From Planning to Action:
Pilot Demonstrations Supporting Integrated, Collaborative Care for People with Intellectual and Developmental Disabilities

Year Three: 2019

(submitted February 2020)

Background

In 2013 the North Carolina Council on Developmental Disabilities (NCCDD) funded the "**Medical and Health Homes for People with Intellectual and Other Developmental Disabilities: Coordination, Collaboration and Community"** to develop recommendations for the management and delivery of primary health care services and long-term services and supports.

In 2016 the NCCDD funded "**From Planning to Action: Integrated, Collaborative Care for People with Intellectual and Developmental Disabilities"** to evaluate two demonstration pilots designed to improve the capacity of primary and community healthcare providers to care for children and adults with I/DD through consultative access to medical and clinical professionals with I/DD expertise.

This report summarizes key 2019 activities associated with NCCDD funding.
It is important to note that there were other activities and many partners engaged in this critical work. We are appreciative of everyone's contributions and support.

Partnership

The I/DD Medical Health Home Initiative (MHHI) is a partnership among The Arc of NC, Autism Society of NC and Easter Seals UCP NC that has advanced integrated care, innovation and access to quality healthcare for people with I/DD and their families. A core focus of the work over the past three years (2017 – 2019) has been to enable primary care providers to increase their knowledge and comfort level in caring for children and adults with I/DD and ASD within their medical practice.

Initiative Goals

- Ensure that state Medicaid Transformation and Standard and Tailored plans address the needs of people with I/DD and their families

- Identify best practices, models, and resources that promote person-centered collaborative care for people with I/DD

- Enhance the ability of primary care and other healthcare providers to address the health needs of patients with I/DD across the life course

- Increase the understanding of integrated care and medical homes by families, individuals with I/DD, and disability service providers

NC DHHS Medicaid Transformation Goals

"Improving the health and well-being of North Carolinians through an innovative, whole-person centered and well-coordinated system of care that addresses both medical and non-medical drivers of health."

Although Medicaid Managed Care is suspended at this time, there is still a unique opportunity to promote person-centered care, improve access and continuity of quality care, and develop collaborative systems of care for children and adults with intellectual and other developmental disabilities.

Partners are an Essential Element

The work of the I/DD Medical Health Home initiative is a result of collaboration with an array of partners across the state. A Community-Academic-Provider (CAP) Advisory was formed in 2013 to bring together the strengths, unique skills and perspectives of community members (individuals with a disability, family members, direct support staff, advocates), academic partners (faculty, students, and researchers), health care and disability providers, government officials, and policymakers. The CAP has supported the identification and advancement of policies and strategies that improve the health and quality of life for people with intellectual and other developmental disabilities.

Core principles are:

- Trust, respect, and genuineness
- Focus on strengths and assets
- Open communication
- Flexibility and compromise
- Shared resources and credit
- Commitment to develop an integrated system of care for people with intellectual and other developmental disabilities in North Carolina

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Evidence-based Consultation Models

Project ECHO: **Extension of Community Health Outcomes**
https://echo.unm.edu/
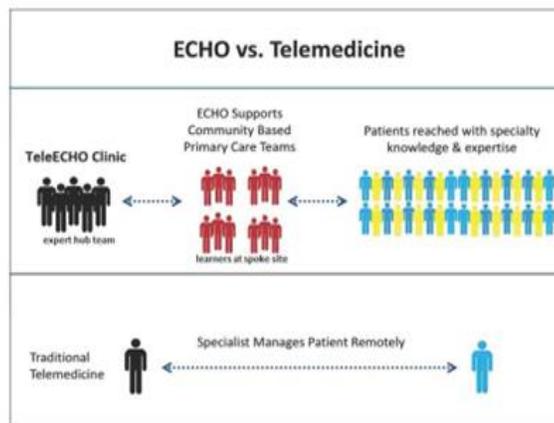
The goal of ECHO is to spread knowledge, expand capacity and accelerate collective wisdom. ECHO utilizes a hub and spokes model linking interdisciplinary teams of specialists (the hub) with primary care providers and other health and human service providers in multiple sites in the community (the spokes). Through tele-mentoring, ECHO creates access to high quality care in local communities. The experts serve as teachers and mentors who share their expertise in a virtual learning community.

Core elements of the EHCO model are:
- o Use of technology to leverage scarce resources
- o Sharing "best practices" to reduce disparities
- o Case-based learning to master complexity

ECHO format:
- o Didactic presentations and discussions of evidence-based practices
- o 1-2 in-depth case discussions led by participants
- o Consultation from the experts and group discussion
- o Follow up after the initial case discussion

Project ECHO has grown to address multiple health conditions and human service needs, such as opioids, Autism, and pain management. Today, Project ECHO operates more than 220 hubs for more than 100 diseases and conditions in more than 30 countries. Dr. Arora, ECHO founder, has stated "*collaboration is at the heart of ECHO*".

Strengths of the ECHO Model

- o Rapid dissemination of best practices and promising practices
- o Promotes consistency of care within the medical home
- o Providers can decrease their professional isolation
- o Patients can access quality care in their community
- o Addresses the needs of rural and low resources communities and providers

ECHO Logistics:

Project ECHO requires the lead organization to have completed ECHO Immersion training and have an approved organizational application and signed agreements. The Hub serves as the "home base" for the multidisciplinary team of subject matter experts. The Spokes are community participants recruited to participate in a topic-specific, often time -limited ECHO cohort. ECHO team roles include:

ECHO Coordinator/Administrator:

- o communicates with spokes before and after ECHO sessions,
- o requests case presentation review forms to ensure PHI and HIPAA information is removed before documentation is sent to ECHO participants prior to ECHO session,
- o takes notes during ECHO sessions, complies session summary, and identifies items needing follow-up,
- o assigns ECHO ID number to each spoke for evaluation, compiles evaluation information and related demographic information.

ECHO facilitator(s) ensures members are engaged, have an opportunity to share case presentations, ask questions, and contribute ideas. Keeps the ECHO session focused.

IT support staff ensures technology is working so hub members can focus on didactic presentations, case reviews, and group discussion. Provides support to hub and spokes re: equipment necessary to effectively participate in ECHO sessions.

Costs are dependent on hub staff composition. A "typical" EHCO meets twice a month for 6 months, for one-hour sessions. Time must be dedicated to planning activities, including curricula development, recruitment, and evaluation. Weekly sessions require an estimated 1 hour of preparation time, 1 hour of ECHO session time, and 1 hour of follow up time for selected members of the hub team.

TEACCH, UNC-CH: Increasing Access to Autism Spectrum Disorder Specialty Care in Rural North Carolina: A Project ECHO Pilot.

Many families receive treatment and care from primary care providers in their communities rather than specialty providers. Families in rural communities often experience greater delays in diagnosis and referral to appropriate treatment services.

The TEACCH Autism ECHO project was designed to:
- improve the quality of lifespan care received by individuals with autism spectrum disorder by increasing community providers' diagnostic screening and treatment of common medical and behavioral health comorbidities experienced by individuals with autism spectrum disorder (ASD)
- increase primary care providers' knowledge of ASD and I/DD resources and referral processes.

The Autism ECHO project is a partnership among the Autism Society of NC, Carolina Institute on Developmental Disabilities (CIDD) at UNC-CH, and Area Health Education Center (AHEC).

In 2018 and 2019 **five TEACCH Autism ECHO cohorts** were completed, enrolling **92 participants from 20 counties in Eastern North Carolina**: 31 medical providers (2 cohorts); 39 mental health providers (2 cohorts), and 22 military medical providers (1 cohort)

The TEACCH ECHO primary care curriculum topics were developed based on input from primary care providers and families.

What is Autism and While You Wait	Feeding Issues and Autism
Autism Screening (MCHAT) and Follow-Up	Sleep and Autism
Parent Support	What is an IEP
What is Applied Behavior Analysis (ABA) and Structured TEACCHing strategies	Anxiety, Autism: Differential Diagnosis & Medication Management
Resources- Local, State, Regional, and National	Transition to Adulthood
ADHD &Autism: Differential Diagnosis & Medication Management	Behavior from the ASD Perspective- Irritability, transitions, and sensory issues

Similar curricula topics were covered in the mental health and military Autism ECHOs.

Evaluation Findings: TEACCH Autism ECHO demonstrated:

- ✓ Improved ability to care for individuals with ASD.
- ✓ Increased MCHAT screening rates
- ✓ Connecting with peers and colleagues through Autism ECHO
- ✓ Greater confidence in working with patients with ASD
- ✓ Using Autism ECHO information with a patient and family
- ✓ Presentations and case-based learning are enhancing their knowledge about autism.

Changes in Provider Autism Knowledge

Bar chart titled "% Correct" by category Medical and Mental Health, comparing Pre (light blue) and Post (purple):
- Medical: Pre ~47, Post ~63
- Mental Health: Pre ~56, Post ~73
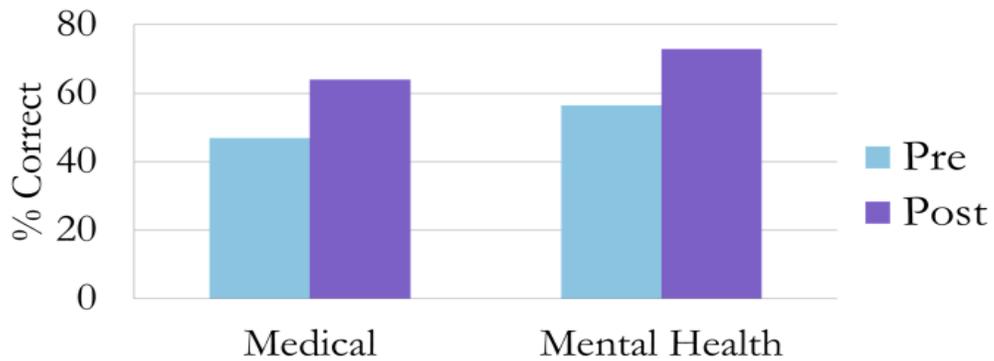
Changes in Screening for Autism at 18 & 24 Months
Modified Checklist for Autism in Toddlers (M-CHAT)

% of Screenings

Bar chart comparing Pre and Post:
- Pre: 56%
- Post: 90%
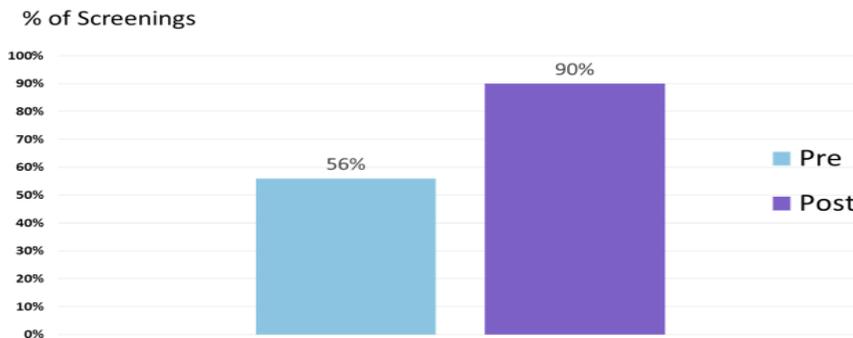
Medical Provider Self-Efficacy
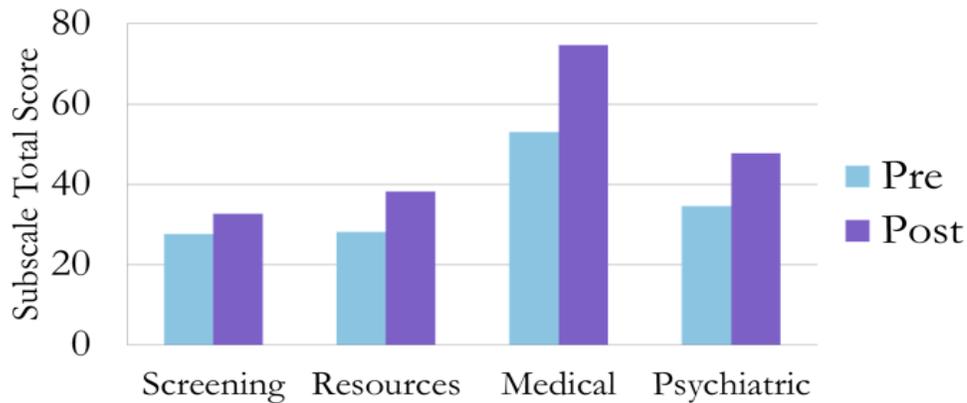
Medical Satisfaction Scores

Provider Satisfaction (5=strongly agree, 1=strongly disagree)	Medical (N=22) M	(SD)
Participation improved my ability	4.45	.60
I learned best practice	4.55	.51
I was able to connect with peers	4.5	.51
Specialists provided guidance	4.59	.50
I respected the professional advice I received	4.82	.39
The didactic presentations enhanced my knowledge	4.73	.46

Mental Health Satisfaction Scores

Provider Satisfaction (5=strongly agree, 1=strongly disagree)	Mental Health (N=24) M	(SD)
I learned best practice	4.63	.49
Specialists provided guidance	4.75	.44
I respected the professional advice I received	4.83	.38
The didactic presentations enhanced my knowledge	4.63	.58
I have been satisfied with the technology	4.83	.38
The technology functioned smoothly	4.75	.53

TEACCH Data Analysis

Data from the Carolina Data Warehouse for Health that encompasses the EPIC electronic medical record chart system from the UNC Healthcare System were matched to the same timeframe and I/DD diagnosis codes as the NC PAL I/DD chart review. The data encompassed 11,272 patients with 956,211 encounters. Summary analysis:

- 2,513 patients were assigned a diagnostic code for ASD.
- More males with ASD (77%: 23%) than females compared to individuals with IDD (53.7%: 46.3%).
- ASD group (M = 15.12 years) was significantly younger than I/DD group (M = 24.30 years).
- Individuals with ASD were more likely to have a diagnosis of anxiety (18.1%) than individuals with I/DD (11.8%)
- Individuals with ASD were more likely to have depression than individuals with I/DD, although rates were similar for both groups (8%)
- Individuals with ASD were more likely to have obesity than individuals with I/DD, although rates were similar for both groups (7%).
- Individuals with ASD (0.3%) were less likely to have heart disease than individuals with IDD (2.5%), controlling for age.

This is one of the first studies to use electronic health record data to compare health services utilization for children and adults diagnosed with ASD and I/DD. These findings can inform future research and provider education. Of note:
- Patients with ASD and patients with I/DD demonstrated different patterns of individual and health characteristics.
- Individuals with ASD were younger and had higher rates of anxiety, whereas individuals with I/DD had higher rates of heart disease.
- Despite having similar overall rates of obesity and depression, when controlling for age differences, individuals with ASD were more likely to have these diagnoses.

TEACCH Autism ECHO Participant Feedback:

"The most valuable aspect of this project was learning about the resources available for me and my patients. I've also enjoyed how there is a team giving their unique feedback based on different roles caring for the patient. This has helped me broaden my vision of the care required for best outcomes."

"I cannot speak highly enough of this opportunity, the ECHO Project service/technology, and the team of specialists who led this endeavor. I came in with basic, and largely limited, knowledge of how best to assess for and identify ASD and after having been a part of this program, have successfully identified ASD in several of my pediatric patients, which has lent way to linking they and their families with resources, support, and more extensive evaluative services."

"I know I feel that I better understand the "how's" and "whys" of the behavioral functioning of children with autism in addition to a greater level of understanding of the learning styles and how these impact the daily functioning of a person with autism. Additionally, I have gained a wealth of knowledge regarding interventions and approaches to interventions. This training is truly insightful, practical, and empowering. Hands down, this training is an effective use of time and is yielding fruitful results."

Follow-Up Evaluation

The TEACH Autism ECHO will be conducting follow-up surveys and interviews with participants of the 2018 and 2019 cohorts. Areas of focus include the impact of the TEACCH Autism ECHO on providers' ability to care for children with autism, knowledge of best practices, increased access to specialists, knowledge of resources, and increased confidence in ability to manage behavioral issues and medical problems in children with Autism. Participants will also be asked if they are interested in participating in another ECHO on Autism and EHCOs on other topics.

NC Family Support ECHO pilot

Families with loved ones with I/DD (including Autism Spectrum Disorder) often struggle to access comprehensive, updated information while navigating multiple complex systems in our state. In May 2019 nine individuals working in eight organizations attended the EHCO Immersion training, required of all programs interested in implementing an ECHO program. The specific aims of the Family Support ECHO are to:

- provide training and mentoring to those who provide family support services
- increase availability of quality family support services and
- develop a consistent and statewide approach to family support services.

The planning team represented The Arc of NC, Autism Society of NC, Mission Children's Hospital Family Support Network of Western NC, First in Families NC, TEACCH, Trillium Health LME MCO, and Vaya Health LME MCO. Over the next six months the planning team met to develop recruitment materials, didactic content, and evaluation surveys. Didactic topics were selected based on feedback from those providing family support services and other stakeholders. Topics include housing services and opportunities, accessing Medicaid services, guardianship, perspective of self-advocates, health and wellness, community resources, and self-care.

The Family Support ECHO pilot launched on January 15, 2020 and will run through June, 2020. Hub members from The Arc of NC, Autism Society of NC, Family Support Network of Western NC, and Vaya Health, are serving as hub members who share their expertise with a community of providers who support families across western North Carolina. Spokes: Recruitment was open to individuals who provide family support to children and adults with I/DD and ASD in western NC who would like to enhance their knowledge, expertise and connections as they help individuals of all ages with disabilities achieve their full potential.

ECHO Work Group

Dr. Arora, ECHO founder, has stated "*collaboration is at the heart of ECHO*". In this spirit, we have convened a time-limited work group to explore ways to enhance efforts in North Carolina to utilize ECHO to address an array of health, education, and human service needs. The goal for this work group is to build momentum and recommendations for an infrastructure that supports ECHO projects across our state. The strategy is to bring together key organizations and individuals engaged in the planning, implementation and evaluation of ECHO projects across our state.

Proposed Work Group Tasks:
- ➢ Map current and completed ECHO projects.
- ➢ Identify proposed and potential ECHO projects.
- ➢ Discuss IT needs and resources available.
- ➢ Discuss evaluation findings and tools.
- ➢ Discuss recruitment strategies and partners.
- ➢ Discuss finance strategies utilized in other states, such as Missouri, and explore options feasible for North Carolina.
- ➢ Develop summary report and recommendations for NC DHHS, MCO PHPs, LME MCOs, and other stakeholders.

Co-facilitators are Rebecca Knight, Senior Director of Operations, NC AHEC Program Office and Dr. Laura Klinger, Executive Director of TEACCH and Associate Professor of Psychiatry, UNC School of Medicine. Members represent NC DHHS (Office of Rural Health, Division of MHDDSAS, Medical Assistance), Pre-Paid health Plans, LME MCO, healthcare professional associations, AHEC, academic programs, and disability providers.

Growth Opportunities for ECHO implementation:

- o Continued implementation and evaluation of ECHO cohorts with the support of diverse payors: NC DHHS, Prepaid Health Plans awarded the Standard Plans, LME MCOS, Tailored Plans, foundations, and grant funders
- o Continued collaboration with the national Autism ECHO collaborative
- o Utilizing the ECHO model to address new topics, including family support, education, TBI, care managers, and crisis services
- o Convening an ECHO work group to explore sustainability and statewide infrastructure.
- o National recognition and support: The American Medical Association has pointed to Project ECHO as an example of a promising strategy used to improve care. The AMA has also expressed its support to CMS for healthcare payers to offer additional payment or incentive payments for physicians who participate in clinical practice improvement activities, such as Project ECHO and the MCPAP.

Evidence-based Consultation Models

Massachusetts Child Psychiatry Access Program (MCPAP) model
www.mcpap.com

The Massachusetts Child Psychiatry Access Program (MCPAP) is a system of regional children's behavioral health consultation teams designed to help primary care providers and their practices to promote and manage the behavioral health of their pediatric patients as a fundamental component of overall health and wellness. MCPAP supports the integration of behavioral and physical health. Teams are available to consult with behavioral health clinicians working in primary care setting as well as the primary care provider and other members of the primary care team.

The Massachusetts teams are staffed with two full-time child and adolescent psychiatrists, independently licensed behavioral health clinicians, resource and referral specialists, and program coordinators. Through consultation and education MCPAP improves the pediatric team's competencies and comfort with:

- screening, identification and assessment,
- treating mild to moderate cases of behavioral health disorders according to current evidence-based practices, and in
- making effective referrals and coordinating care for patients who need community-based specialty behavioral health services.

Evaluation has documented that pediatricians have developed increased knowledge and comfort in treating mental health conditions, and the prescription of psychotropic medications has decreased. At the start of MCPAP, 8% of pediatricians thought they could meet the psychiatric needs of their patients. After a few years 63% of those enrolled in MCPAP felt they could meet these needs. MCPAP now has 95% of pediatric providers enrolled in their services. Funding from state Medicaid and a required per member per month contribution from commercial health plans covers 1.5 million kids with 6 teams.
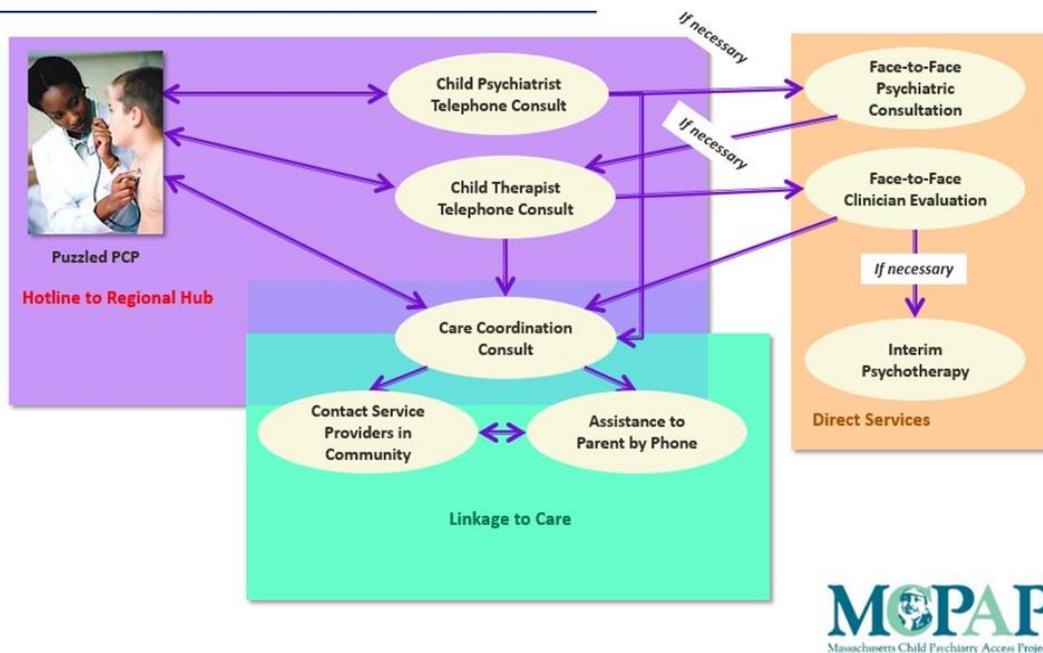
Strengths

- Utilization among physicians increased over time (both the volume of participants and repeat calls from individual providers).

- Two outcomes of significance noted were increased complexity of questions showing capacity and willingness to care for more complicated patients AND reduction in specialty system utilization as patients were increasingly served in primary care settings.

- Physician participants stated that the medical provider-to-provider consultation assisted in the delivery of highly technical information quickly and made them more likely to use and trust the resource.

- Ability to support physicians and patients without opening an official medical file reduced administrative burden, duplicative files, and cost.

- Knowledge translation was most successful when "experts" answering calls had worked in and felt passionate about community-based care.

- Development of the National Network of Child Psychiatry Access Programs that works to further national progress toward effective integration of mental health with primary care. https://nncpap.org/

Duke University: Primary Care Pediatric Telephone Consultation for Children and Youth with Intellectual and Developmental Disability (NC PAL I/DD)

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 living in the community. NC PAL I/DD piloted the MCPAP model with

two primary practice networks: Duke's Children's Pediatric Primary Care that serves approximately 25,000 children primarily in Durham, Wake, and Orange counties and the UNC Complex Care Pediatric Service that serves several hundred children with complex medical needs, including many children with I/DD. The core team consists of Duke Integrated Pediatric Mental Health, UNC General Pediatrics, UNC Carolina Institute for DD, and NC START Central. Partners include Duke and UNC pediatric practices and providers, Alliance and Cardinal Innovations LME MCOs, Autism Society of NC, community agencies, self-advocates and families.

Case Finding and Chart Review

NC PAL I/DD identified the need to provide proactive outreach to primary care practices and providers, and not just react or respond when an individual patient is in crisis or distress. To facilitate this proactive process Duke conducted an extensive review of more than 498 charts meeting study criteria of intellectual and developmental disability diagnosis and assignment to the Durham Pediatric Clinic in 2017.

Case Findings of Note

- Most of the patients are between the ages of 3 and 21
- 76% have been seen at primary care practice within last 6 months
- 60% are on Medicaid
- 67% have Autism Spectrum Disorder (ASD) diagnosis
- 27 % have an intellectual disability diagnosis
- 2 of the most frequent Mental Health diagnosis are AHDH (32%) and anxiety (17%)
- **69% have never been screened for IDD service eligibility**
- **Only 10% are receiving Innovations Waiver services**
- **Only 11% are on the registry of unmet needs**.

Case Finding

	N	%
I/DD and related diagnosis (pts may have more than 1 diagnosis)		
ID	91	18
ASD	344	60
Congenital/chromosomal	91	18
Down's syndrome	48	10
Other	92	18
Mental Health Diagnosis (pts may have more than 1 dx)	155	31
ADHD	80	16
Anxiety		
Sleep/Wake disorder	65	13
Disruptive, Impulsive, Conduct d/o	38	8
Eating disorder	20	4
Adjustment disorder	20	4
Depressive	18	4
Mood	18	4
Trauma/stress related d/o	14	3
CAP-C	Yes: 19 No: 479	4 96
Seizures	Yes: 50 No: 433 Historically: 15	10 87 3
Engaged in Behavioral Health – Mental Health Services	Yes: 212 No: 286	43 57
Engaged in Behavioral Therapy	Yes: 87 No: 411	17 83
Engaged in Medication Management	Yes: 182 No: 316	37 63
Innovations Waiver		
Never screened	346	69
Screened, not on Registry of unmet needs	30	5
On Registry of unmet needs	55	11
Enrolled in Innovations Waiver	49	10
Unknown	18	4
Behaviors in last 6 months	Yes: 202 No: 296	41 59
Category of Behaviors		
Tantrums	129	25
Aggression	109	23
Impulsivity	90	18
Self-injurious behavior	44	9
Property destruction	18	4
Wondering/elopement	20	4

Primary Medical Diagnosis:

Adrenal insufficiency, allergic rhinitis, Angelman Syndrome, anoxic brain damage, asthma, blindness, brain tumor, bronchomalacia, cardiac dysrhythmia, cerebral palsy, chronic kidney disease, congenital heart disease, Crohn's disease, deafness, Dravet syndrome, dysphagia, encephalopathy, epilepsy, fetal alcohol syndrome, GERD, Graves' disease, Hirschprungs' disease, hypertension, hypopituitarism, hypothyroidism, microcephaly, migraine, obesity, panhypopituitarism, Peters plus syndrome, Pompe's disease, prediabetes, pre-hypertension, seizure disorder, septo-optic dysplasia, short stature, spastic quadriplegia, spina bifida, static encephalopathy, paroxysmal supraventricular tachycardia, thyroiditis, tuberous sclerosis and visual impairment.

NC PAL I/DD call line was launched in May 2018. As anticipated, initially there were a limited number of calls, and most of the requests for consultation came through EHR (electronic health record) messaging and face to face contacts. Many of the calls focused on a need for case/care management, systems navigation, resource linkage and referrals. Over time the number of calls increased. Below is a summary of the consultation requests:

Reactive Consultation Summary (May 2018 through December 2019)
Number of Unique Contacts: 95
Age Ranges   • 3-5 y.o. --- 17   • 6-10 y.o.--- 33   • 11-13 y.o.--- 15   • 14-17 y.o.--- 13   • 18+ y.o.--- 17   •
Resource Needs   • I/DD Services (including NC START, respite) --- 72   • Testing/Educational advocacy-- 18   • MH Services --- 51   • Guardianship Information --- 5   • Medication Consultation --- 1   •
Providers' Method of Reaching Out   • Calls --- 9   • Message (in-basket or email) --- 50   • MH Referral -- 41   • Face-to-face --- 13   •

Reactive and Proactive Strategies

NC PAL I/DD identified the need to provide proactive outreach to primary care practices and providers, and not just react or respond when an individual patient is in crisis or distress. To develop a robust consultative service for the I/DD population, it is necessary

to have BOTH reactive telephone consultation to provide information to parents and providers in real time <u>AND</u> proactive strategies to support individuals with I/DD, including case finding, needs identification and outreach.

NC PAL I/DD has also emphasized the importance of family support and the role of a family partner (family member with experience raising a child with a disability) who can provide resource assistance, emotional support, encouragement, and systems navigation. Common requests made by families are the need for respite, questions about how to apply for Innovation Waiver services, how to access Applied Behavior Analysis (ABA) services, medical insurance, educational supports, guardianship, and transition.

NC PAL User Feedback Survey

Statement	Response	Response	Response
My comfort level for treating children and youth with mental health conditions increased after the consultation	**9/22** Strongly Agree	**9/22** Agree	**4/22** Neutral
Participation in the DUKE NC-PAL consultation program improved my ability to care for persons with mental health conditions in my practice	**15/16** Improved My Ability		**1/16** Neutral
Did your interaction with DUKE NC-PAL reduce any patient's immediate need for a mental health specialist or higher level of care such as needing an ambulance, an emergency room or to need to see a child psychiatrist immediately	**12/20** Reduced Immediate Need		
Overall, how satisfied are you with the DUKE/NC-PAL program	**19/22** Very Satisfied	**3/22** Satisfied	

"*A lot of the phone calls received are "Things are bad right now. Can you help us?"*

"We're deciding if they need to go to an emergency department."

NC PAL I/DD developed an **I/DD Resource Guide** in response to the many questions that primary care providers and community partners had about services available to children and adults with I/DD and their families.

The Table of Contents covers:

- LME MCO structure

- Accessing services and supports including Medicaid, SSI, IDD services, and services available outside of Medicaid

- Psychological Testing & Special Education

- Guardianship & Alternatives to Guardianship

- Residential Living Arrangements and

- Appendices.
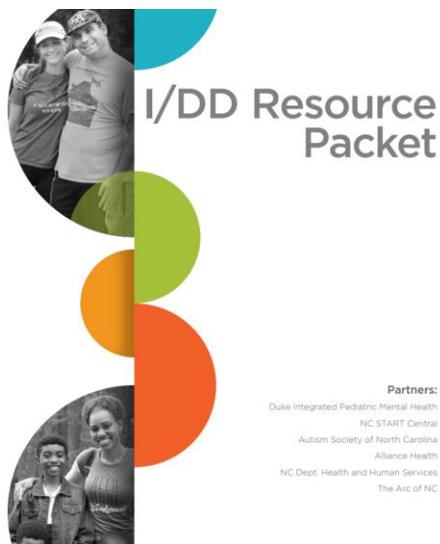
Contributing partners were Duke Integrated Mental Health, NC START Central, Autism Society of NC, The Arc of NC, Alliance Health LME MCO, and NC DHHS.

Evolution of NC PAL I/DD:

The project developed a robust model that blended reactive consultation with other proactive approaches:

- Reactive telephone consultation for physician to physician support

- Reactive in-person, telephone or electronic care coordination support

- Family Partners and Family Support

- Case identification and

- Proactive Outreach

North Carolina Tele-health Partnership: Child and Adolescent Psychiatry Access (NCTP-CAPA)

North Carolina is one of 18 states to receive a 5-year Health Resources and Services Administration (HRSA) grant to scale the MCPAP telephone/telehealth consultation statewide to address pediatric behavioral health. The lead applicant is the NC DHHS, Division of Public Health. Partners include Duke University and Community Care of NC (CCNC). The plan is to expand the NC PAL program telephone consultation to reach statewide penetration by year five. This grant provides another opportunity to sustain and expand the work of NC PAL I/DD and promote the intentional inclusion of the needs of children and adolescents with I/DD in statewide efforts to address integrated care. The state also received a second HRSA grant addressing maternal depression. The lead applicant is the NC DHHS, Division of Public Health, in partnership with UNC-CH and Duke University. Of note is that only three states received both HRSA consultation grants. These multi-year awards provide the opportunity to expand the implementation and evaluation of telephone consultation services, address the educational needs of primary care providers, and promote the inclusion of children and adults with I/DD in target patient populations.

Evaluation

Interviews with TEACCH, Duke, and UNC CIDD team members engaged with Autism ECHO and NC PAL I/DD: (abbreviated highlights)

The external evaluation team conducted ten interviews with members of the DUKE NC PAL and TEACCH Autism ECHO projects. Interviews consisted of fifteen prepared questions about the planning and development process, lessons learned, benefits, obstacles encountered, data and sustainability.

TEACCH Autism ECHO

Planning: The first primary care cohort launched in 2018 took the time to talk with parents and providers to identify the needed didactic content area that would be most

important for providers in rural eastern NC.

Recruitment: It is important to be mindful of the many time demands placed on primary care providers and to be thoughtful about how their time constraints may impact participation. One significant incentive for primary care was the opportunity to acquire Maintenance of Certification (MOCs) through the partnership with AHEC. Recruitment does require some "hands-on activity": an in-person meeting with a brief introduction to Autism ECHO program, explanation of how ECHO can benefit providers, and sharing feedback from previous participants. An informational meeting combined with emails, phone calls, and flyers is necessary. Recruiting multiple team members within a primary care practice can amplify the impact.

ECHO format: Securing case presentations in the primary care cohorts was sometimes a challenge, in contrast to ease of enlisting the mental health participants to present case reviews. TEACCH did individual outreach to encourage spoke participants to sign up for case presentations and to assist them with their case preparation.

Resources Challenges: Many participants did not know how or where to find ASD and I/DD community resources. TEACCH developed county resource guides that providers could make notes on and share directly with families. The providers liked having something to physically share with families that emphasized topics they had discussed. The Autism Society of NC shared several of their toolkits and resources.

Follow-Up: The TEACCH hub team thinks follow-up and periodic support is helpful to reinforce the EHCO learning. They have invited NC PAL staff to attend the last session of an ECHO series to introduce NC PAL and encourage ECHO participants to utilize this consultation service.

Benefits: Having access to experts that participants would not otherwise be able to consult with is valued. Sharing resources has been especially beneficial to rural providers.

Sustainability: There needs to be a funding mechanism available since there is currently no billing code that allows physicians to bill for their time when attending ECHO meetings. Currently, consultation billing can only be done when the consultation is connected to a specific patient. Of note is that a few states have utilized Medicaid funds to support ECHO.

Duke NC PAL I/DD

Planning: It is important to spend time learning about the communities to be served: providers, community leaders, available resources, and social determinants of health that families encounter. This understanding informs the development and implementation of the model to best serve North Carolina populations and communities.

Electronic Medical Records (EMR): Project staff needed to spend time getting EMR systems to be able to document and capture encounters and information resulting from NC PAL. Other core team activities conducted during the planning phase included outreach to potential partners and practices and internal communications between all parties involved, including Duke Health leadership.

Model Adaptations: NC PAL surveyed providers and learned that they usually did not need an immediate return call and, in many cases, would be better to call NC PAL back at the end of their business day.

Provider engagement and pro-active outreach: It is difficult for primary care providers to find time in their schedules to review their patient caseloads and identify patients that could benefit from NC PAL services. So, NC Pal took a pro-active approach and went to practices, reviewed caseloads and identified potential I/DD cases. The resource consultant would then follow up with the PCP and assist them with patient and family

outreach. Although this deviates from the MCPAP model and fits more with Collaborative Care Model and use of a patient registry, it clearly addresses North Carolina needs. "At different stages it was reframing. What we learned most clearly is that consultation needs to be paired with proactive strategies."

Sustainability: "When we first started rolling this out, telephone consultation to a provider was not a billable service. Our EMR system is based on billable services, so we had to create our own billing code. As this program went on, the billing code changed. Now we have someone in the billing department that can track these encounters better. One of the interesting things is finding out how much work goes into these things that you think should be easy."

Resources: It is important to have key contacts at organizations and agencies as this linkage can help to streamline referral process and minimize the time it takes to resolve issues and receive answers. This has become particularly important since there has been a need for more case management and system navigation assistance than was originally anticipated.

Benefits: Having tiered psychiatric support. Connecting with and building relationships with MCO's, NC START, and other major players. Having contacts at these organizations facilitates quicker communications for information and problem solving. Being able to educate providers about existing resources. *"I have been able to amplify the scope of my own practice and avoid a whole lot of referrals that I would have had to make in the past by having pretty direct access to a pair of child psychiatrists with the expertise that they can lend to my care that can amplify the scope of care that I can provide as a general practitioner*."

Lessons Learned: The project team had to adapt their expectations of the amount of staff time and resources this program requires, given there has been a much larger need for case management and contact with families than initially anticipated.

It is critical that the medical home determine if a patient is receiving needed I/DD and other services or has ever been screened for eligibility by the LME-MCO.

Barriers and Challenges: Communication across institutions, organizations, and providers (adhering to HIPAA and overcoming technological hurdles of sharing information between different EMR systems). "*Families have so many hurdles and often get discouraged. This is a very hands-on process and is very time intensive*."

Case finding: Finding a way to identify current patients. Currently only able to identify patients retrospectively. Working to shift paradigm of working in silos (many providers have been trained in this perspective) to working in more integrated settings. Education on validity and value in providing care for this population. Reducing stigma with issues surrounding mental health and helping providers to be more comfortable talking about these things with their patients and families. Working within the changing Medicaid system. "*How do we identify and wrap our hands around patients who you normally wouldn't find, who are just under the radar*."

Sustainability: A dedicated phone number with open access is a resource intensive and expensive undertaking that will require significant commitments for funding organizations such as the state Medicaid program, MCO's, and private insurance. This reality was considered when looking at other state models, as well as how to adapt these models to meet the needs of a diverse population in our state. Although North Carolina has some large urban centers, it is the second most rural state among the ten most populated states.

2019 Summit

Pathways to Innovation, Integrated Care and Sustainability: what we are learning from North Carolina consultation projects and partnerships was held on May 23, at the McKimmon Center in Raleigh. It was attended by more than 80 people representing individuals with I/DD, families, DD providers, researchers, healthcare providers, state government, and advocates.

Agenda

9:00 am	**Welcome and Opening Remarks**
	Kody Kinsley, Deputy Secretary, Behavioral Health and I/DD, NC DHHS
	Kerri Eaker, NC Council on Developmental Disabilities
	Karen Luken
9:30am	**The Promise of Health Reform for Children and Adults with Disabilities and Next Steps**. Dr. Kathleen Thomas

Consultation Demonstrations

10:15 am	**Project ECHO Autism: Building Capacity for Integrated Healthcare Services for Individuals with Autism Spectrum Disorder in NC.** Dr**.** Laura Klinger and Kevin Fitzgerald
11am	Break
11:15 am	**Supporting the Medical Home for Children and Young Adults with Intellectual/Developmental Disability**. Dr. Gary Maslow
12 pm	**Morning Summary and Group Discussion**
12:30– 1:15 pm	Lunch onsite, networking, group discussion

North Carolina Perspectives

1:15 – 2:00 pm	**DD Plus: An Interdisciplinary Learning Collaborative to Improve Rural Primary Care for Children with Complex Needs**
	Christine Malloy and Kerri Eaker
	Introducing the WNC Adult I/DD Assessment Clinic
	Dr. Rebecca Thomson, Dr. Krista Brinkeroff, Nina Vinson
2:00 – 3:00 pm	**Panel: What This Means for North Carolina. Facilitated Q and A**
	Dr. Courtney Cantrell, Tara Larson, Dr. Rob Christian, Andrew Clendenin, Mya Lewis
3:00 – 3:30 pm	**North Carolina's Next Steps**
3:30 pm	**Conclusion and Wrap Up**

2019 Summit Evaluation Feedback

Structure: appreciated the opportunity to meet others and have time to network; conference size was small enough to hear everything with no concerns about missing anything.

- o *"Really amazing opportunity to be in a room with so much passion and expertise. Loved hearing what was happening around the state. "*

Speakers: Praise for quality of speakers, presentations and hearing what is happening across multiple projects.

- o *"I enjoyed hearing about the great projects that are being incorporated throughout the state. I also thought it was great to have people there from all walks of life and professions and you can see multiple sides to the story."*

Learning Opportunity: strong endorsement of the opportunity for in-depth learning and sharing and the emphasis on processes, results and the stories of the presenters.

- o *We can learn from each other what works and doesn't work, so we can replicate and/or avoid processes when designing delivery systems.*
- o *It was refreshing to be with others that are working together for a common good instead of discussing how to comply with thousands of rules and regulations. I walked away with actionable ideas to implement into service delivery models.*
- o *Better understanding of the concepts of integrated care. Will be key in implementation strategies. I knew where the IDD/BH providers where in their understanding but now have a better understanding of where the Physical health side really is. The AMH implementation is going to need assistance.*
- o *Learned more about what it will take to offer integrated care in our state to individuals with I/DD and the need to focus on the collaboration between the PCP and the I/DD providers.*

- *Info on expenses for families of children with IDD; the lack of MDs specializing in DD is a concern and we have a lot of work to do to spread info on IDD Services.*

Plan of Action: what will you do differently now?

- *Structure data collection and quality improvement more rigorously*
- *Consider a diverse array of ways to support families and coordinate care (family navigators, community health workers, LCSW and RN led care management teams, etc.).*
- *I have already engaged our LTSS care management staff to discuss how to include the missing education on IDD resources in primary care and in care manager training; it was great to hear where we could help!*
- *I am going to re-think how we attempt to connect folks to primary care and specialty care.*
- *Enhanced training for staff when serving the families that they understand the importance of culture when coordinating services for family and having conversations.*
- *Interested in working to develop a family mentoring program*

Sustainability Suggestions

- *Another summit with payors, including people from others states who have made it work.*
- *Continue sharing the models that are working and how they evolved.*
- *Would be great if each of the innovation teams could develop and share an implementation guide or toolkit based on their experiences.*
- *Develop a collaborative proposal for melding the best of NC PAL and ECHO and other models and present a least common denominator basic plan to the state and ask that it be "baked in" to policy and adequately funded. Should be payer agnostic but aligned with care management protocols and systems, eg. consultation support system and learning collaborative facilitated through AHEC*

system or similar neutral body. Engages primary care, care management providers, payers, others.

- *Host a summit annually*

NC Dept. of HHS

- *Getting discussion with the Dept. of HHS to have them pull down the federal share for offsetting cost of the technical assistance. I think this would fall well into what Medicaid can fund and the 1115 transition activities.*
- *Medical providers are seeing the value of Project ECHO, and TEACCH said they are learning things that can be applied to support many other diagnoses. Will DHHS or another entity see this value and want to continue to fund Project ECHO cohorts beyond NCCDD's grant?*
- *I think knowing if/how specifically DHHS and other state agencies are interested in this work and assign priority to it would go a long way towards helping systems make changes.*

Primary Care and Advanced Medical Homes

- *Tie into Medicaid Transformation overall readiness for primary care. Tie into PCMH responsibilities for primary care. Use this interest to build bridges between primary care and LME/MCOs and PHPs, NOW.*
- *Use this interest to educate primary care about family and patient advocacy, which is robust in IDD, less robust in medical realms. Tie into other initiatives on patient advocacy and shared decision making.*
- *Family support/ navigator expansion sounds like an excellent thing to get behind.*
- *Lots of important pieces to consider for Tailored Plans and Care Management; feedback from lots of stakeholders and especially those involved in the summit are important.*

Outreach and Education

The initiative developed a website as another means of disseminating information to multiple audiences. http://www.iddmedicalhealthhomencinitiative.com/.

2019 Presentations:

- *Promoting Person-Centered Care within an Inclusive, Integrated System of Care for People with Developmental Disabilities*. Georgia Learning Collaborative for DD, December 2019.

- *Improving the Oral Health of People with Intellectual and Developmental Disabilities*, North Carolina Council on Developmental Disabilities, November 2019.

- *Supporting Integrated Care for People with Intellectual and Developmental Disabilities: Opportunities for Impact within the Tailored Plan,* NC DHHS Chief Medical Officers of the LME MCOs, November 2019.

- *Meeting the Oral Health Needs of Diverse Populations,* NC Community Health Center Association meeting of the dental directors, November 2019.

- *Jazz It Up! Building on Our Potential,* National Association of Council on Developmental Disabilities, New Orleans, July 2019.

- *The Role of Person-Centered Principles and Practice in Promoting Health and Life Long Integrated Care*, Turning Point Services annual staff meeting, Morganton, NC, June 2019.

- *Providing Integrated Health Supports to Children with Intellectual and Developmental Disabilities and Their Families*, NC START conference, Raleigh, NC, April 2019.

- *Building a Person-Centered and Integrated System of Care for People with Intellectual and Developmental Disabilities*, Eastern AHEC Developmental Disabilities Conference, Greenville NC, March 2019.

- *Understanding and Supporting Autism in the Early Years*, *TEACCH Autism ECHO project,* 39th TEACCH Autism Program Conference, Chapel Hill, NC, October 2019.

The **North Carolina Academy of Family Physicians** published the article "Innovations Support Family Physicians Caring for the Intellectually and Developmentally Disabled" in their 2019 summer magazine that was distributed to over 4,000 members. The article highlights four projects supporting family medicine physicians and residents to meet the healthcare needs of children and adults with intellectual and other developmental disabilities: DD Plus, TEACCH Autism ECHO, NC PAL I/DD and MAHEC I/DD clinic.

https://issuu.com/ncafp1/docs/ncfpv15n3-web-final, pages 28- 30.

Leveraging Funds and Partnerships and Opportunities

In addition to the funds provided by the NCCDD, the I/DD Medical Health Home initiative has received support from other funders:

> **2017**: NCCDD, NC DHHS, Vaya Health LME MCO, Alliance Health LME MCO, NC Oral Health Collaborative
> **2018:** NCCDD; NC DHHS, Vaya Health LME MCO
> **2019:** NCCDD; NC DHHS, Vaya Health LME MCO, NC Division of Public Health, Oral Health Section

Opportunities for Impact Moving Forward within Medicaid Transformation: Standard and Tailored Plans

We know there is huge variation in the availability of I/DD expertise within the healthcare system. Primary care providers often have had limited training in I/DD, especially in the care of adults. Medicaid Transformation is an opportunity to:

- Increase primary care providers knowledge, skills, and confidence to care for children and adults in the medical home
- Support Advanced Medical Homes to provide accessible, comprehensive, high quality care to children and adults with I/DD and their families

- Promote appropriate utilization of specialists

- Decrease use of Emergency Departments for non-urgent use

- Management of multiple chronic health conditions

- Address health issues for individuals on the Registry of Unmet Needs

- Reduce polypharmacy

- Enhance family support

The NC DHHS "Behavioral Health and Intellectual/Developmental Disability Tailored

Plan: Tailored Care Management Provider Manual" states:

"3.2. Clinical consultants. The BH I/DD Tailored Plan will be required to ensure that organizations providing Tailored Care Management (AMH+ practices, CMAs or the BH I/DD Tailored Plan itself) have **access to clinical consultants** in order to access expert support appropriate for the needs of the panel under Tailored Care Management. **Clinical consultants are not part of the care team for any given member; rather, the role of clinical consultants is to provide subject matter expert advice to the care team.** The consultants must be contracted by the AMH+, CMA, or CIN and should be available by phone to staff within AMH+ practices and CMAs to advise on complex clinical issues on an ad hoc basis. …….. AMH+ practices and CMAs may demonstrate that they have access to clinical consultants themselves or can contract with other provider organizations to arrange access. The PMPM rate for Tailored Care Management will take these costs into consideration. **"**   *(page 17)*

Sustainability Work Group

Following the September 2019 meeting of the Community-Academic-Provider advisory

group we have convened a work group to continue the discussion of lessons learned

from TEACCH Autism ECHO, Duke NC Pal, and other partners that can be aligned

with Medicaid Managed Care implementation within the Standard and Tailored Plans.

Members include the five Pre-Paid Health Plans awarded the Standard Plan contracts,

DHHS leadership, NC PAL, and DD providers.

The Medical Home has a critical role in the implementation of integrated care and Medicaid Managed Care.

> "The medical home has to pay attention to patients' lives outside of the narrow window of their medical condition and offices must be serve as a facilitator of community connection and engagement. The medical home must work to ensure that each individual with an intellectual or developmental disability is connected to ALL of the systems that they need and to ensure that these systems are working in concert."

> Dr. Gary Maslow, MD, MPH, Duke Integrated Mental Health

Systems Coordination is Required Across Multiple Sectors, Services and Organizations

SYSTEM	NEEDS	STATUS	PLAN
Medical	Primary care Specialist care Hospital care Medications Treatments Therapies		
Educational	IEP Transition Supports		
I/DD and Behavioral Health	Innovation Waiver B3 Registry of Unmet Needs START Behavioral Health		
Community	Vocational Rehabilitation Community programs Peer supports Family supports Natural supports		

Lessons Learned and Recommendations

➢ Both TEACCH and Duke consultation projects have evolved to meet North Carolina's needs and address gaps and needs in our unique system.

➢ Both programs have identified the need for a consistent and comprehensive focus on care management, systems navigation and family support.

- Sustainability and efficacy require linkage between consultation, navigation, family support, and a robust care management network.
- Data-supported decision making is critical on both a practice and systems level.
- For Standard Plans and Tailored Plans, it will be critical to bring case finding resources to primary care practices to support the medical home.

As North Carolina progresses with Medicaid Transformation it is critical that North Carolina implement a **responsive, robust and multi-faceted approach to integrated care.** This requires a commitment to multiple principles and elements:

- ❖ A blended consultation and education infrastructure will better meet the needs of primary care, healthcare specialties and disability providers.

- ❖ Individuals with I/DD are part of every health system and health plan; thus, ALL health plans should utilize case finding, consultation, education, navigation and family support services.

- ❖ Optimal health and connection to services and supports (both I/DD-specific and more general social determinants) are the building blocks to achieving quality of life, maximum independence, community living, and meaningful employment.

- ❖ Successful implementation of Medicaid Transformation requires a dynamic process: stakeholder engagement and input → demonstration projects: implementation and evaluation → data-informed adjustments → sustainability and scalability supported with policies and resources.

- ❖ Continuous efforts to identify evidence-based practices and emerging models that promote person-centered collaborative care for people with I/DD across the life course.

The NC Council on Developmental Disabilities has played a critical role in improving the opportunities and lives of North Carolinians with I/DD through advocacy, capacity building, and systems change. This leadership and investment will continue to be essential in future years.

This report summarizes key 2019 activities associated with NCCDD funding. It is important to note that there were other activities and many partners engaged in this critical work. We are appreciative of everyone's contributions and support.

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MEDICAL HEALTH HOMES
Promoting Integrated, Person-Centered Care for People with Intellectual & Developmental Disabilities

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