

NCCDD INITIATIVE 2022



Changing the LANDscape of IDD Care in North Carolina: A Coordinated Campaign to Impact the Registry of Unmet Needs (Year 2)

10/1/2021 – 9/30/2023

System Gap Addressed

- People with developmental disabilities typically benefit from various home and community-based services or Medicaid Waiver services that allow them to access healthcare and live successfully in their community of choice as defined by Olmstead.
- Currently, many individuals - and their families - who wait (often for over a decade) for a Medicaid Waiver in North Carolina, suffer and are at risk with minimal support.
- The Registry of Unmet Needs (RUN), also referred to as the waitlist of the Medicaid Innovations Waiver, is 15,000 and growing.
- Overall, it is difficult for individuals and their families to find and understand information about I/DD services and navigation.
- There is further disparity in access to I/DD services for minority populations.
- The ability for those with I/DD to live more independently in communities is impacted by the direct support professional workforce crisis, affordable housing, etc.
- All of these factors have led to significant unmet service and support needs for North Carolina's I/DD community.

Initiative Goals and Timeline

- During Year 1, create a cross-system, cross-disability Advisory Council bring together leading organizations, state agencies and advocates to develop a common agenda for systemic change for I/DD long-term community services and supports.
- Develop a learning community to initiate and enact systemic change.
- Begin a groundswell of interest within the I/DD community regarding Meet the Need NC: Changing the I/DD landscape across the state and build broad, strong relationships.
- Develop branding for the initiative.
- Put processes in place to manage initiative interest and grow support.
- Listen to further understand the current service and support needs across the state, including underserved populations.
- Educate, inform and begin plain language communication efforts to increase stakeholder understanding around issues that impact I/DD services and supports, including Medicaid Transformation, Tailored Plan, 1915i, Waiver/RUN, and DSP Workforce crisis.

Description of Activities

- Held quarterly Advisory Council meetings and monthly Workgroup (Community Engagement, Data & Stories, Communications, Policy) meetings leading to a common agenda.
- Finalized initiative's common agenda: Meet the service and support needs of the I/DD community in North Carolina. Developed infographic to reflect the common agenda with plain language I/DD terms on back of page.
- Named initiative and developed logo: Meet the Need NC: Changing the I/DD landscape across the state.
- Developed and launched web site for initiative; Ended year with 1,800 stakeholder database.
- Helped to launch self-advocate podcast series.
- Worked toward integrated 6-Month Workplan with Workgroups.
- Completed self-advocate / advocate survey to further validate I/DD community landscape issues.
- Presented at i2i Center for Integrative Health Spring Conference and Hispanic/Latino Resource Fairs about unmet service and support needs of I/DD Community in NC.
- Developed email communications and professional survey to further understanding of the NC General Assembly's knowledge around I/DD.
- Improved relationships with key stakeholder groups, including NC DHHS leadership and DD Consortium.
- Two Meet the Need NC events held in rural communities in the western and eastern parts of the state.

Outcomes to Date

- Year 1: Fully engaged Advisory Council and Workgroups.
- Better understanding of the problem and issues surrounding it.
- Relationships with key I/DD stakeholder groups and ability to relay messages through their participation in initiative increased.
- Black and Hispanic/Latino I/DD community inclusion.
- Beginning to increase knowledge of gaps in I/DD community services and supports for key policymakers.
- Information gap between beneficiaries/families and providers/agencies identified; Need for plain language communications highlighted.

Expected System Change as Result of Initiative

- Meet the Unmet Service and Support Needs of the I/DD community in North Carolina.