NCCDD Initiative 2024



Meet The Need NC – Year 3 (of 4) 10/1/2021 – 9/30/2025

System Gap Addressed

- It is hard for individuals, families, and staff to find, navigate, keep, and best use services.
- Many people who need help and support are not getting it. People can't ask for help if they do not know what help is available.
- People of all ages with I/DD and their families are just surviving, not thriving.
- There are a lot of changes and transitions going on, including Medicaid Transformation and Expansion, and 1915(i).
- The Registry of Unmet Needs (RUN) is 17,900 and growing; the number of slots is not.
- A Direct Care/Service Professional (DSP) work force shortage is a key factor impacting the ability of individuals to live in the community.
- People don't always agree on what is best for people with I/DD to live or work in the community.
- All of these factors have led to significant unmet service and support needs for North Carolina's I/DD community.
- There are increased health disparities for those in underserved communities, including Black, Latino/Hispanic, Native American and rural communities.

Initiative Goals and Timeline

- Be a catalyst for I/DD systemic change in NC using a Collective Impact model to meet the service and support needs of those with I/DD and their families throughout their lifespans. Focus on reducing the Innovations Waiver Waitlist and Direct Care/DSP work force shortage.
- Garner the support of the I/DD Community as a whole and other stakeholders groups to meet the specific goal of the NCCDD-funded portion of initiative: Meet the service and support needs of those on the Registry of Unmet Needs.
- Develop and expand a statewide I/DD grassroots lived experience movement to become the message driver of I/DD systems change and ensure sustainability of the initiative.
- Drive a groundswell of interest regarding the Meet the Need NC movement, including underserved communities.
- Understand and impact the level of understanding of those outside the I/DD Community regarding I/DD.
- Continue putting processes in place to manage initiative interest, integrate programming and grow support for community living options for those with I/DD.
- Increase stakeholder awareness and understanding around key issues that impact I/DD services and supports, including Innovations Waiver/Wait list, Direct Care/DSP workforce shortage, Medicaid Transformation, Tailored Plan, Tailored Care Management, 1915(i), and Medicaid Expansion; Inspire the use of plain language and accessible communications for beneficiaries.
- Inspire the use of plain language and accessible commutations to beneficiaries.
- Build and maintain authentic relationships with key stakeholder groups, including state agencies and understand populations, around meeting the service and support needs of I/DD Community.
- Listen well and consistently to constituencies across the state to further understand the similar and diverse service and support needs, including underserved populations, amidst ongoing changes in our Medicaid and Managed Care systems.
- Engage stakeholder groups in and outside of I/DD community.
- Continue to refine Shared Measurement as part of the Collective Impact model and develop an integrated 2024-2025 Work Plan.
- Meet overall 2024-2025 Work Plan goal: By the adjournment of the 2025 NCGA long session, Meet the Need NC will educate key members of the NCGA to reduce and/or eliminate the Innovations Waiver Waitlist while supporting the growth of a pool of DSP workers to ensure community living choices.

Description of Activities

- Increase stakeholder awareness and understanding around key issues that impact I/DD services and supports through monthly disability advocacy webinars, follow-on newsletters, presentations in and outside I/DD Community.
- Ongoing participation in other collective impact initiatives and advisory groups relating to initiative issues.

- Using key values and guiding principles for interactions, form and maintain a highly engaged "Advisory
 Collaborative" of leading key stakeholders, thought leaders, and organizations with diverse perspectives from the
 developmental disability community to advise initiative that meets quarterly.
- Develop a lived experience advisory group that meets monthly to develop content for initiative's communications
 vehicles and to grow a grassroots network across the state.
- Develop communication materials to reach community-based organizations to mobilize, focus, and amplify initiative's messages across the state.
- Educate/inform individuals with I/DD and their families at the community-based level about the Innovations Waiver, waitlist, and services and supports available while waiting.
- Build and maintain authentic relationships with key stakeholder groups, including state and local policymakers and other groups outside of the NC I/DD Community.
- Listen well and consistently to constituencies across the state to further understand the similar and diverse service and support needs, including underserved populations.
- Continue to refine Shared Measurement as part of the Collective Impact model.
- Develop an integrated 2024-2025 Work Plan.

Achievements and Outcomes to Date

- Formed and maintained an Advisory Collaborative, lived experience advisory group, and 2024-2025 Work Plan Task Force across developmental disabilities, level of need, lifespan, region, and marginalized communities.
- Hosted a hybrid 2023 I/DD Policy Think Tank with 78 participants representing 47 organizations across systems, disabilities, ages, level of need, marginalized communities, and state; 62% of attendees were new voices to the table as a precursor to the development of the 2024-2025 Work Plan.
- Used data from 2023 I/DD Policy Think Tank to bring to Meet The Need NC advisory groups and two Meet The Need NC webinars to develop 2024-2025 Work Plan.
- Assisted in selecting and organizing diverse group of 20+ people with I/DD lived experiences for May 2024 I/DD
 Caucus meeting at the NC General Assembly for a listening session, and helped drive press conference for
 event.
- To date, hosted seventeen monthly webinars with I/DD thought leader speakers with accessible communications
 vendors including ASL translation and Spanish translation; wrote and organized sixteen follow-on newsletters
 including lived experience blogs, recordings of webinars, and other resources relating to webinar topics to
 increase awareness around key initiative topics, help unify NC I/DD Community, and drive overall awareness and
 support for Meet The Need NC movement.
- Lived experience advisory group developed, tested, and launched Innovations Waiver Pathway and Tip Sheet as toolkit to bring into community-based meetings to help educate and inform on the Innovations Waiver, waitlist, 1915(i) and other tips of things to do while waiting for an Innovations Waiver slot.
- Surveyed mailing list at the end of Year 3 with a survey instrument implemented in Year 1 to identify with whom Meet The Need NC has helped to increase the awareness for the Innovations Waiver, waitlist, and other topics related to I/DD services and supports in North Carolina.
- Developed comprehensive set of communications vehicles including social media, webinars, newsletters, podcasts, website, and toolkit to deliver an integrated set of at least 100,00 I/DD targeted awareness messages to date. Grew targeted mailing list to approximately 2,000 people.
- Increased competencies for working with Hispanic/Latino, Black and I/DD rural communities through webinars, newsletters, presentations, and representation on other advisory committees.

Expected System Change as Result of Initiative

- Reduce/eliminate Innovations Waiver Waitlist and Direct Care/DSP work force shortage.
- People with lived experience at the community level are key to driving system change along with seasoned statewide policy advocates from a bottom up and top-down approach.
- Disability groups work together to realize the value of collective impact.
- Individuals with developmental disabilities join together with families to form united grassroots movement across the state.
- Those with I/DD lived experience are more strategically joined with policymakers to tell their stories in a unified, focused way.