

# **Connecting Expertise to Communities to Support Comprehensive Care for People with I/DD: Building on North Carolina's Assets**

June 2020

# Objectives

- ▶ Identify core elements of evidence-based models that improve knowledge and skills of healthcare professionals to care for people with I/DD and ASD
- ▶ Identify current opportunities for providers, payors, and policy makers to promote integrated care for people with I/DD and ASD
- ▶ Outline a plan that emphasizes collaborative strategies that align with Medicaid Managed Care

# Agenda

- ▶ Background
- ▶ TEACCH Autism ECHO: Teleconsultation with a focus on professional development and education
- ▶ Duke NC Psychiatry Access Line: Telephone consultation focused on direct patient care needs, provider education, and proactive case finding
- ▶ CIDD Complex Care Consultation: Combining telehealth, consultation, direct patient care needs and longer-term connections
- ▶ Wrap Up

# Background

- ▶ In 2013 the NC Council on Developmental Disabilities 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 implement 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.
- ▶ **Medicaid Transformation** provides a critical unique opportunity to promote person-centered care, improve access and continuity of quality care, and develop collaborative systems of care for people with I/DD and their families.

# Investing in Primary Care

- ▶ 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. These projects were intended to:
  - ▶ Increase primary care providers knowledge, skills, and confidence to care for children and adults in their medical home
  - ▶ Support 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
  - ▶ Promote best practices in the management of multiple chronic health conditions
  - ▶ Reduce polypharmacy
  - ▶ Enhance family support

“A strong and robust primary care delivery system is an essential source of coordinated, comprehensive, and patient-centered care and is the only health care service positively associated with both improved and more equitable health outcomes.”

“Investing in Whole Person Health: Working Toward an Integration of Physical, Behavioral, and Social Health”  
NC Medical Journal, May 2020, 81 (3) 177-180.

# Presenters

- ▶ **Dr. Laura Klinger**, PhD, Executive Director, TEACCH, UNC-CH, Associate Professor, Department of Psychiatry, UNC School of Medicine
- ▶ **Dr. Gary Maslow**, MD, MPH, Assistant Professor of Psychiatry and Behavioral Sciences, Co-Director of Child and Family Mental Health and Developmental Neurosciences, Assistant Professor of Pediatrics, Duke University School of Medicine
- ▶ **Dr. Rob Christian**, MD, FAAP, Assistant Professor of Psychiatry and Pediatrics, Carolina Institute for Developmental Disabilities, UNC-Chapel Hill
- ▶ **Kerri Erb**, Chief Program Officer, Autism Society of NC
- ▶ **Karen Luken**, Disability and Health Consultant

# A Few Key Points of Emphasis

- ▶ Each model and service is in use and has the potential to be expanded
- ▶ Each model utilizes technology to increase access to I/DD and ASD expertise
- ▶ Family support and systems navigation is a critical element in each model
- ▶ Integrated care demands both reactive AND proactive approaches to consultation, education, case-finding, and family support
- ▶ NO single consultation or education model is sufficient: the needs and resources of individuals with I/DD, families, and providers vary across the state and over time
- ▶ These models are applicable to Medicaid members who will be in Standard Plans and Tailored Plans, and individuals who have other health insurance plans
- ▶ Individuals with I/DD are and will be a part of every health system



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# Project ECHO Autism: Connecting Expertise to Communities to Support Comprehensive Care



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**TEACCH**<sup>®</sup>

Autism Program  
*Services Across the Lifespan*

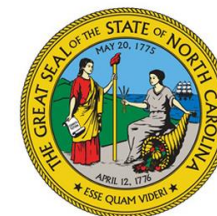
Laura Grofer Klinger

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**NCCDD**  
North Carolina Council on  
Developmental Disabilities



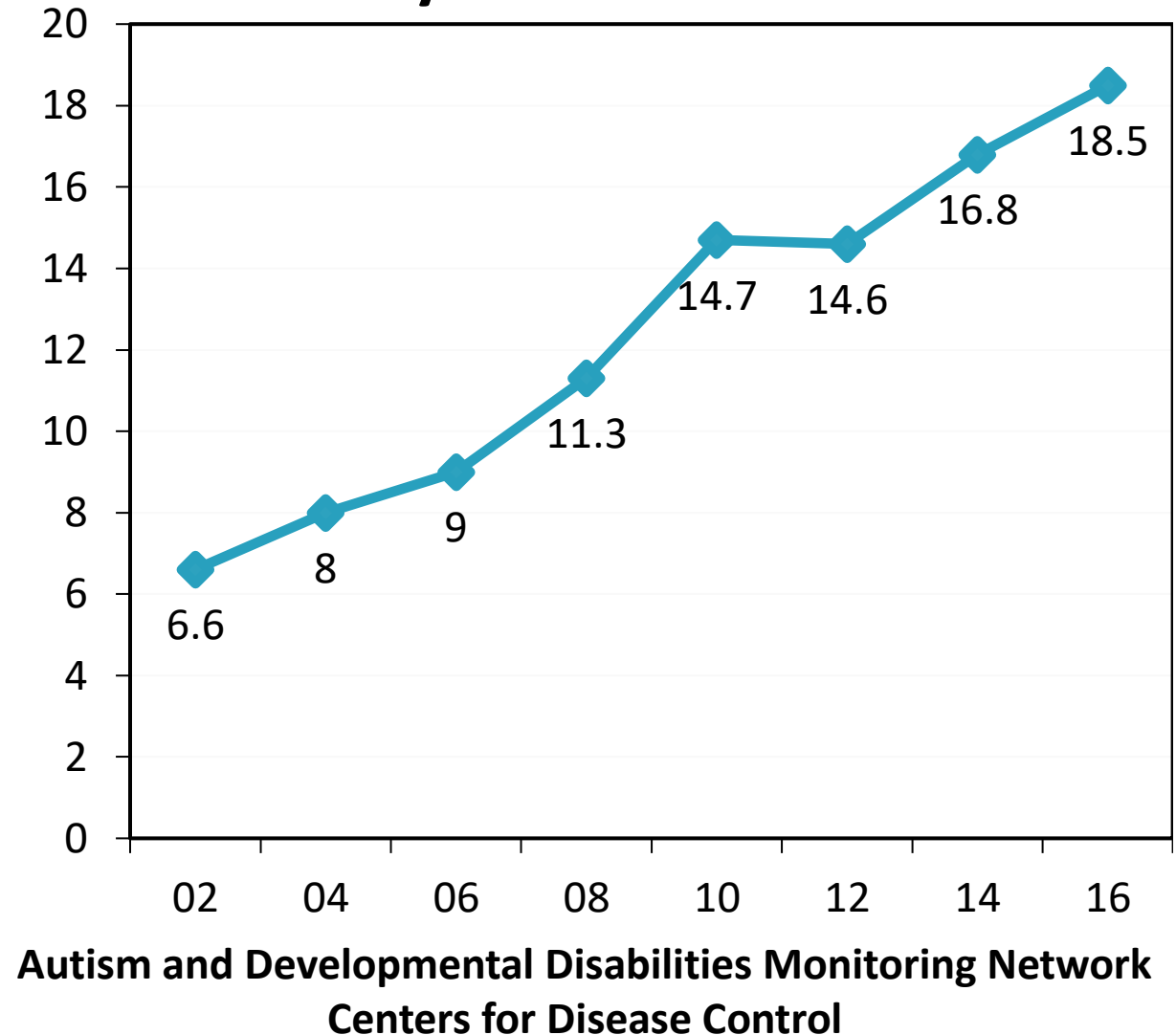
NC DEPARTMENT OF  
**HEALTH AND  
HUMAN SERVICES**



# Changing Prevalence of ASD

- Prevalence increase from 1 in 150 to 1 in 54 8-year-old children across the US
- Between 2015-2017, UNC Health treated 11,272 patients with ASD and/or IDD
- Increasing prevalence of comorbid mental health issues
- Evaluation and treatment of autism is rarely covered in primary care and/or behavioral health training

## Prevalence per 1000 of 8-year old Children





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# TEACCH

## Autism Program

*Services Across the Lifespan*

### Mission

**Creating and disseminating community-based services, training programs, and research to enhance the quality of life of individuals with Autism and their families.**



99 of 100 counties  
have been served  
by TEACCH



24% of TEACCH  
families are non-  
English speaking



TEACCH Service  
population is 35%  
minority groups

# What is Project ECHO? (Extension of Community Health Outcomes)

<https://echo.unm.edu/>

- Through tele-mentoring, ECHO creates a virtual community of providers with a hub of experts providing didactic training and case consultation.
- Tele-mentoring occurs twice/month across 6 months



# Specific Aims

Implement Project ECHO Autism Teleconsultation Programs to:

- Improve ASD-specific knowledge and treatment self-efficacy of rural **primary care** and **behavioral health** providers in North Carolina.
- Create regional provider communities.
- Connect provider communities to regional and state experts.





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Autism Society  
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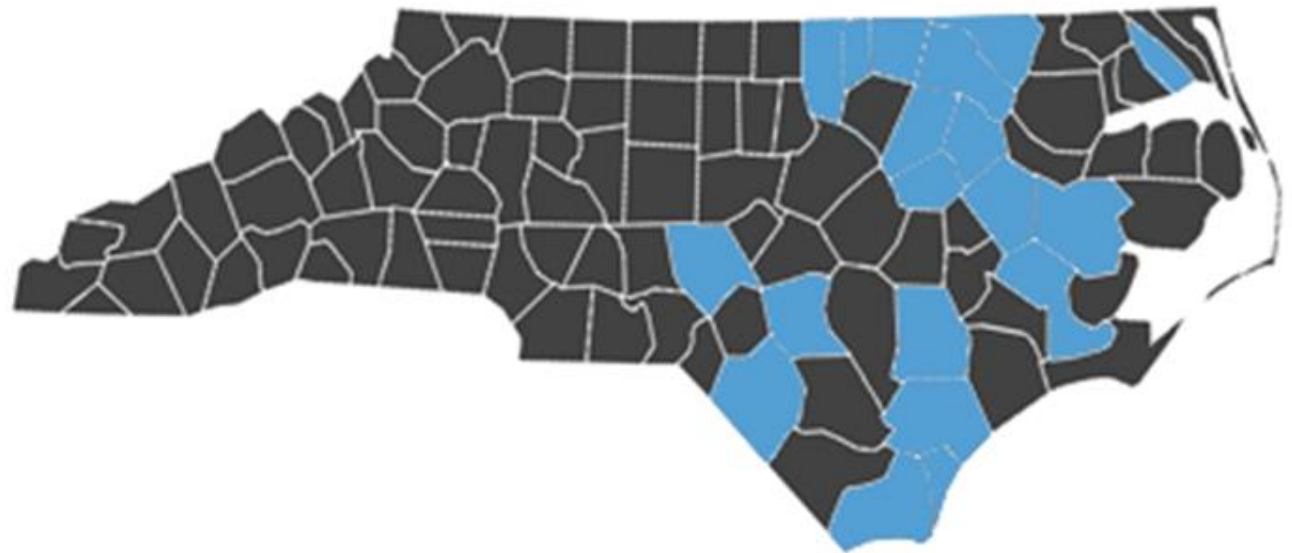
# Innovative Partnerships: Coalition of Autism Experts



# Project ECHO Autism: North Carolina Pilot Projects (2018 and 2019)

92 providers (5 cohorts)  
participated across 20 counties  
in Eastern North Carolina:

- 31 Primary care providers  
(2 cohorts)
- 22 Military primary care  
providers (1 cohort)
- 39 Behavioral health providers  
(2 cohorts)



# Typical Case Consultation Topics

- Screening:
  - Evaluation & referral
- Managing comorbid medical conditions:
  - Sleep disturbance
  - Hyperactivity
  - Nutrition
- Managing behavioral health concerns:
  - Behavioral challenges
  - Anxiety
  - Depression
  - Social skills

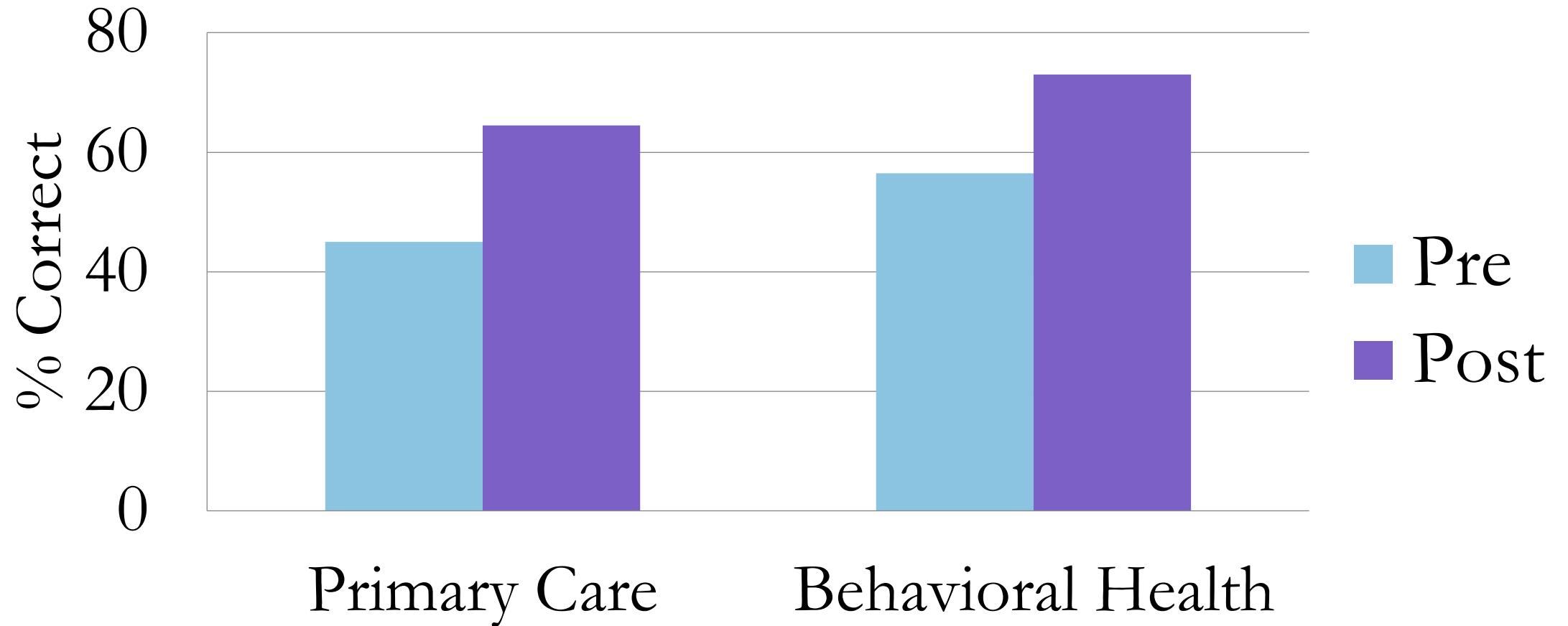
# What Does the Data Say?



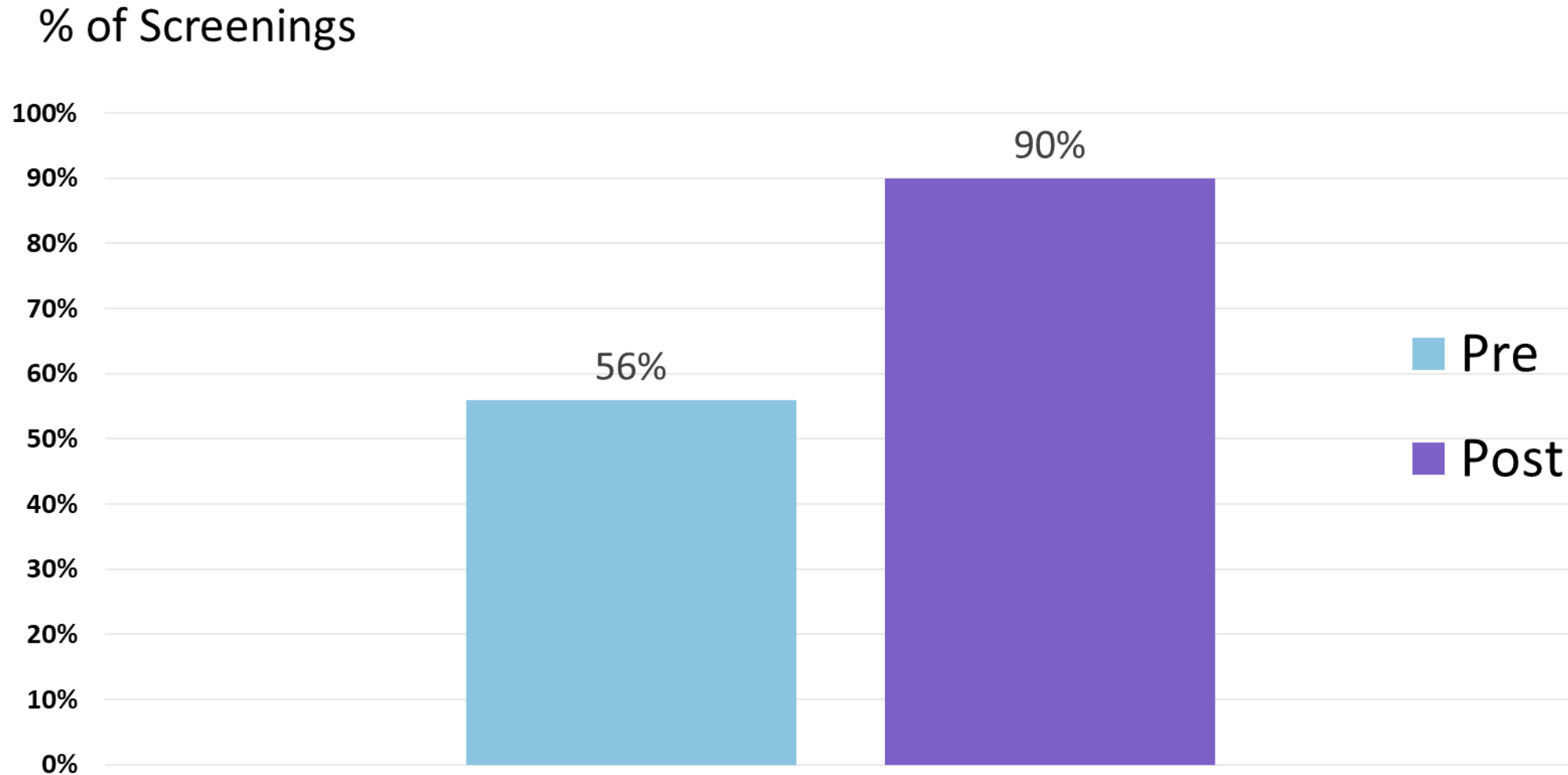
“I cannot speak highly enough of this opportunity, the ECHO Project service/technology, and the team of specialists who led this endeavor. I came in with basic, and largely limited, knowledge of how best to assess for and identify *ASD* and after having been a part of this program, have successfully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



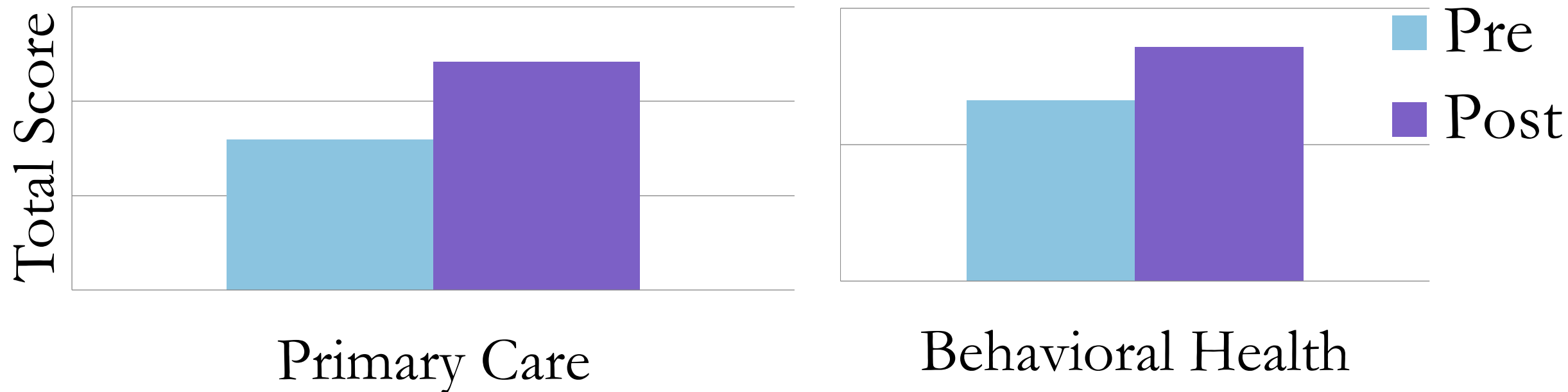
# Changes in Provider Autism Knowledge



# Changes in Screening for Autism at 18 & 24 Months Modified Checklist for Autism in Toddlers (M-CHAT)



# Changes in Provider Self-Efficacy



# Summary

<https://teacch.com/trainings/project-echo-autism/>

- Project ECHO is an evidence-based approach to professional development that connects expertise to support community-based care:
  - Creates a regional cohort of community providers.
  - Connects providers to regional experts.
  - Provides CME/CEU.
- What happens after ECHO participation:
  - If necessary, providers can refer to local “hub” experts.
  - Access to NC Psychiatry Access Line (NC PAL) for consults.

# Project ECHO Expansion & Sustainability

- Partner with DHHS, PHPs and MCO's to offer provider access to ECHO Autism to primary care and behavioral health providers across the state.
  - WellCare Charlotte Region Primary Care ECHO
- Create Autism ECHO programs outside of primary care settings.
  - Family Support ECHO
  - Autism ECHO for Educators
- Statewide Project ECHO Working Group



# Speaker Bio: Dr. Klinger, Ph.D.

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- ▶ Associate Professor in Department of Psychiatry, UNC-CH School of Medicine
- ▶ Executive Director of the UNC TEACCH Autism Program
- ▶ Oversees TEACCH's clinical services, international training program, and its community-based research program
- ▶ Serves on a variety of community advisory boards, consults to school systems and employment programs internationally about best practices for supporting the transition to adulthood including supports for employment and postsecondary education
- ▶ Research includes the study of learning differences in individuals with ASD and the development of community-based intervention programs to promote successful adult outcomes
- ▶ Principal Investigator (PI) of longitudinal study examining outcomes related to employment, quality of life, and aging in 25-60 yr.-old adults with ASD served by TEACCH during childhood
- ▶ PI of school-based pilot intervention study examining the effectiveness of the TEACCH School Transition to Employment and Post-Secondary Education Program
- ▶ PI for the Autism Project ECHO programs

<https://teacch.com/>



# The North Carolina Psychiatry Access Line: NC-PAL

- Funding disclosures
  - Active research funding support from Pfizer and the National Institute of Nursing Research
  - Active funding through the Health Resources and Services Administration
  - NC Council on Developmental Disability and NC ARC
  - NC Department of Health and Human Services
  
- Other disclosures
  - Gary Maslow, MD, MPH is a commissioner on the NC Commission for Children with Special Healthcare Needs



NC-PAL is a statewide federally-funded program that **provides telephone psychiatry consultation and community referral identification for primary care providers\*** to address *direct behavioral health needs* of their pediatric patients.



**NC-PAL Phone Line**  
**(919) 681-2909**

**Phone Line Hours**

8 a.m. – 5 p.m.,  
Monday – Friday  
*(excluding major holidays)*

**Q&A**

Non-clinical provider  
questions can be sent to:  
**[ncpal@duke.edu](mailto:ncpal@duke.edu)**

**NC-PAL is not an emergency/crisis line.** If you are in need of emergency support services, please call 911 or go directly to your nearest emergency department.

**Contact NC-PAL today**  
**(919) 681-2909 | [ncpal@duke.edu](mailto:ncpal@duke.edu)**

\* Pediatricians, family physicians, physician assistants and nurse practitioners.



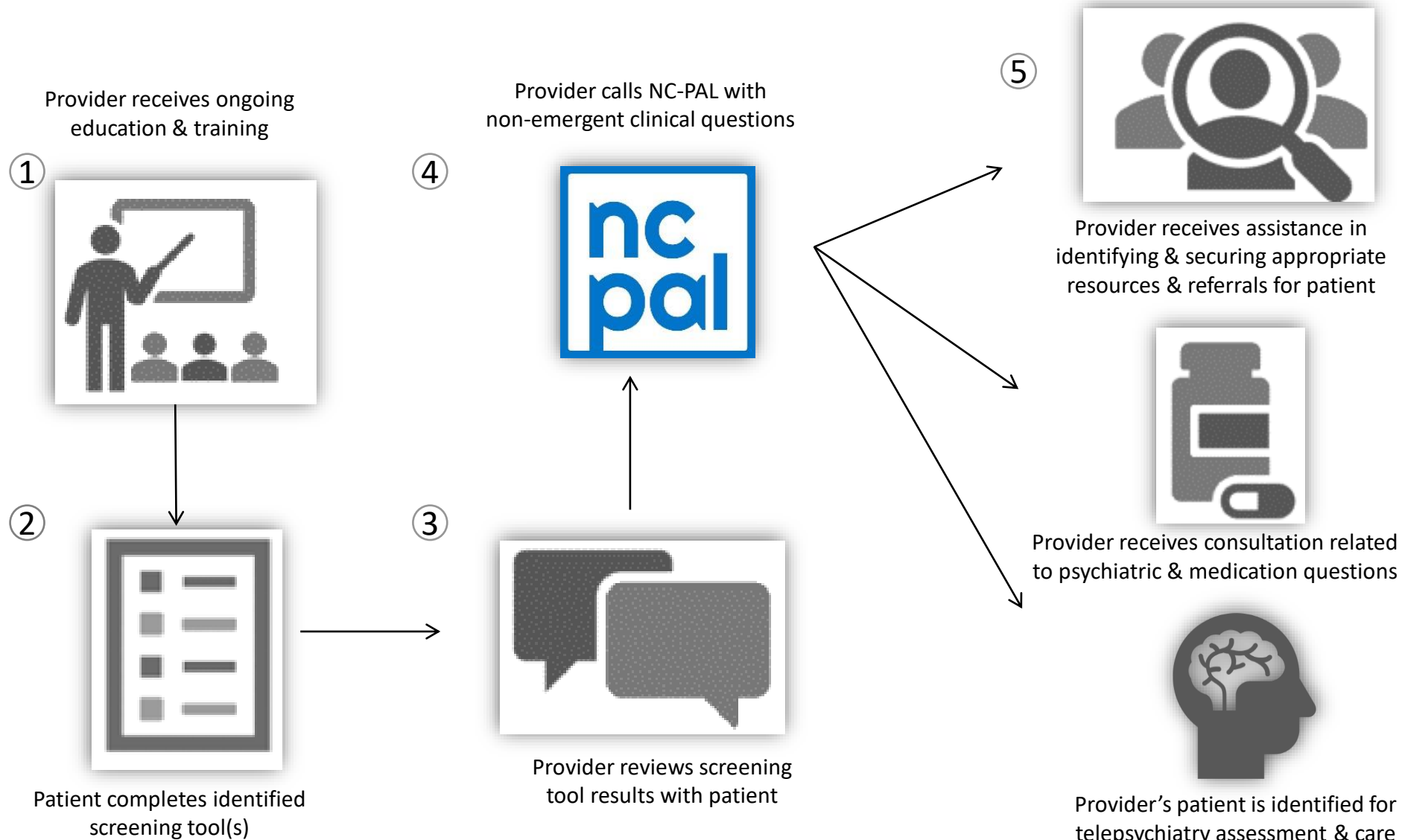
## Screening, Assessment, & Treatment

- Enhance systems for screening, assessment, and treatment of behavioral health disorders in pediatric patients

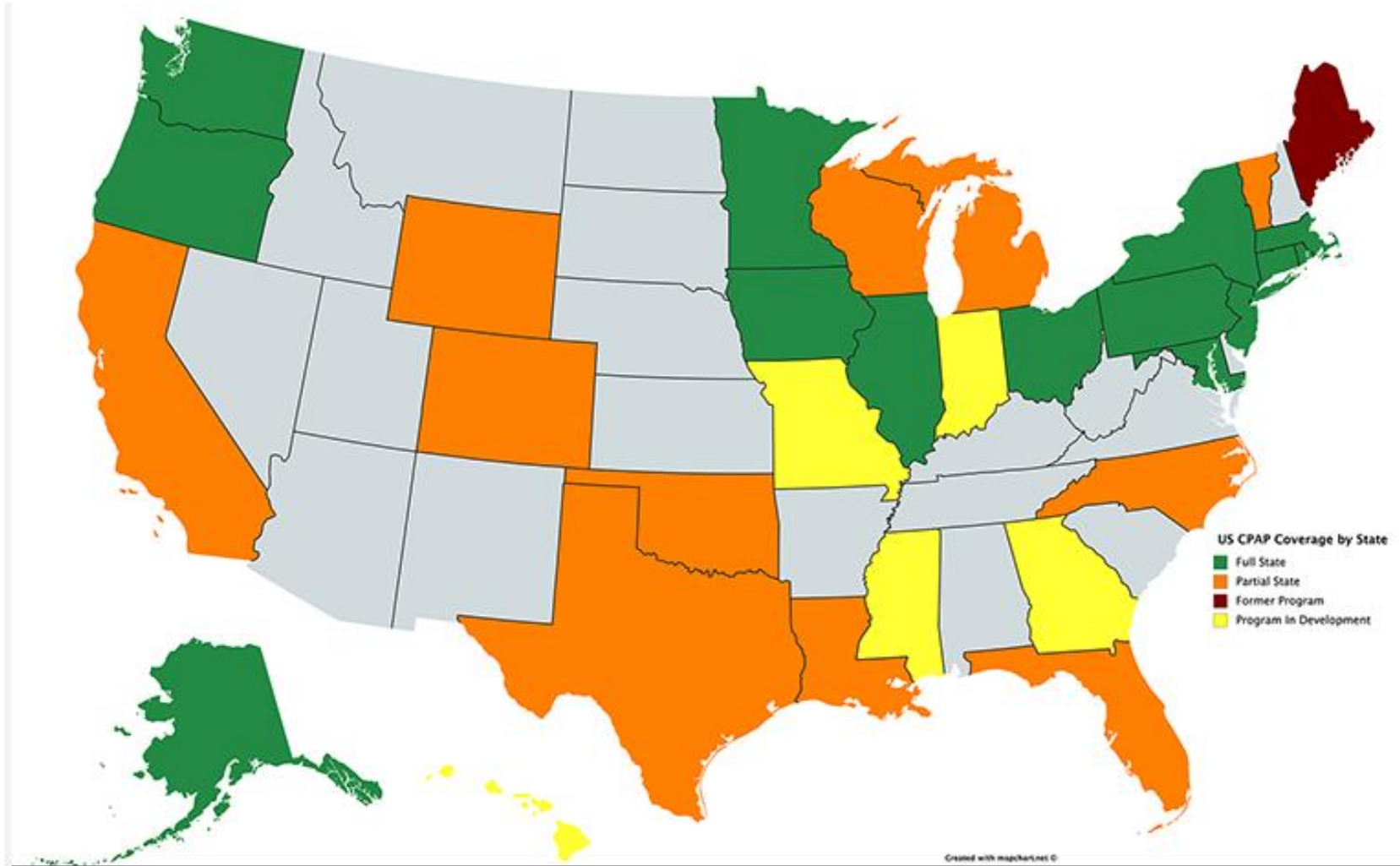


## Continuing Education

- Support local providers through training and in the integration of maternal mental health into primary care practice



# Where are Similar Programs Nationally?



## NC-PAL IDD (Intellectual and Developmental Disabilities)

- Partnership between Duke University – Gary Maslow, MD, MPH, Marlyn Wells, Amanda Zaski, MSW
- UNC- Chapel Hill – Robert Christian, MD, Neil DeJong, MD
- NC START – Jill Hinton, PhD, Jillaine Baker
- created a multidisciplinary resource that develops the knowledge and abilities of primary care and community providers to better service individuals with intellectual and developmental disabilities

Pilot conducted within Duke Children's Primary Care Pediatric Practice and UNC Complex Pediatric Service included:

- Reactive consultation
- Family Partner in clinic support
- Case Identification
- Proactive outreach



Intellectual/  
Developmental  
Disability

Used administrative data to identify patients at Duke Children's Primary Care Pediatrics with IDD, similar to the approach that will be taken to determine Tailored Plan eligibility

- Reviewed 500 charts of patients identified
- Findings
  - approximately half of patients had a mental health diagnosis
  - 41% of patients had had a significant behavioral problem noted in the chart in the last 6 months

	n = 498	%
<b>Behaviors (Within Last 6 Months)</b>		
Yes	206	41%
No	292	59%
<b>Category of Behaviors</b>		
Tantrums/ Emotional Outbursts	126	25%
Aggression Towards Others	109	22%
Impulsivity	90	18%
Self- Injurious Behaviors	44	9%
Property Destruction	18	4%
Wander/Elopement	20	4%

Based on case finding MSW and Family partner worked on proactive outreach

- Contacting PCPs for each patient to let them know about resources
- Preparation of resource guide to share with patients
- Calls to patients who had been to the ED previously
- Reviewing lists of patients with LME/MCO

	n = 498	%
<b>Managed Care Organization</b>		
Alliance BHC	406	82%
Cardinal Innovations	81	16%
Sandhills Center	6	1%
<b>Engaged in Behavioral/ Mental Health Services</b>		
Yes	212	43%
No	286	57%
<b>Engaged in Behavioral Therapy</b>		
Yes	87	17%
No	411	83%
<b>Engaged in Medication Management</b>		
Yes	182	37%
No	316	63%
<b>Innovations Waiver</b>		
Never screened for IDD eligibility	346	69%
Screened for IDD eligibility; not on RUN	30	6%
On Registry of Unmet Needs	55	11%
Enrolled on Innovations waiver	49	10%
Unknown	18	4%

- About 1/3 of calls to the main NC-PAL line are for IDD related concerns
- For NC-PAL IDD relatively few direct physician to physician consultations are requested
- Reactive consultation much more focused on resource identification/case coordination
- From Primary Care Pilot 52 unique contacts (calls/messages/face-to-face) over past year
- Resource Needs Provided:
  - I/DD services (NC-START, respite),
  - MH services,
  - Educational advocacy,
  - Guardianship/supportive decision-making information
  - Vocational rehabilitation linkage
  - Connection to community resources



- Family partner
  - in clinic 4 hours per week
  - Meets with children and youth and parents
  - providing direct support and community navigation support
  - 94 contacts in 1-year period. (3-4 per clinic)
  - Contacts can be brief or up to 2 hours and involve follow-up by phone or email afterwards
- Type of support:
  - 50% resource support and 50% emotional support, encouragement
  - Common themes: IEP, educational support, modifications and accommodations in high school and college, independent living; Social/recreational support; advocacy resources; guardianship questions; transportation concerns; financial concerns; insurance; IDD waiver; parental stress
- Developing secure telephone/text interface to allow for family partners to provide support remotely.

There are over 70,000 individuals in NC with IDD.

There are over 10,000 primary care providers across the state caring for children – Pediatricians, Family Physicians, NP, PA

A broad system is needed to care for children with IDD that includes

- Reactive Consultation – NC-PAL
- Case Identification – Partnership with LME/MCO – Tailored plans in future
- Family support – Family Partner one type of Family Support
- Proactive Outreach – important to not just wait for crisis but proactively identify and offer support
- Education – link to provider and families to provide education



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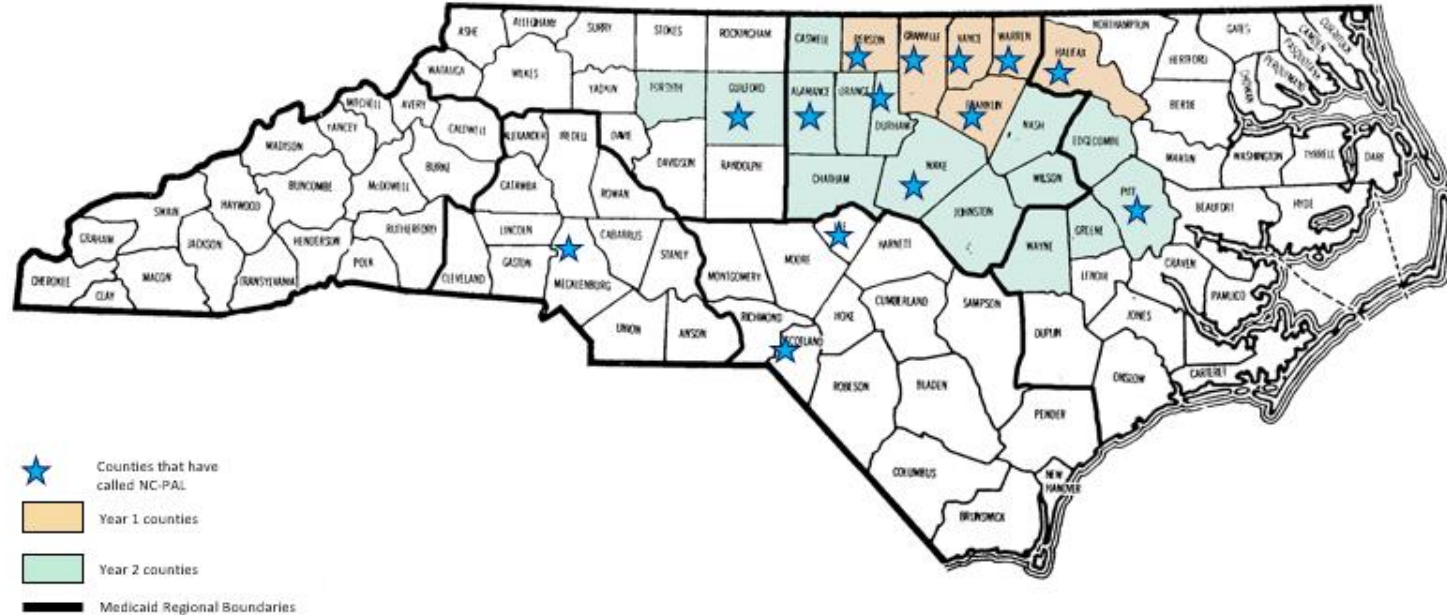
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# Speaker Bio: Dr. Maslow, MD, MPH

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- ▶ Co-Chief in the Division of Child and Family Mental Health & Developmental Neuroscience and the Medical Director of the Integrated Pediatric Mental Health Clinical Practice Unit at Duke Health
- ▶ Completed 3 residencies in pediatrics, psychiatry and child and adolescent and psychiatry
- ▶ Completed residency at Rhode Island Hospital and Brown University and attended Dartmouth Medical School
- ▶ Author of numerous peer reviewed publications that focus on health care transitions for youth with disabilities, ADHD, peer support, and depression and suicide
- ▶ Investigator on NC Telehealth Partnership for Child and Adolescent Psychiatry HRSA grant
- ▶ Investigator on numerous grants including NC Integrated Care for Kids Model, Peer i-coaching for Activated Self-management Optimization in Adolescents and Adults with Chronic Conditions

# The CIDD Pediatric Complex Care Partnership

Dr. Robert B. Christian, MD



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# History/Context

- ▶ Carolina Institute for Developmental Disabilities
  - ▶ freestanding interdisciplinary center within UNC School of Medicine focusing on I/DD research, clinical service, training, and technical assistance
- ▶ CIDD is clinically focused predominately on complex multidisciplinary evaluation
- ▶ Behavioral Medicine Team provides assessment and treatment



# History/Context

- ▶ **Behavioral Medicine Clinic started in 2009 at CIDD**
  - ▶ Multidisciplinary team to evaluate and provide ongoing medical and behavioral consultation to individuals with IDD and their families who have significant emotional/behavioral challenges.
    - ▶ Pediatrics/Adult Psychiatry/Child Adolescent Psychiatry
    - ▶ Psychology
    - ▶ Social Work/Family Support/System Navigation



# History/Context

- ▶ UNC Pediatrics Complex Care Clinic
  - ▶ 2 locations @ UNC Chapel Hill & Rex
  - ▶ Staffed by 5 faculty pediatricians
  - ▶ Evaluate and treat complex presentations
    - ▶ Headaches
    - ▶ Chronic constipation
    - ▶ Complex confusing medical presentations with overlapping Mental Health
    - ▶ 30-50% of this clinic population with I/DD
  - ▶ High rate of challenging behaviors in the I/DD population
  - ▶ No assistance from psychology or system navigation support



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# Partnership Development

- ▶ Began with informal medication focused tele-consultation
  - ▶ “Curbsides”
- ▶ Proposal to NC DHHS in Fall 2019 to support an enhancement of Complex Care Clinic for patients with I/DD and psychiatric/behavioral complexity



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# Key Features of the Model

- ▶ Direct Clinical Component
  - ▶ Behavioral Consultation
  - ▶ System Navigation with ongoing support
    - ▶ System Navigator should be a parent with extensive IDD system experience
  - ▶ Enhanced Access to Formal Diagnostics
  - ▶ Psychiatric consultation when needed
  - ▶ Access to CIDD Pediatric Neurology
- ▶ Case Finding/Community Outreach
  - ▶ Identifying those in UNC Pediatric population with IDD and potential for future Behavioral Complexity
  - ▶ Tele Outreach to those families attempting to identify gaps in:
    - ▶ Resources: Innovations Waiver, Formal Assessment, therapies



# Capacity Building

- ▶ Enhancing capacity of UNC Pediatricians to manage in terms of behavioral management, medication management, and IDD system knowledge/services
- ▶ UNC Pediatric Residents
- ▶ CIDD Trainees
  - ▶ Psychology
  - ▶ Social Work



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# Timeline

Proposal  
Fall 2019

First Clinical  
Encounters  
Jan 2020

Assembling  
Team  
Nov/Dec 2019



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# Team

- ▶ UNC Complex Care Pediatricians led by Dr. Neal deJong, MD
- ▶ Parent/System Navigator- Darragh Davis
- ▶ CIDD Social Work- Morgan Parlier, MSW
  - ▶ CIDD LEND Social Work Trainees
- ▶ CIDD Psychology Team led by Drs. Jean Mankowski and Laura Hiruma, Ph.D
  - ▶ CIDD LEND Psychology Trainees
- ▶ CIDD Psychiatry- Dr. Rob Christian, MD; Michelle Franklin, MSN
- ▶ CIDD Pediatric Neurology- Dr. Diana Cejas, MD



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# Timeline

Expansion of  
Clinical Encounters  
Winter/Spring 2019

Ongoing  
Development  
Spring/Summer  
2020

Covid 19 Pandemic  
Adaptation  
March 2019



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# Process of Clinical Component



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# Next Steps and Possibilities

- ▶ Period of Behavioral Consultation
- ▶ Referral for Formal Assessment
- ▶ Referral for Behavioral Health Services Internally/Externally
- ▶ Ongoing Care via UNC Pediatrics



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# Proactive Component

- ▶ Developing patient reports/lists from EMR Data
- ▶ Refining case-finding process
- ▶ Practicing outreach at pilot level with select cases to gain experience



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# Key Outcomes of Interest

- ▶ Numbers of Patients Served at Various Levels
  - ▶ Contact, Screening, Ongoing Support
- ▶ Numbers of Patients Attaining New Outside Services or Successfully Placed on Waitlists
  - ▶ Examples: Innovations Waiver, Behavioral Therapy
- ▶ Patient and Family Satisfaction
- ▶ Provider Competency Self-Assessment
  - ▶ Pediatricians/Residents
  - ▶ Trainees



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# Some Numbers to Date

- ▶ Total New Patients Enrolled Through Clinical Arm:
  - ▶ **39**
- ▶ Patients Referred For Further Formal Evaluation/Testing:
  - ▶ **12** ( In person testing stalled/on hold due to Covid-19)
- ▶ Patients Connected to New Service or Waitlist:
  - ▶ **14**
- ▶ Pediatricians/Residents/Other Trainees Exposed to Model
  - ▶ **14**



# Future Steps

- ▶ Expand slowly into UNC Primary Care Pediatrics beyond Complex Care Clinic
- ▶ Full launch of proactive arm
- ▶ Enhance our current patient tracking registry
  - ▶ Excel → RedCap
- ▶ Consider how and where to replicate model
- ▶ Work to connect various regional models
  - ▶ Duke NC Pediatric Access Line
  - ▶ Mission Health/Olson Huff DD Plus



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# Speaker Bio: Dr. Rob Christian, MD, FAAP

rob.christian@cidd.unc.edu

- ▶ Assistant Professor of Psychiatry and Pediatrics at the Carolina Institute for Developmental Disabilities at UNC-CH
- ▶ Training in General Pediatrics and Adult/Child and Adolescent Psychiatry
- ▶ Works in an interdisciplinary team
- ▶ Teaches LEND trainees and participates in numerous innovative projects
- ▶ Research includes attempting to understand how to best provide medical/behavioral services to individuals who have both neuro-developmental disorders and behavioral/emotional/psychiatric challenge and understanding the real-world effectiveness of psychotropic medication usage in this population

<http://www.cidd.unc.edu/>

# What We Have Learned

 Champions, organizational leadership, and commitment to innovation are a starting point

 Technology is an essential tool to increase access to I/DD and ASD expertise and a necessity in today's world

 Family support and systems navigation is critical

 Integrated care demands responsive, robust and multi-faceted strategies that offer reactive AND proactive approaches to consultation, education, case-finding, and family support

 No single model or service is a perfect fit for every system

 These models are applicable to Medicaid members in Standard Plans and Tailored Plans and individuals with other health insurance

 Individuals with I/DD are and will be a part of every health system

# Thank You

- ▶ Additional information on these projects can be found at the IDD MHHI website, [www.iddmedicalhealthhomencinitiative.com](http://www.iddmedicalhealthhomencinitiative.com)
- ▶ Dr. Laura Klinger, [laura\\_klinger@med.unc.edu](mailto:laura_klinger@med.unc.edu)
- ▶ Dr. Gary Maslow, [gary.maslow@duke.edu](mailto:gary.maslow@duke.edu)
- ▶ Dr. Rob Christian, [rob.christian@cidd.unc.edu](mailto:rob.christian@cidd.unc.edu)
- ▶ Kerri Erb, [kerb@autismsociety-nc.org](mailto:kerb@autismsociety-nc.org)
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*Many thanks to the individuals with I/DD, families, champions, leaders, partners, funders, and stakeholders who have informed and contributed to this work.*

# Speaker Bio: Kerri Erb

kerb@autismsociety-nc.org

- ▶ Chief Program Officer, Autism Society of North Carolina
- ▶ Regional and statewide responsibility for the development and implementation ASNC's various programming, including Clinical consultation, Research Based Behavioral Health Treatment, Parent navigation and statewide ASD/IDD services.
- ▶ Educational background includes the National Leadership Consortium on Developmental Disabilities, UNC Wilmington Quality Enhancement for Nonprofit Organizations Program and North Carolina State University's Master of Public Administration
- ▶ Expertise in system design, implementation of best practices, outcomes design and measurement, data-driven management, waiver and policy design and implementation process, and quality management

<https://www.autismsociety-nc.org/>



# Speaker Bio: Karen Luken

**karenluken@gmail.com**

- ▶ Project director for the “Medical Health Homes for People with Intellectual and Developmental Disabilities”
- ▶ Commitment to evidence-based practice, health care reform, and systems change shaped by her work at the North Carolina Office on Disability and Health, Center for Recreation and Disability Studies at UNC-CH, UNC Hospitals, and community mental health
- ▶ Research interests include cancer screening and education for women with developmental disabilities, cardiovascular disease and adults with disabilities, the role of consultation services in supporting the patient-centered medical home, family support, and building healthy inclusive environments for people with disabilities

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