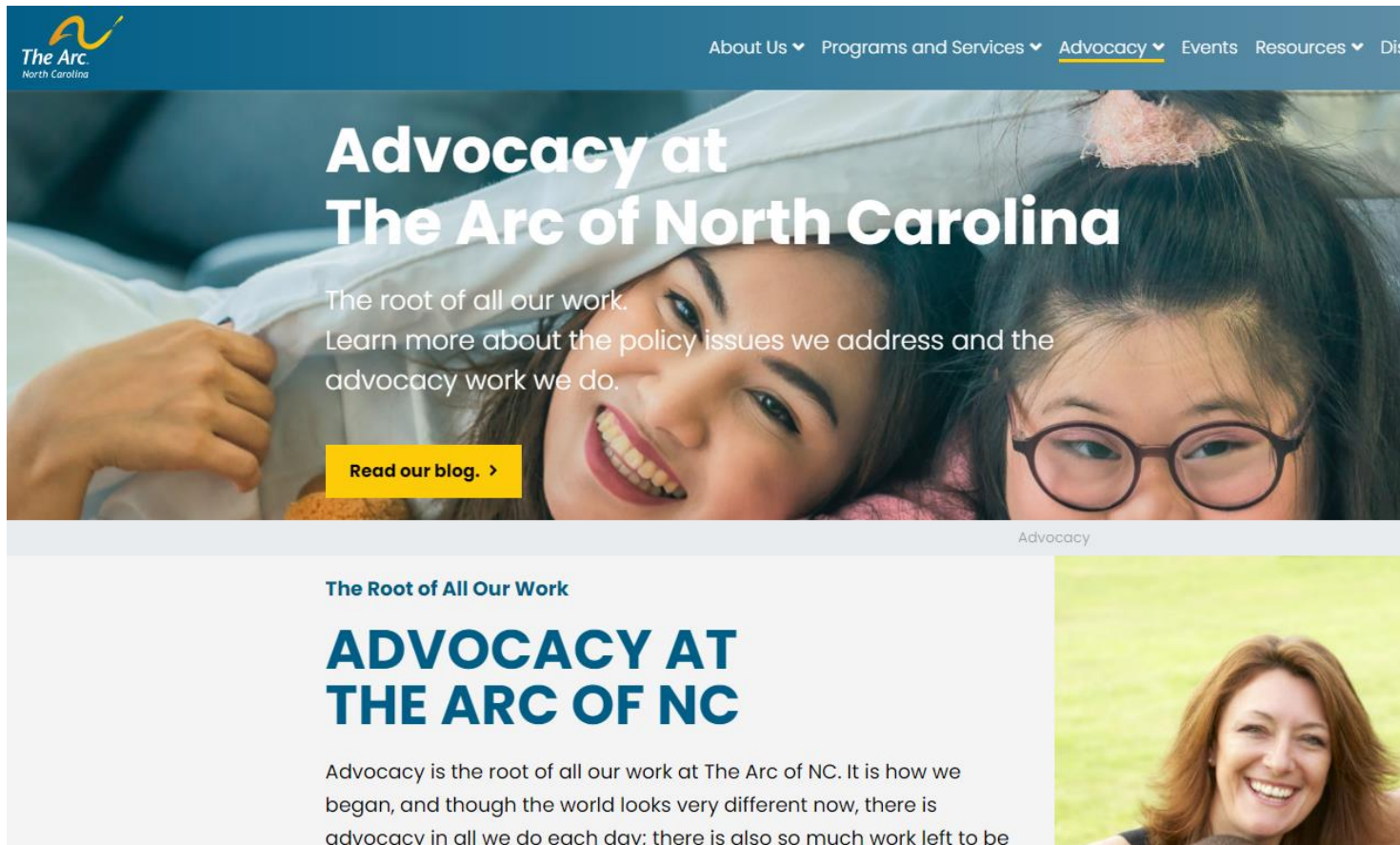
ASNC Autism Resource Specialist



Find the Autism Resource Specialist in your area of North Carolina:

autismsociety-nc.org/ars

The Arc of NC



The Arc of North Carolina

About Us ▾ Programs and Services ▾ Advocacy ▾ Events Resources ▾ Dis

Advocacy at The Arc of North Carolina

The root of all our work.
Learn more about the policy issues we address and the advocacy work we do.


[Read our blog. >](#)

Advocacy

The Root of All Our Work

ADVOCACY AT THE ARC OF NC

Advocacy is the root of all our work at The Arc of NC. It is how we began, and though the world looks very different now, there is advocacy in all we do each day; there is also so much work left to be



<https://www.arcnc.org>

How to find Crisis Resources in your county

CRISIS SOLUTIONS NORTH CAROLINA



AN INITIATIVE OF THE NC DEPARTMENT OF HEALTH AND HUMAN SERVICES - DIVISION OF MENTAL HEALTH, DEVELOPMENTAL DISABILITIES AND SUBSTANCE ABUSE SERVICES

HOME ▾

NC CRISIS SERVICES FOR INDIVIDUALS AND FAMILIES

Do You or Someone You Know Need Help with a Crisis?

CALL 911 if this is a medical or life-threatening emergency.

If you need the police, ask for a CIT officer. They have received extra training in handling these situations.

CALL 988, Text or Chat the 988 Suicide & Crisis Lifeline if you or someone you know need help with a mental health crisis.

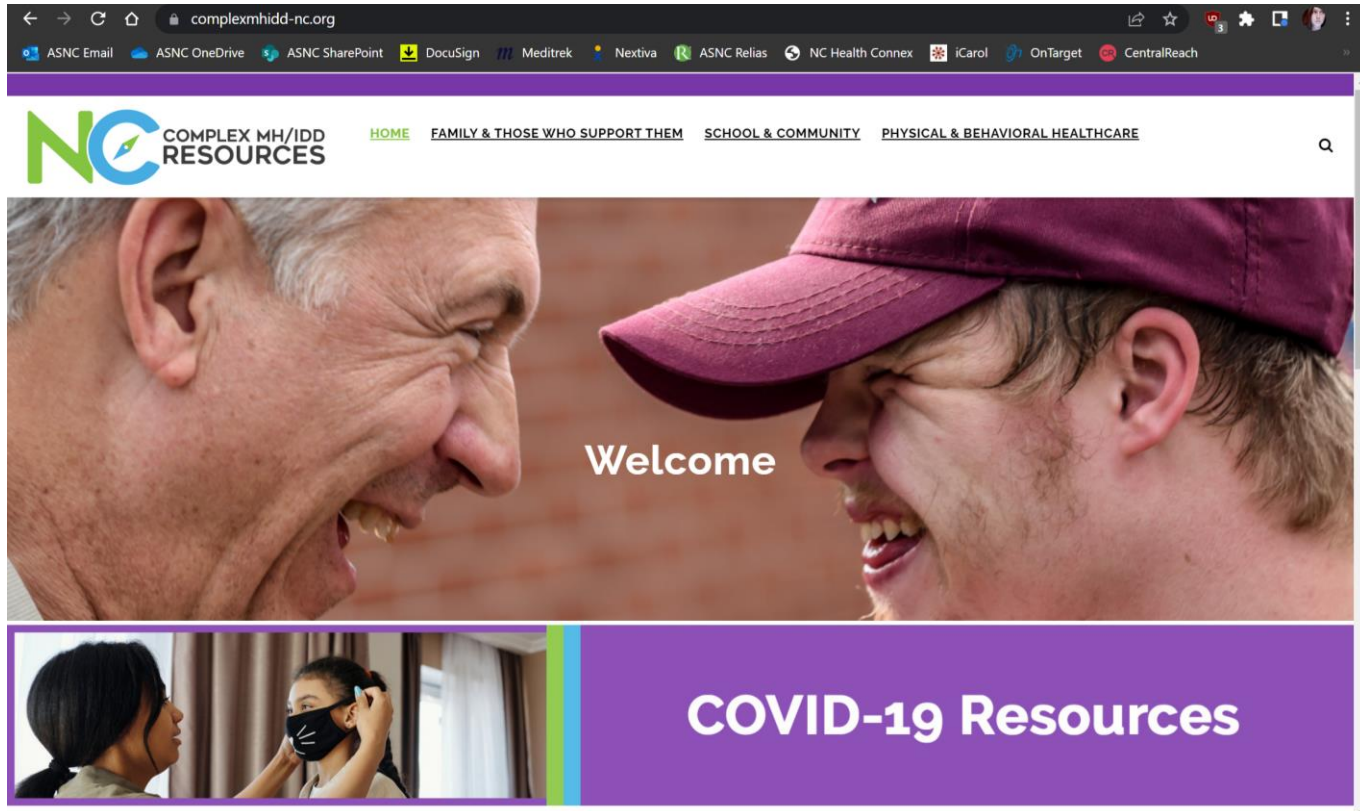
If this is NOT a medical or life-threatening emergency, look in the directory below for resources in your county.

FIND HELP FOR A MENTAL HEALTH OR SUBSTANCE USE CRISIS IN YOUR COUNTY

Select County ▾

<http://crisissolutionsnc.org>

NC Complex Needs Resource



complexmhidd-nc.org

NC DHHS Children with Complex Needs

Each MCO has an assigned contact person/coordinator - call and ask!

NC DHHS Definition:

Children with Complex Needs are ages 5 and under 21, with a developmental and/or intellectual disability and a mental health disorder diagnosis who are Medicaid eligible and at risk of not being able to return to or maintain placement in a community setting.

If clients, families and guardians experience any barriers to services please contact Rachel Johnson, the Statewide Administrator for Children with Complex Needs, at Rachel.Johnson@dhhs.nc.gov or 984-236-5050.

NC START

North Carolina Systemic, Therapeutic, Assessment, Resources and Treatment (NC START)

North Carolina Systemic, Therapeutic, Assessment, Resources and Treatment (NC START) is a statewide community crisis prevention and intervention program for individuals age 6 and above with intellectual/developmental disability and co-occurring complex behavioral and/or mental health needs. START crisis prevention and intervention services are provided through clinical systemic consultation, training, education, therapeutic respite, crisis response and therapeutic coaching. The model works to improve the lives of the individuals served and their families by providing services and supports using a person-centered, positive, multidisciplinary, cost-effective, systemic and evidence-informed approach.

NC START West:
888-974-2937

NC START Central:
919-865-8730

NC START East:
888-962-3782

Map of programs & counties: www.ncdhhs.gov/media/7933/open

Tailored Care Management

Individuals with Medicaid who are included in the Behavioral Health I/DD Tailored Plan will be **assigned a single care manager** who supports a multidisciplinary care team to **provide whole-person care**.

To find out if you qualify for Tailored Care Management, contact your LME-MCO.

More information here:

<http://Medicaid.ncdhhs.gov/tailored-care-management>



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