



MEDICAL HEALTH HOMES

*Promoting Integrated, Person-Centered Care for
People with Intellectual & Developmental Disabilities*

POLICY RECOMMENDATIONS

JUNE 2023

Promoting optimal health outcomes for children and adults with I/DD across the life span requires intentional and on-going collaboration across multiple systems, including healthcare, education, employment, social services, legal, and community. This collaboration must be conducted in partnership with individuals with I/DD and families and promote accountability and transparency. Below is a list of policy targets that have been informed by the experiences and opinions of individuals with I/DD, families, providers, advocates, and policy makers:

- Developing, piloting, and evaluating value-based reimbursement (VBR) system(s) to address relevant and valued health AND quality of life outcomes of persons with I/DD and their families. This is critical as Tailored Care Management continues to evolve and the state prepares for the launch of the Tailored Plans. In addition to HEDIS measures there must be a focus on personal outcomes that align with person-centered principles and practices and are specific to the needs of people with I/DD.
- Developing, implementing, and evaluating intentional and inclusive pre-service and continuing professional development education on the health of persons with I/DD across the life span. The audiences for this critical education should include medical, dental, behavioral health, allied health, public health, and social services. Partners include universities, community colleges, NC AHEC, provider organizations, families, and individuals with I/DD. As the state continues to invest in a variety of workforce initiatives it must include ongoing training on the needs of people with I/DD across all related professions.
- Establishing integrated data documentation, coding, collection, analysis, and reporting that works across medical, disability, educational and human service systems. The NC DHHS LME MCO dashboard needs to provide a context for the data, offering a current snapshot and a historical perspective that allows the user to determine the “state of the state”. Consistency of data definitions and reporting across agencies is critical so that the information can be used to make informed policy and resource allocation decisions. Data on children and adults with I/DD should be clearly identified.
- Development of a system that regularly inventories and shares best practices in services and supports for families and individuals with I/DD. The inventory should be accessible to providers, payors, families, and individuals with I/DD and contribute to increasing capacity and access to quality care.
- Provide funding and administrative flexibility for the development and evaluation of diverse models of family support and navigation that establishes a statewide infrastructure promoting collaboration, efficiency, effectiveness, and statewide reach across organizations. Data should include family perspectives on how family support has helped them resolve their issue, access services, avoid or limit the use of crisis services, and remain in the residential option of choice.
- Ensure NC DHHS documents, communications and initiatives that address BH and SUD are inclusive of persons with I/DD and families. Examples are the Governor’s Roadmap for \$1

billion investment in BH and Resilience that outlines three major areas for investment and the Proposed Rule Amendments, 10A NCA 27G.0104 Staff definitions.

- Ensure a developmentally appropriate focus on health promotion, wellness, and self-care within Tailored Care Management and Care Coordination. Promote the use of education and resources that are vetted by individuals with I/DD and families and engage them as trainers.
- Develop standard methods to ensure newborns diagnosed with I/DD from birth have access to Tailored Care Management or family navigation to support and coordinate early intervention, treatment options and family support.
- Invest in a review of policies that create barriers to accessing services, specifically access to diagnostics outside of urban locations. Families who need the services most have the most difficult time obtaining required diagnostics to access services.
- A comprehensive approach to address the needs of individuals with I/DD and families that are uninsured through outreach that identifies and links them to services.
- Create department communication standards that provide written and verbal explanations in plain language with clear concepts to support the accessibility needed by people with I/DD, their families, and others.
- Establish additional regional sites to conduct multi-modal evaluations for children and adults with I/DD and complex health and behavioral health needs, working collaboratively with NC START, regionally based providers and academic medical centers.