



From Planning to Action: Integrated, Collaborative Care for People with Intellectual and Developmental Disabilities (I/DD)

<p>System Gap Addressed</p>	<p>From Planning to Action: Integrated, Collaborative Care for People with I/DD is a partnership among The Arc of NC, Easter Seals UCP, and the Autism Society of NC that transitions the systems-change planning groundwork of the Medical Health Home Initiative into actionable demonstrations that advance innovation and access to quality healthcare for people with I/DD.</p> <p>Primary care practices and providers have identified the need for access to colleagues with I/DD expertise to increase their competence and comfort in caring for children and adults with I/DD in their community.</p>
<p>Initiative Goals and Timeline</p>	<ul style="list-style-type: none"> • Develop consultation services and networks that are multidisciplinary resources that improve knowledge and skills of primary care and community healthcare providers so individuals with I/DD can access care in their community. • Conduct evaluation to measure the effectiveness of two demonstration pilots and consultation models for scalability and adoption by policymakers and state health systems and payors. • Inform Medicaid Transformation policy, practices and resource allocation to improve access to care and desired outcomes for individuals with I/DD and their families.
<p>Description of Activities</p>	<ul style="list-style-type: none"> • TEACCH, UNC-CH: Increasing Access to Autism Spectrum Disorder Specialty Care in Rural North Carolina: A Project ECHO Pilot. Partnership with Autism Society of NC, Carolina Institute for DD (CIDD) at UNC-CH and Area Health Education Centers. Goals are to improve quality of lifespan care received by individuals with Autism Spectrum Disorder (ASD) by increasing specific knowledge and treatment self-efficacy of rural primary care providers, improving treatment of common medical conditions, and increasing diagnostic screening of ASD. The ECHO model uses tele-mentoring to create access to high quality specialty care in local communities, promotes knowledge sharing networks among specialists and community providers, and supports the patient's medical home. Five ECHO cohorts were recruited from 20 counties in eastern NC: 31 primary care providers (2 cohorts); 22 military medical providers (1 cohort) and 39 mental health providers (2 cohorts). • Duke Health: Primary Care Pediatric Telephone Consultation for Children and Youth with Intellectual and Developmental Disabilities. Partnership with CIDD, Children's Complex Care Clinic at UNC, and NC START Central team. Goals are to establish telephone consultation infrastructure to provide timely consultation regarding medical and behavioral health needs of youth with I/DD AND provide referral support for youth with I/DD and families to connect with appropriate resources. Consultation calls have increased over time (95 unique contacts); are spread across age groups; and reflect a high need for resource information, referral linkages and system navigation. The in-depth chart review and case finding revealed that only 10% of patients with I/DD diagnosis were on the Innovations Waiver and only 11% had been referred to the Registry of Unmet Needs managed by the LME/MCOs. • Stakeholder engagement through Community-Academic-Provider Consortium, topic-specific workgroups, contributions to Cross-System Navigation in a Managed Care Environment initiative, presentations, articles and website (http://www.iddmedicalhealthhomencinitiative.com/). • Policy Summits convened in 2015, 2016, 2018 and 2019 to highlight best practices in integrated care, NC investments in innovation, and opportunities for growth and sustainability that align with Medicaid Managed Care Transformation. 2020 Summit will focus on Family Support and Navigation.

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Achievements and Outcomes to Date

- **TEACCH Autism ECHO:** Evaluation has documented improvement in providers' confidence and ability to care for individuals with ASD; increased diagnostic screening rates; increased knowledge of ASD as a result of didactic presentations and case-based learning; enhanced connections with peers and colleagues; and satisfaction with the pace of the Autism ECHO. TEACCH has leveraged the initial NCCDD support for the primary care Autism ECHO to develop additional Autism ECHOs, collaborations and time-limited funding sources.
- **Duke NC Pediatric Access Line:** Developed a model that blends reactive consultation with proactive approaches: reactive telephone consultation for physician to physician support; reactive in-person, telephone or electronic care coordination support; family partner; case identification; and proactive outreach. Developed an I/DD Resource Packet for primary care providers to increase their understanding of how to access services, psychological testing, special education, guardianship and alternatives, residential living arrangements, and related resources. Evaluation data indicates high satisfaction with NC PAL service, increased comfort in caring for children with complex needs and a reduced need for higher level of care for some patients. The North Carolina Tele-health Partnership for Child and Adolescent Psychiatry Access grant provides an opportunity to infuse Duke's work in NC PAL-IDD into efforts to build a statewide coalition, provide psychiatric consultation to primary care providers, offer resource and referral coordination, and educate providers.
- **Family Support NC ECHO pilot:** Launched in January 2020, is exploring the use of the ECHO model in the development of a statewide approach to training, mentoring and professional development as one means of decreasing barriers and increasing access to quality family services and supports in a variety of settings.
- **Outreach and Dissemination:** The initiative has presented on integrated care, Medicaid managed care, person-centered care and related topics to more than 1,000 people including families, individuals with I/DD, disability providers, healthcare professionals, policymakers and state government. The NC Academy of Family Physicians magazine (direct mailed to 4,000 members) and TEACCH 2019 annual review (distributed via Facebook and email to more than 12,000 people) highlighted the work of this initiative. TEACCH and Duke have presented to professional colleagues in North Carolina and nationally.
- **Sustainability:** Membership in the Community-Academic-Provider group has grown over time and represents multiple stakeholders and thought leaders invested in Medicaid Transformation, systems change and reduction of health disparities. Recommendations and lessons learned have been shared with NC DHHS, Prepaid Health Plan managed care organizations, healthcare professionals, LME/MCOs, disability providers and advocates. 2020 activities will continue the focus on opportunities within the Standard AND Tailored Plans to incorporate ECHO and NC PAL into core services, clinical policies and resource allocation.
- **Oral Health:** Partnering with the Oral Health Section of the NC Division of Public Health to offer a series of regional workshops on "Improving Access to Dental Care for Children and Adults with I/DD."

Expected System Change as Result of Initiative

- Healthcare professionals will have increased knowledge and capacity to address the health and support needs of individuals with I/DD and their families.
- People with I/DD and their families will partner with healthcare professionals in decisions affecting their healthcare and disability services.
- Relevant health outcomes and measures will be identified and aligned with value-based payments and incentives.
- Sustainability plan that promotes expansion, scalability and adoption of consultation services and infrastructure by state health systems, managed care organizations, and insurance plans.