

Appendix 1: Recruitment Email

North Carolina General Assembly Study
8-24-2022 Version



A program of Mental Health Transformation Alliance

Email to Legislators:

Dear _____,



I am Dr. Michelle Scotton Franklin, a researcher at Duke University. I am reaching out to you as a member of *Meet the Need NC: Changing the I/DD Landscape Across the State* funded by the North Carolina Council on Developmental Disabilities to meet the service and support needs of the I/DD (Intellectual and Developmental Disability) community in North Carolina. There are thousands of North Carolina residents waiting for services and many more who have not yet been identified.

As part of this initiative, we are conducting a study with North Carolina General Assembly members with the goal to identify the current level of understanding about the unmet needs of the I/DD community, the NC Innovations Waiver, and the Registry of Unmet Needs.

We are emailing today to ask you to participate in this study by completing a brief online survey that has been approved by the Duke University Campus Institutional Review Board. I have provided more information below about the survey.

What will I be asked to do?

Complete an online survey that should take **approximately 10-15 minutes**.

How will my survey responses be used?

Responses from the survey will help us to learn how to better support the unmet needs of your constituents so that they can live the life they want to live safely and healthily in the community. The responses will also help to identify the areas that this initiative can focus its outreach and education efforts. All responses will be kept confidential.

What are the next steps?

Please click this **link** to review the study consent form and complete the survey. If you have questions, you may contact Dr. Michelle Scotton Franklin at michelle.franklin@duke.edu, or the Duke University Campus Review Board at 919.684.3782.

Thank you for your consideration of this request.

Sincerely,

Michelle Scotton Franklin, PhD, APRN, FNP-BC, PMHNP-BC, CNS

Assistant Professor

Duke Department of Psychiatry

Duke-Margolis Center for Health Policy

Appendix 2: Adult Informed Consent

Adult Consent Form

Dear _____

Your expertise as a General Assembly member is valuable to us. We are asking for your consent to complete a survey.

Key Information

What is the purpose of this research study?

This study is funded by the North Carolina Council on Developmental Disabilities (NCCDD) as part of the initiative *Meet the Need NC: Changing the I/DD Landscape Across the State* to address the service and support needs of the I/DD (Intellectual and Developmental Disability) community in North Carolina. The goal of the study is to identify the current level of understanding about the unmet needs of the I/DD community.

What will I be asked to do in this study?

You will be asked to complete a single brief online survey in Qualtrics that will include questions about funding priorities, understanding about I/DD, understanding of the unmet needs of the I/DD community, the NC Innovations Waiver, and the Registry of Unmet Needs. We will also ask for basic demographic information. The survey will take approximately **10-15 minutes** to complete.

Will my responses be kept private?

Your privacy is important to us so all of the information you provide will be kept confidential. We will not ask for your name, so no one can connect your answers to you. However, at the end of the survey you may choose to share your contact information if you would like to discuss potential efforts to support the I/DD community in North Carolina. If you do choose to provide your contact information, it will **not** be linked to the rest of your survey responses.

Electronic data from the survey will be stored on Duke University's secure cloud-platform, Duke Box. Information about you will be de-identified in our reported findings and no survey responses will be

attributed to you as an individual. Data that is not linked to your identity may be published or used for future research purposes.

What happens if I decide to not participate in the study?

Your participation in this study is completely voluntary. You have the right to skip or decline to answer any survey question or stop participating in the study at any time without penalty or consequence.

Are there any risks involved in participating in the study?

There is a minimal risk for participating in this study. To prevent breach of confidentiality we have protections in place to ensure your responses are kept confidential and are securely stored, and are only accessible by the study team.

Are there any benefits from participating in the study?

Although participating in this study has no direct benefit to you, the responses from the survey will help us to learn how to better support the unmet needs of your constituents so that they can live the life they want to live. The responses will also help to identify the areas that the initiative can focus its outreach and education efforts. Broadly, the findings from this study have the potential to positively impact the lives of individuals with I/DD and their families.

Who do I contact if I have questions about the study?

If you have questions about the study, you may contact Dr. Michelle Scotton Franklin at michelle.franklin@duke.edu. For questions about your rights as a research participant, please contact the Duke University Campus Review Board at campusIRB@duke.edu and reference protocol #2023-0065.

Please check the box below to indicate you agree to participate in this study by completing this survey.

Yes, I consent to participate in the study.

Appendix 3: Survey Administered through Qualtrics

LAND General Assembly Survey

Funding Priorities

1. What are your top 3 policy priority areas? (examples: health, economy, environment, criminal justice)
 - Free Text Response #1
 - Free Text Response #2
 - Free Text Response #3

Understanding and Attitudes about Intellectual and Developmental Disabilities (I/DD)

2. How familiar are you with the term intellectual and developmental disability (sometimes abbreviated as I/DD) and the conditions that are considered I/DDs?
 - Not at all familiar (1)
 - Slightly familiar (2)
 - Somewhat familiar (3)
 - Moderately familiar (4)
 - Extremely familiar (5)
3. (If mark answers 2-5 above will have this follow up questions) What has made you familiar with the term I/DD? Mark all the apply.
 - Have a family member with I/DD
 - Have an acquaintance with I/DD
 - Work experience
 - Literature or other education
 - Information from lobbyist
 - Other (free text)
4. I/DDs are disorders that begin prior to birth or during childhood and that negatively affect the individuals physical, intellectual and/or emotional development (examples: autism, Down syndrome, cerebral palsy). Have you had personal experience with someone with an intellectual and developmental disability (I/DDs)?
 - Yes
 - If yes (free text) Optional: describe more
 - No
5. Do you know anyone with the following conditions that are examples of I/DDs?
 - Autism
 - Yes
 - No
 - Fetal alcohol spectrum disorder
 - Yes
 - No
 - Down syndrome

- Yes
 - No
 - Cerebral palsy
 - Yes
 - No
 - Spina bifida
 - Yes
 - No
 - Traumatic brain injury that occurred prior to the age of 21 years old
 - Yes
 - No
 - Intellectual disability that occurred prior to the age of 21 years old
 - Yes
 - No
6. What percent of adults in North Carolina with I/DD do you think are employed?
- 0-15%
 - 16-25%
 - 26-50%
 - 51-75%
 - 76-100%
7. What do you think is the best option for where people with I/DD should live?
- In their community with as much independence as possible (examples: living alone, living with a family member, living with a roommate)
 - In a home with other people with I/DD
 - In a nursing home
 - In an institution for people with I/DD
8. Have you ever personally visited
- a. A group home for people with I/DD?
 - Yes
 - No
 - b. A nursing home?
 - Yes
 - No
 - c. An institution for people with I/DD?
 - Yes
 - No

Understanding of the Unmet Needs of the I/DD (Intellectual and Developmental Disability) Community, the NC Innovations Waiver, and the Registry of Unmet Needs

9. How well do you believe North Carolina is meeting the support needs of people with I/DD in public education?

- Poorly (1)
- Neutral – neither poorly nor well (2)
- Well (3)
- Don't know (0)

10. How well do you believe North Carolina is meeting the health care needs of people with I/DD?

- Poorly (1)
- Neutral – neither poorly nor well (2)
- Well (3)
- Don't know (0)

11. How well do you believe North Carolina is meeting the needs of people with I/DD in the criminal justice system?

- Poorly (1)
- Neutral – neither poorly nor well (2)
- Well (3)
- Don't know (0)

12. How well do you believe North Carolina is meeting the housing needs of people with I/DD?

- Poorly (1)
- Neutral – neither poorly nor well (2)
- Well (3)
- Don't know (0)

13. How well do you believe North Carolina is helping people with I/DD be actively included in their community?

- Poorly (1)
- Neutral – neither poorly nor well (2)
- Well (3)
- Don't know (0)

14. How well do you believe North Carolina is meeting the employment needs of people with I/DD?

- Poorly (1)
- Neutral – neither poorly nor well (2)
- Well (3)
- Don't know (0)

15. Which current concerns do you have, either personally or because of complaints you have received from constituents, regarding the I/DD community and their families? Select all that apply:

- Difficulty accessing quality physical health care services
- Difficulty accessing quality mental health services
- Difficulty finding stable employment
- Difficulty being included in the community

- Difficulty with transportation
- Difficulty navigating the education system and receiving adequate education support
- Difficulty securing stable housing
- Lack of respite care (someone looking after child with I/DD that is not the parent or other regular caregiver)
- Inadequate workforce (difficulty accessing Direct Support Professionals and others to deliver services)
- Other (free text response)
- No current concerns

16. Are you aware that North Carolina has a supports and services waiver called the NC Innovations Waiver for people with I/DD that helps people live and work in their communities?

- Yes
- No

17. If yes, how familiar are you with the NC Innovations Waiver?

- Not at all familiar (1)
- Slightly familiar (2)
- Somewhat familiar (3)
- Moderately familiar (4)
- Extremely familiar (5)

The NC Innovations Waiver is North Carolina's Medicaid Home and Community-Based Services 1915(c) waiver that is a customized program to address the needs of people with intellectual and developmental disabilities who are at high risk for needing institutional-based care. Waiver services enable people with I/DD get long-term care services and supports in their home or community rather than an institutional setting.

18. To what degree do you believe NC legislators are familiar with the eligibility standards, the purpose of, and services provided by the Innovations Waiver?

- Not at all familiar (1)
- Slightly familiar (2)
- Somewhat familiar (3)
- Moderately familiar (4)
- Extremely familiar (5)

19. Based on what you currently know, how much do you agree with the following statement: I believe the NC Innovations Waiver is meeting the needs of people with I/DD that have an Innovations Waiver slot.

- Strongly disagree (1)
- Disagree (2)
- Neither agree nor disagree (3)
- Agree (4)
- Strongly agree (5)

Explain (Optional):

20. Are you aware that NC has a waiting list (also known as the Registry of Unmet Needs sometimes referred to as the RUN) for these supports and services waiver slots?
- Yes
 - If yes, how long do you believe the current average waiting time is?
 - Less than 1 year
 - 1-5 years
 - 6-10 years
 - 11-15 years
 - 16+ years
 - No
21. How many do you think are currently waiting on this waiting list (Registry of Unmet Needs)?
- 1-4,999 people
 - 5,000-9,999 people
 - 10,000-14,999 people
 - 15,000+ people
22. What do you think are the current barriers to expanding the amount of NC Innovations Waiver slots to address the waiting list?
- free text response
23. The US Supreme Court's *Olmstead* Decision requires states to provide community-based services as an option for many people with disabilities who are at serious risk of entering or who live or work in publicly funded, segregated settings, so that they receive services in the most integrated setting appropriate to their needs. Such services are often provided by Direct Support Professionals (DSPs), people who work directly with people with physical disabilities and I/DD assisting with accessing the community and activities of daily living (examples: eating, bathing, toileting). Unfortunately, NC has a serious shortage of DSPs, causing people to be without DSPs and at risk of entering facilities. The current pay of DSP's is approximately \$12/hour. Do you support raising the Medicaid reimbursement rate for DSPs, so DSP's can receive a pay increase in line with the current workforce average?
- Yes
 - No
24. Please describe any ideas you have ideas to address the Registry of Unmet Needs (waiting list).
- Free text (optional)
25. Please describe any ideas you have to address the unmet needs of the people with I/DD that are privately insured and do not yet have Medicaid or a NC Innovations Waiver slot (example: children).
- Free text (optional)

26. To what degree do you believe NC General Assembly members are familiar with the Home & Community Based Services [1915\(i\) that can also be used to help address unmet needs of people with I/DD living in the community?](#)

- Not at all familiar (1)
- Slightly familiar (2)
- Somewhat familiar (3)
- Moderately familiar (4)
- Extremely familiar (5)

27. Please describe any ideas you have to address the unmet needs of other I/DD subpopulations such as those from historically marginalized communities (example: Black and Brown communities), people residing in rural areas, or having less visible needs (example: autism, fetal alcohol spectrum disorder).

- Free text (optional)

28. Based on your experience, how would you describe NC General Assembly members' current priority level for addressing the unmet needs of the I/DD community?

- Not a priority (1)
- Low priority (2)
- Neutral (3)
- High Priority (4)
- Essential Priority (5)

Explain (optional):

29. Please describe any ideas that you have that would help General Assembly members have greater understanding about the unmet needs of the I/DD community, the NC Innovations Waiver, and/or the Registry of Unmet Needs (waiting list)?

- Free text response

30. What would you think is the best way to engage General Assembly members in efforts to address the unmet needs among the I/DD community?

- Free text response

31. How influential do you believe you are in addressing the unmet needs among the I/DD community?

- Not at all influential (1)
- Slightly influential (2)
- Somewhat influential (3)
- Very influential (4)
- Extremely influential (5)

32. Have you sponsored or supported a bill with provisions to address the service needs among the I/DD community?

- Yes
- No
- Prefer to not answer

33. We are grateful for the legislative advocacy for the I/DD community that we have seen from General Assembly members. Are there specific members who you think that we should work with on these issues?

- Free text response

Demographics

34. What is your gender?

- Male
- Female
- Prefer to self-describe: _____
- Other

35. How old are you?

- 21-30 years
- 31-40 years
- 41-50 years
- 51-60 years
- 61-70 years
- 71-80 years
- 81 + years

36. How would you describe your race/ethnicity? Please check all that apply.

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- Other

37. Do you identify as Hispanic/Latino?

- Yes
- No

38. Please check all that apply to you:

- Person with a disability
- Family member of a person with a disability
- LGBTQ
- Identify with a cultural identity (nationality, ethnicity, locality) that reflects diversity in a US context

- Speak a language other than English at home

39. Lastly, is there anything else that you would like to share?

40. (Optional) If you would like to further discuss efforts to support the I/DD community in North Carolina, please feel free to provide your contact information. This information will **not** be linked to other study data.

- Name
- Email
- Phone

Appendix 4: Meet The Need NC Infographic

MEET THE NEED NC

Changing the I/DD landscape across the state

Systemic change for I/DD community services and supports requires a common agenda.

Where Are We Now

regarding Unmet Needs for North Carolina's I/DD community?



It is difficult for individuals and their families to find and understand information about I/DD services.



Families and individuals who wait for the Medicaid Innovations Waiver, many for over a decade, suffer in many ways with minimal support.



The ability for those with I/DD to live more independently in communities is impacted by the direct support professional workforce crisis, affordable housing, and many other factors.



The Registry of Unmet Needs* is 15,000+ waiting **and growing.**



There are many who should be on the Registry of Unmet Needs who are not.



Those with lived experience are key to our educational efforts.



Medicaid Transformation: Tailored Plans and 1915(i) go into effect on December 1, 2022.

The terms Registry of Unmet Needs (RUN) or Registry refer to the waitlist of the Medicaid Innovations Waiver.

VISION STATEMENT

Awareness & Understanding Expanded

Meet the service and support needs of the I/DD Community in North Carolina

Increased Services & Supports

Equitable Access

Informed Families

Reduced Wait Time on the Registry of Unmet Needs

HOW WE WILL GET THERE



Collect information



Inform and educate target communities



Increase funding for additional I/DD services and supports



Meet the needs of those on the Registry of Unmet Needs

Disclaimer: This data is current as of May 2022.

LEARN THE LINGO

I/DD - Intellectual/Developmental Disabilities The umbrella term “developmental disability” means a pervasive, lifelong disability attributed to a mental/cognitive or physical impairment or combination of mental and physical impairments diagnosed or that become obvious before the age of 22. **Examples of developmental disabilities include: intellectual disability, Autism Spectrum Disorder, Cerebral Palsy, Down syndrome, and Fetal Alcohol Spectrum Disorder.** In North Carolina, individuals diagnosed with a TBI (traumatic brain injury) may also be eligible for I/DD services.

Medicaid Medicaid provides health coverage to millions of North Carolinians, including eligible low-income adults, children, people who are pregnant, aging adults and people with disabilities.

Medicaid Expansion This refers to the expansion of Medicaid services to cover more low-income individuals in the “coverage gap”. North Carolina is only one of 12 states who have not expanded Medicaid.

Medicaid Transformation The North Carolina General Assembly established two types of health plans for Medicaid recipients: **Standard Plans** for the largest portion of Medicaid recipients; and **Tailored Plans** for people with I/DD and other conditions who have the need for more intense, or “tailored” services and supports.

NC Medicaid Innovations Waiver The NC Innovations Waiver (formerly known as “CAP”) includes federally funded services designed to meet the needs of Individuals with I/DD who prefer to get long-term care services and supports in their home or community.

RUN - The Registry of Unmet Needs A Registry, or wait list, for individuals who are eligible for the NC Medicaid Innovations Waiver. Those on the Registry may or may not have Medicaid.

LME-MCO Licensed Management Entities - Management Care Organizations. Six LME-MCOs now manage services and supports for NC Medicaid beneficiaries who receive care for developmental disabilities, substance use disorders, or severe and persistent mental illness. <https://www.ncdhhs.gov/providers/lme-mco-directory>

1915(i) Home & community-based, entitlement services for those on Medicaid. In December 2022, many b3 services currently available for those on the Registry will be replaced by 1915(i) services.

HCBS Home and Community-Based Services. Disability services received in the community rather than an institutional setting. These services include housing, employment, professional caregivers, and therapies. The ability for those with I/DD to live more independently in their communities is currently impacted by the DSP (Direct Support Providers) workforce crisis, affordable housing, and many other factors. DSPs help support those with IDD in their daily lives. DSPs help people become integrated and engaged in their community. They aim to assist people in realizing their full potential.

RESOURCES

The Arc of North Carolina: <https://bit.ly/Medicaid-Transformation>

NC Department of Health & Human Services Innovations Waiver: <https://bit.ly/Innovations-Waiver>

NC Department of Health & Human Services 1915(i) Transition: <https://bit.ly/1915-Transition>

THE PEOPLE WORKING WITH US: LAND/MEET THE NEED NC ADVISORY COUNCIL

This initiative brings together leading organizations, state agencies, and advocates across North Carolina to address the unmet needs of the I/DD Community. The LAND/Meet the Need NC Advisory Council is charged to bring the voices together to build and advocate for appropriate I/DD services and supports for individuals and their families. To keep abreast of our efforts, scan our QR code or click the link [Welcome to NC LAND!](#)



A Program of Mental Health Transformation Alliance

To learn more about Meet The Need NC, contact Beth.Field.LAND@gmail.com