

NC Group Awarded Grant to Develop Coordinated Campaign to Impact Medicaid Waiting List for People with Intellectual and/or Developmental Disabilities

November 15, 2021 (North Carolina) - The Mental Health Transformation Alliance (MHTA), an interdisciplinary team across North Carolina, has been awarded a four-year grant to develop and carry out a coordinated approach to positively impact the Medicaid Innovations Waiver waiting list in North Carolina.

NC LAND, the program of Mental Health Transformation Alliance (MHTA), obtained a four-year grant award to develop and carry out a coordinated approach to positively impact the Medicaid Innovations Waiver waiting list in North Carolina. The grant kicked off on October 1, 2021.

The Innovations Waiver is a Federally approved Medicaid Home and Community-Based Services (HCBS) Medicaid Waiver designed to meet the needs of individuals with intellectual or developmental disabilities (I/DD). It is designed to promote long-term care services and supports in the home or community, rather than in institutional settings.

Individuals with I/DD who qualify for the Waiver are placed on a Waiting List which is also called the Registry of Unmet Needs (RUN), also referred to as the Registry. Currently, there are approximately 15,000 people on the Registry in North Carolina. People on waitlists for Medicaid Waivers in other states in the U.S. have an average wait time of almost three years. North Carolina's average wait is 9.5 years.

The goals of the grant are not only to increase the number of Waiver suggesting a lower cases for slots, but to advocate for other ways the state can address the unmet needs of people who are on the Registry. It is also important to ensure others who may need services sign up for the Registry.

Funded by the North Carolina Council on Developmental Disabilities, the LAND program of MHTA established a 30+ person Advisory Council, bringing together agency leaders, family advocates, individuals with I/DD, research teams, and community organizations with a unified focus on educating, informing, and building grassroots efforts around meeting the unmet needs of individuals on the Medicaid Innovations Waiver waiting list in North Carolina.

An interdisciplinary team including agency leaders, family advocates, individuals with I/DD, research teams, and community organizations have established a 30+-person Advisory Council aimed at educating, informing, and building grassroots efforts around meeting the unmet needs of individuals on the Registry.

“I could not be more pleased with the incredible array of stakeholders LAND has brought together to begin the Registry initiative,” said NCCDD Executive Director Talley Wells. “Now is the time when we need to engage the I/DD community across the state to take on the unmet needs of thousands of North Carolinians with I/DD.”

Elizabeth Field will serve as the lead for the multi-year initiative, which is occurring at the same time that the state is engaged in major systemic efforts that impact individuals with I/DD in the state. The state is engaged in systemic strategic planning for people with disabilities through the creation of an *Olmstead* Plan. *Olmstead* is the U.S. Supreme Court decision which held that individuals have the right to receive services in the community rather than in institutions.

The state is also in the midst of changing how Medicaid is delivered through a process called Medicaid Transformation. This will result in individuals with I/DD on Medicaid receiving a “Tailored Plan” with a new system of care coordination starting in July 2022. Relatedly, the state is contracting to develop a “unified waitlist system,” which will positively impact the data and information collected and available regarding the needs of individuals waiting for I/DD services.

In response to the the state’s systemic changes underway and the need to move people with I/DD off of the Registry, the four-year initiative aims to do the following:

1. Educate individuals with I/DD, family members, professionals, policymakers, and legislators so that they have accurate information about the Registry to assist in developing a more coordinated and cohesive strategy to address the needs of individuals on the Registry.
2. Educate professionals, policymakers, and legislators about the critical unmet needs facing individuals with I/DD who are on the Registry, as well as the critical unmet needs of individuals who are not yet on the Registry and who also are in need of services. These needs will continue to intensify as parents of individuals with I/DD, who are often their primary caregivers, age and pass away.

3. Develop and implement collaborative communication and policy education strategies to positively impact the Registry of Unmet Needs.
4. Empower self-advocates and family members of individuals with I/DD to meaningfully improve systems in North Carolina that can better address the unmet needs of individuals on the Registry.

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