Medical and Health Homes for People with Intellectual and Other Developmental Disabilities (I/DD)

System Gap Addressed	 Children and adults with I/DD receive long-term, habilitative and health services through a fragmented system of care that can put the health and safety of individuals at risk, as well as raising costs of care: In 2012, people with I/DD experienced 17,709 emergency room visits, with a 29.7% hospitalization rate. Approximately 46% of North Carolina Medicaid funding is expended by populations with special healthcare needs due to disability or aging. For HCBS and ICF/MR service, North Carolina cost per person exceeded the national average by 21.3%. NC efforts to promote integrated care across public and managed health services have focused on diverse populations, but have often not purposefully addressed the needs of people with I/DD and their families, despite their complex and high health risk factors. Individuals with I/DD who have "typical" health needs can be served in a patient-centered medical home, if care is coordinated with other services and supports (disability services, family, and the community) and the medical staff are able to access "specialty" and consultation services as needed.
Initiative Goals and Timeline	 To develop a blueprint for coordinated, cost-effective, primary healthcare services for people with I/DD who are Medicaid eligible. Ensure that state Collaborative and Integrated Care, Medical Home, and Medicaid Reform initiatives, committees and activities reflect the needs and contributions of people with I/DD and their families. Identify best practices, models, strategies and resources that promote collaborative care, build opportunities for coordinated team care, and move the systems toward integrated care for people with I/DD. Promote systems change by encouraging a shift in the way that our State and the many stakeholders engaged in services, advocacy, education and reform make decisions about policies, programs, allocation of resources and, ultimately, in the way services are delivered.
Description of Activities	 Convene a Community-Academic-Provider (CAP) Advisory Consortium to develop specific action plans that address priority issues. The CAP group includes physicians, providers, advocates and other stakeholders representing over 20 statewide healthcare entities. Formed two new work groups to address dental health and medication and pharmacy issues as identified as primary needs by the CAP Consortium. Reviewed state Medicaid claims data to analyze the health status (demographics, access, costs, outcomes) of people with I/DD in order to identify trends, gaps and specific opportunities for integration and improvement. Provide healthcare information and recommendations related to coordinated care for people with I/DD to increase the knowledge and skills of disability service providers, advocates, and nursing and dental professionals across the State.

North Carolina Council on Developmental Disabilities

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Achievements and Outcomes to Date	 Developed an initial list of recommendations for better coordination and collaboration in the management and delivery of primary healthcare services and long-term services and supports for individuals with I/DD. Participation on multiple statewide health groups including the Integrated Care (IC) steering committee. Collaboration across multiple departments at CCNC (pharmacy, behavioral health, foster care, staff development, clinical educations and dental). Referred to as a model for integrated care for I/DD by the North Carolina General Assembly and invited by legislators to inform the Medicaid Reform process. Increased focus on education and the potential to develop community learning labs for education on medical home and chronic disease self-management for adults with I/DD, families and direct support professionals. Development of practice opportunities for care managers regarding health education, patient engagement and communication with adults with I/DD.
Expected System Change as Result of Initiative	 People with I/DD and their families have the same access to health and wellness services and resources as other community members, be supported to achieve and sustain good health, and always be able to find the "right door" for accessing healthcare. Ensure that stakeholders across multiple sectors are engaged, educated, and responsive to the needs of people with I/DD and their families in order to change in the way we conceptualize, organize, deliver, evaluate and incentivize healthcare and long-term services and supports. Build a system that cares for the whole person and coordinates care across sectors, addressing long-term service and support needs, promoting shared decision-making and informed consent, and paying for outcomes that matter to the person, family, provider and system.