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, 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, 1915(i), and the end of The Public Health Emergency.
- The Registry of Unmet Needs (RUN) is 17,000 and growing; the number of slots is not.
- Our current K-12 education system is not preparing those with I/DD for living their most successful lives.
- Community living and inclusive employment are not realities in NC for those with I/DD; Opinions vary 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.

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.
- Develop and expand a statewide I/DD grassroots, lived experience network to become the driver of Meet the Need NC, and ensure sustainability of the initiative.
- Drive a groundswell of interest regarding Meet the Need NC through regular communications around key, timely topics to spearhead an I/DD "Learning Community".
- Understand and impact level of understanding of those outside the I/DD Community regarding what enables I/DD-informed communities.
- Continue putting processes in place to manage initiative interest, integrate programming and grow support.

Description of Activities

- Increase stakeholder understanding around key issues that impact I/DD services and supports, including Innovations Waiver/Wait list, DSPs, Medicaid Transformation, Tailored Plan, 1915(i), and Medicaid Expansion; Inspire the use of plain language communications for beneficiaries.
- Build and maintain authentic relationships with key stakeholder groups, including state agencies.
- 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 environmental change.
- 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 Work Plan.

Updated January 2024

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Meet the Need NC Year 3 (of 4) (continued)

Achievements and Outcomes to Date

- Using key values and guiding principles for interactions, evolved over Year 1 and 2 to form a highly engaged "Advisory Collaborative" of 30+ leading key stakeholders and organizations with diverse perspectives.
- Developed a vision for the Lived Experience Network Speaks (LENS) and they are organizing to begin growing a grassroots network across the state.
- Hosted a hybrid (in person and online) I/DD Policy Think Tank with 78 participants representing 47 organizations across systems, disabilities, ages, level of challenge and state; 62% of attendees were new voices to the table.
- Developing a Work Plan for Year 3 based in the data gathered from the I/DD Think Policy Tank, and analyzed by Meet the Need NC advisory groups (Advisory Collaborative and LENS).
- Hosting monthly Meet the Need NC Lunch and Learn "Hear.Share.Act," webinars to highlight and drive conversation around key I/DD issues around system change; Publish monthly newsletter to extend learnings of webinars.
- Formed Lived Experience Network Speaks (LENS) advisory group (self-advocates and advocates) and developed a strategic purpose and outcomes statement for it to extend Meet the Need NC's policy agenda through grassroots efforts.
- Increased cultural competencies for working with Hispanic/Latino I/DD communities.
- Finalized North Carolina General Assembly survey report with researchers.
- Exhibited and presented at December 2023 i2i conference highlighting the value of having people with I/DD lived experience at the table where decisions are made about them.

Expected Systems Change as Result of Initiative

Overall:

- Meet the Unmet Service and Support Needs of the I/DD community in North Carolina.
- People with lived experience are key to our efforts drive change.
- If we reach our vision of meeting the service and support needs of the I/DD community, these are the outcomes we expect to see (from our Meet the Need NC common agenda):
 - Awareness and Understanding Expanded; Equitable Access; Informed Families regarding I/DD Service and Supports and their navigation for all who need them in NC
 - Increased Services and Supports
 - Reduced Time on the Registry of Unmet Needs
 - An Educational System that Prepares our Children with I/DD for a Successful Adulthood
 - Community Inclusion Embraced/Expected (Naturally) In and Outside the I/DD Community across the Lifespan
 - Collaborative Advocacy for Change is the Norm