

MEET THE NEED NC

Changing the I/DD landscape across the state

Responses to Questions During the November 2023 Meet the Need NC Lunch & Learn Webinar Topic: I/DD and Mental Health

What mental health treatment is available for those with I/DD who are nonverbal and/or or more intellectually disabled?

The key to accessing appropriate MH treatment for someone with more significant cognitive and communication differences is a thorough assessment by someone who has understanding and expertise in I/DD and MH. As mentioned in the presentation, it is essential to take a biopsychosocial approach to assessment and to understand the different ways people with I/DD present psychiatric symptoms, often with externalized symptoms like aggression. (Remember the most common diagnoses are depression, anxiety, and trauma). Often the first go-to are antipsychotic medications to simply sedate someone.

As we discussed, it is not easy to find therapists and psychiatrists who specialize, but it is worth the time to seek these out. People with more significant I/DD can benefit from trauma informed strategies, modified EMDR (Eye Movement Desensitization and Reprocessing), modified DBT (dialectical behavior therapy) strategies, and self-regulation strategies. Finding a psychiatrist who will work collaboratively with other providers and understands that medication is not the only treatment is important.

Resources: DM-ID is a good resource for diagnosing. It includes modifications to DSM diagnosis for people with differing levels of I/DD.

This link is to a free prescribers' guide for treating people with IDD:
<https://centerforstartservices.org/IDD-MH-Prescribing-Guidelines>

How do we get help with finding the right providers to look at whole person?

Our panel had the following suggestions:

1. Connect with other parents and/or family by joining your local support group including groups offered by The Autism Society of North Carolina, the Family Support Network, the Down Syndrome Alliance, the Arc of NC, NAMI NC, etc. Other parents can help you connect with resources that have been helpful to them.
2. These same groups often have resource databases that include local community resources that may be able to assist with those with complex needs.
3. Reach out to your LME/MCO and start pushing for them to prioritize including providers in their network that serve people with more than one diagnosis. LMEs can prioritize offering cross disability training to providers, increased rates for complex cases, care management that supports multiple diagnosis and other programs that would support those with more than one diagnosis.

Do you have a resource guide that has a list of providers that do treat both? And possibly if they accept Medicaid or private insurance?

Your regional LME/MCO is the first stop to see if they have lists of resources and/or referrals to providers that treat both I/DD and behavioral health disorders. Since they are the managers of Medicaid MH, SUD and I/DD services they *should* have lists of providers that take Medicaid.

If you have a care manager or care coordinator, they should be helping you research providers in your area that can address multiple issues a person might be dealing with.

Some advocacy groups like ASNC, Family Support Network and others also keep databases of community resources.

- FSN Navigating Care site: <https://ncfamilynavigation.org/>
- FSN main page – find your local group <https://fsnnc.org/>
- ASNC – Talk with an Autism Resource Specialist <https://www.autismsociety-nc.org/talk-with-a-specialist/>
- NC Care 360 is a statewide Health and Human Services directory for North Carolina <https://nccare360.org/>

How can we identify a case manager who can help caregivers coordinate needed services for IDD individuals across disciplines and payor sources (Medicare vs Medicare eligible services)?

You may have to ask questions of care management companies about their expertise with dually diagnosed individuals or talk to the individuals supervising the care management program about developing better knowledge across disciplines. Ultimately, your care management provider should be prioritizing gaining the knowledge and skills to provide support to the individuals they are serving. Our whole system is moving in the direction of supporting the WHOLE PERSON and care management is central to this effort. If your care manager is not able to help navigate resources across different diagnosis and payor sources, talk with your LME/MCO about what other care management resources exist in your area for those with multiple diagnosis and complex needs.

This is something that the NC DHB should also be prioritizing in the development of care management resources across NC: organizations that can or will commit to working with those with complex needs.

Jennifer, you are a warrior for MH-I/DD. How do we get NCDHHS and General Assembly to help solve these problems?

Thank you! A couple of thoughts come to mind.

The main one is having the NCGA prioritize funding for moving people off the Registry of Unmet Needs faster. As I mentioned in the talk, waiting a decade or more for help is a mental well-being issue for both the person with a disability and their loved ones supporting them.

This could be done with a combination of a TEFRA waiver to include more people with diagnosed I/DD and other conditions in Medicaid, especially those under 18; a commitment to ensuring rates across I/DD, MH, and SUD services are tied to inflationary increases so that those with Medicaid maintain access to critical health and support services, and increasing access to home and community based waivers like Innovations, TBI, CAP C, CAP DA etc. all of which allow for an array of health and support services for the individual.

Schools also should be funded in a way that ensures they are able to fully support those under 22 with disabilities in the school system without resorting to the overuse of “homebound” services, without exclusionary discipline, and without the use of traumatic restraint and seclusion. All of which are signs that schools are UNDER-RESOURCED to support children and youth – many of whom are on the registry and also need long term supports and therapeutic services outside of school.

My son has I/DD and Autism. When he was in crisis a couple of months ago. There was not one inpatient treatment center in NC who would take him because of his dual diagnosis. They had beds but would not take someone with I/DD if they were a mental health facility. How do we change this?

There are a complicated set of issues involving how psychiatric hospitals are funded and regulated that prevent people with an IDD diagnosis from being admitted and treated there. This isn't a state issue, but one with a long history across the United States and goes back to unfair and inequitable confinement of people with I/DD in medical/psychiatric/treatment facilities (hospital or otherwise) when they could have been released to community-based services. Medicaid and other payors stopped paying for people with I/DD to be served in psychiatric hospitals to prevent them from being over-used and inappropriately used for those with I/DD.

A better way to look at it might be, what kinds of services and supports could we put in place for the person that *isn't* an inpatient treatment center where they could remain in a community setting and still get the treatment they need? Could we increase access to programs like NC START or Murdoch Developmental Center's STARS program that support those with dual diagnosis? Would having a permanent set of supportive services for your son like those in a HCBS waiver (Innovations, TBI, etc.) or 1915(i) services prevent him from getting to a point where he would need inpatient care?

Thank you for recognizing adults who suffered through mental health services only to find later in life they have high functioning Autism. Now trying to engage in the workplace. PLEASE educate Vocational Rehab. I've experienced several Regions in NC whose VR settings are clueless in a practice level.

We are so sorry to hear that your experiences in DVRS Vocational Rehabilitation have not supported your experience of having both a mental health diagnosis and autism. If this is an ongoing situation and you would like to talk with one of our resource specialists or employment specialists at ASNC about how to navigate VR, you can reach out via our talk with a specialist form found at <https://www.autismsociety-nc.org/talk-with-a-specialist/>. The folks at ASNC are doing their best to educate those VR staff we work with, but this is definitely a long-term issue to educate, train, and mentor EVERYONE across our entire services system!

What does EMDR stand for in the treatment option?

EMDR is Eye Movement Desensitization and Reprocessing. It is a trauma treatment that involves less language than other treatments. It has been shown to help people

who have symptoms and emotional distress from trauma or stressful life events. There is emerging research showing that it is effective for people with I/DD. There are minimal modifications needed for people with I/DD. Some studies have shown that for people with more significant I/DD, certain aspects of EMDR can reduce dysregulation and create calming and soothing without using any language.

ANY updates on *Samantha R.* and ICF Homes? Parents and caregivers get old they need options for their love one.

There have not been any updates on the *Samantha R.* lawsuit. We'd recommend reaching out to folks at Disability Rights NC or following their news feed for any updates at <https://disabilityrightsncc.org/news-events/drnc-newsfeed/>.

How does a parent join LAND?

Anyone can join our mailing list and receive monthly webinar invites, newsletters, and alerts for Meet the Need NC, the initiative that LAND (Leadership Alliance for Neurodevelopmental Disabilities) is spearheading through a grant from the NC Council for Developmental Disabilities. Here is the link to join the mailing list: <https://meettheneednc.org/sign-up-for-our-mailing-list/>.

This is how we are encouraging everyone in our I/DD Community to become part of our Meet the Need NC "Learning Community." It is going to take our I/DD community (individuals with I/DD, families, providers, agencies, non-profits across disabilities, and more) to join together with those outside of our I/DD community to make systemic change and to ultimately meet the service and support needs of the I/DD community in NC.

Please stay tuned in the new year as we start to educate more on our lived experience network called LENS (Lived Experience Network Speaks). This network has an advisory group currently made up of adult self-advocates (those with an I/DD) and parent advocates. We intend to start moving LENS across the state in 2024.

LAND is the backbone organization for our collective impact initiative called Meet the Need NC. Here is a link to more information about LAND <https://mentalhealthtransformationalli.godaddysites.com/land>. LAND is program of the national 501c3 nonprofit, Mental Health Transformation Alliance (MHTA). LAND is involved in other initiatives across the state and U.S.

Meet The Need NC Funding and Disclaimer Statement

Meet The Need NC is an initiative, funded by the North Carolina Council on Developmental Disabilities, that is changing the intellectual and other developmental disabilities (I/DD) landscape across the state. The initiative recognizes systemic change for I/DD community services and supports requires a common agenda. The content from Meet The Need NC aims to provide individuals, families and professionals education and information on intellectual and other developmental disabilities. It is not intended to replace professional medical, psychological, behavioral, legal, or educational counsel. Reference to any specific agency or legislation does not necessarily constitute or imply its endorsement, recommendation, or favoring by Meet the Need NC or the North Carolina Council on Developmental Disabilities.

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Meet the Need NC is driven by the Leadership Alliance for Neurodevelopmental Disabilities (LAND), a program of the 501c3 nonprofit, Mental Health Transformation Alliance (MHTA). LAND is a disability advocacy organization made up of family members and individuals with I/DD “lived experience” and other professionals dedicated to improving the lives of those with I/DD and their families.”