

2023 Peer-to-Peer Exchange: Family Navigation: Enhancing Culturally Responsive Partnerships and Sustainability

North Carolina Navigating Care (NCNC) Team Introduction
June 13, 2023, 8:50 – 9:00 am

Becky Pretzel, PhD, Associate Director at the Carolina Institute for Developmental Disabilities, University of North Carolina-Chapel Hill



Becky Pretzel, PhD, is a psychologist and the Associate Director at the Carolina Institute for Developmental Disabilities, UNC-CH. She also serves as the LEND Director, co-Director of the UCEDD, and CDC's Act Early Ambassador for North Carolina. Becky has many years of experience in early identification, diagnosis and treatment planning for young children with or at high likelihood of having ASD/DD and their families. Becky is the PI of several state contracts and grants focused on intellectual and developmental disabilities, including being co-PI of the current HRSA State Implementation grant.

Julie Williams-Swiggett
Project Coordinator for the North Carolina Navigating Care Project



Julie Williams-Swiggett is the Project Coordinator for the North Carolina Navigating Care Project. She is a graduate of the University of North Carolina at Chapel Hill's M.Ed. program in Early Intervention and Family Support and has over ten years experience in Early Childhood Special Education programming, ranging from classroom teaching and mentoring to consulting on statewide projects supporting young children's Social and Emotional health to providing care coordination services for Part C eligible children and families. Her areas of professional focus include supporting young children and families with Autism Spectrum Disorder who have complex needs, using coaching models to build caregiver and provider capacity, and implementation of solution-oriented projects designed to help families overcome common barriers that arise when accessing coordinated care services.

Building Bridges to Advanced Care: The Role of Family and Peer Navigation for I/DD Individuals in Medicaid
June 13, 2023, 9:00 – 10:00 am

Kim Tizzard

Director of Family Support, Autism Society of North Carolina (ASNC)



Kim Tizzard has been with the Autism Society of North Carolina (ASNC) for a little over 18 years. During this time, she has worked with well over 1,000 families, providing support with school issues, dealing with crisis situations, and developing strategies to overcome a variety of challenges. Additionally, she has personal experience as the mother of a son with autism. In her current role as Director of Family Support, Ms. Tizzard oversees the work of ASNC's Autism Resource Specialists and Support Groups across the State. She advocates for a blended approach in teaching individuals with autism and understands the importance of structure for learning, attending, and independent skills. She represents ASNC on several collaborative projects and efforts that focus on the immediate needs of individuals and caregivers with ASD and I/DD.

Kelly Friedlander

Chief Executive Officer & Principal Consultant of Community Bridges



As the CEO & Principal Consultant of Community Bridges, Kelly Friedlander concentrates on creating a more equitable and inclusive world for everyone, especially those with disabilities. Drawing from her early career experience as a Direct Support Professional and with over 18 years of expertise in advocacy, policy analysis, and program development, she has honed her skills as a strategic problem solver, advocating person-centered approaches and improving outcomes for both organizations and individuals served.

Kelly's consultative services revolve around stakeholder engagement and advocacy concerning managed long-term supports and services. Her specialty is convening and facilitating diverse work and advisory groups to incorporate

the voices of individuals with Intellectual and Developmental Disabilities (IDD) and their families into the public policymaking process. This distinctive approach aids in ensuring that patients and families—particularly those with complex health and social needs—have a say at all levels of the healthcare delivery system — from individual care to health system design and extending to state and national policy.

Cindy Ehlers, MS, LCMHC
Chief Operations Officer, Trillium Health Resources



Cindy Ehlers, MS, LCMHC, serves as the Chief Operations Officer for Trillium Health Resources. She is focused on improving access to health and affordability through emerging analytics and innovative solutions. She leads several major components of Trillium overseeing the strategy and innovation for Trillium along with member and network operations. Trillium Health Resources is a leader in innovation for behavioral health and IDD and the life-long supports needed by these populations in NC.

Cindy is a champion for the implementation of evidence-based practices. Cindy has developed a robust department within Trillium focused on approaches that address opportunities for health and health disparity throughout eastern NC. She has worked in both the public and private sectors and has been a public servant for the past 32 years. Cindy has developed many programs and services in behavioral health and intellectual and developmental disabilities in rural eastern North Carolina overcoming rural barriers and many health disparities in efforts to meet the service needs of the BH-IDD population.

Cindy offers a unique perspective in her role as an Executive in the NC system, as she is both a parent and professional. Cindy has six children- several who have special needs; she was a therapeutic foster parent and is an adoptive parent. Cindy understands the system from the perspective of the MCO, from inside out, and as a parent of children with special healthcare needs from the outside in. Her lived experience is unique to find in healthcare at this level in an organization. Trillium is the only health plan in the state with a parent who has been a foster parent, adoptive parent and is the parent of children with IDD on the Executive team of the organization.

National Trends and Approaches to Assessing and Addressing Early Childhood Developmental Delay

June 13, 2023, 10:15 – 11:00 am

Dr. Kori Flower, MD, MS, MPH

Division Chief of General Pediatrics and Professor of Pediatrics at the University of North Carolina, Chapel Hill



Dr. Kori Flower is a general pediatrician who has provided primary care to medically underserved children for over 20 years and has also led implementation of interventions to improve primary care, including routine screenings for young children, in underserved settings. After pediatric residency, she completed a research fellowship through the Robert Wood Johnson Clinical Scholars Program at the University of North Carolina at Chapel Hill. During her prior work in a federally qualified health center, Dr. Flower designed and led the implementation of autism spectrum disorder screening across the organization's six locations. Her published work also describes the work she has led to improve preventive services and implement Bright Futures guidelines in a national collaborative of pediatric practices. Most recently, Dr. Flower has led another American Academy of Pediatrics national quality improvement collaborative, Project I-SCRN, which engaged 20 pediatric practices across the country in improving screening for

autism and developmental problems, as well as social determinants of health and maternal depression. Currently, Dr. Flower is Division Chief of General Pediatrics and Professor of Pediatrics at the University of North Carolina, Chapel Hill, where her responsibilities including teaching and supervision of residents in the primary care setting, including overseeing autism and general developmental screening and referral.



Elizabeth Crais, PhD

Professor, Division of Speech and Hearing Sciences, UNC School of Medicine

Elizabeth Crais, PhD is a professor and autism researcher at the University of North Carolina-Chapel Hill. Her research includes identification and intervention of young children with ASD. She is also the parent of a youth with disabilities.

Overview of NCNC Family Navigation Guide June 13, 2023, 12:30 – 1:45 pm



Laurel Powell

Program Manager, Family Support Program and the Family Support Network™ of NC University Office

Laurel Powell is the program manager of the Family Support Program and the Family Support Network™ of NC University Office. Laurel began her career as a special educator in Wake County, North Carolina. Since then, she has worked in the I/DD field in a variety of ways including supporting individuals in finding competitive and integrated employment, supporting families, and authentically connecting with individuals with I/DD and those with behavioral health challenges.

Laurel values supporting individuals and families with a strengths-based approach. Laurel is especially interested in the stories that individuals and families have to tell and supporting them in being in positions where their voices are heard. Working within systems to make change for the greater good is Laurel's main professional goal. Laurel works with state level partners, community partners, and family partners to ensure everyone has a valued seat at the table.

Panel: Incorporating Personal Perspectives into Professional Roles**June 13, 2023, 2:15 – 3:15 pm****Brittany Prince, M.Ed., EIS*****Early Childhood Consultant in OCALI'S Center for the Young Child***

Brittany Prince, M.Ed., EIS, is an Early Childhood Consultant in OCALI'S Center for the Young Child. She provides evidence-based coaching to one-year Developmental Specialists and supports OCALI's work in the improvement of early childhood and the use of evidence-based practices for children with autism and related disorders. Brittany has a background as a Developmental Specialist where she provided evidence-based coaching to families of infants and toddlers for 10 years. Brittany primarily worked with children that recently received an autism diagnosis or were waiting to go through the diagnostic process. She used her certifications

in DIR Floortime and Hanen to help parents use a neurodiversity affirming and relationship-based approach to connect, understand, and foster their child's development. Brittany is also a sibling of an adult with a disability. Brittany has been helping her mom and brother navigate services for the last 15 years. Prince has been able to experience the system from multiple ages and stages of life as a sibling. Just as she approaches the families she supports professionally, she is passionate about those providing her brother's services to connect with and understand him, so he can live a life that's happy, safe, and supported. Her lived experiences drive her passions and motivation to work with local organizations to advocate for better funding, training, and access for adult supports, including higher pay for Direct Support Professionals.

**Jessica Simacek, PhD*****Director of the TeleOutreach Center and the TeleOutreach Research Core, University of Minnesota***

Dr. Jessica Simacek serves as the Director of the [TeleOutreach Center](#) at the Institute on Community Integration and the [TeleOutreach Research Core](#) at the Masonic Institute for the Developing Brain, both at the University of Minnesota. Her PhD is in Educational Psychology, with a focus on Special Education from the University of Minnesota and she has 20 years of experience in providing early intervention to children with

neurodevelopmental disabilities and their families in home, clinical, and school-based settings. Jessica specializes in the use of telehealth to overcome barriers to intervention access, the use of

augmentative and alternative communication for children with complex communication needs, and supporting children with significant challenging behavioral concerns.

Jessica is the Principal Investigator on multiple research projects related to the use of distance-learning technologies to improve access to interventions for children with developmental disabilities or complex communication needs and for their families, including the HRSA-funded AutismFIRST project titled, '*Bridging barriers to intervention access for waitlisted families of children with ASD.*' She serves as the Research Director and a faculty mentor to Fellows in the MN Leadership Education in Neurodevelopmental Disabilities ([MNLEND](#)) program and her work has appeared widely in peer-reviewed journals focusing on intervention research.

As much as I love my professional life, at my core I am the proud parent to three amazing, smart, creative, and beautiful children. My middle son loves farm animals, joking around, books, the zoo, swimming, paddle boarding, camping, and fishing. He is funny, thoughtful, and kind. He was diagnosed with ASD just shy of his 2nd birthday, while I was 7 months pregnant with my youngest child. He began early intervention in the first weeks of my maternity leave. I am proud and honest in sharing my lived experience because I appreciate the parents and self-advocates who I have learned from when they have shared their lived experience. I share some of the wonderful parts of my family's journey (My children! The fun things we do, how far we have come, and how very proud I am of them), as well as some of the stressful and hard parts (e.g., long waitlists, sleep, eating, and elopement challenges, infant sibling concerns, balancing enough time for all of my kids). And some of it I keep to myself. As someone who is professionally experienced with supporting families of children with ASD, I took so much of what I learned from those families as I began (and continue) my personal lived experience as a parent of a child with ASD.



Laura Sorg, MD, FAAFP
Medical Director, Ohio Department of Developmental Disabilities

Laura Sorg, MD, FAAFP serves as the Medical Director for the Ohio Department of Developmental Disabilities. Throughout her sixteen-year career as a physician, Dr. Laura has focused on care throughout the life span, rural medicine, and caring for those with intellectual disabilities. Her goal is to expand awareness of preventative care to the over 90,000 Ohioans with developmental disabilities, as well as education to the health care professionals serving them.

Raised on a cattle farm in Southwest Ohio, her passion for caring for others started as a classroom assistant in fourth grade to children with disabilities. Dr. Laura's devotion to the field was cemented when her youngest son was diagnosed with autism at

the age of two.

Her unique perspective as a family physician, mom and medical director has led her to serve on multiple committees in her home state including the State Health Assessment/ State Health Improvement Plan, Ohio COVID-19 R3AP/ Rapid Response Medical Committee and State Oral Health Plan Committee. She has also authored several journal articles including Medical Myth: “Wait and See” in Early Childhood Development and Intellectual Disability Psychiatry: A Primer for PCPs for *The Ohio Family Physician*.

Dr. Sorg’s passion and plan over the next five years is to increase the knowledge base of physicians and other health care professionals while increasing access to those individuals and families most at risk of inequities in health care.



Brushon (Bruce) Moutry II

Brushon is a sibling of a person with autism and a sibling of a person with a very rare genetic condition, but he also has a genetic disorder of his own. Brushon has learned to take their personal experiences to work with children with autism at a summer camp.



Burron Winters-Moutry

Burron is a 17-year-old who lives with Autism (received a late diagnosis two days before his 14th birthday). He enjoys listening to music while he works and likes to spend his free time watching anime and socializing. He has many goals and understands that his brain processes things differently than others.



Ida Winters
Community Outreach Specialist, Waisman Center, Wisconsin LEND Program

Ida Winters is the mother of three young men with special healthcare needs, one of which lives with autism. She currently works with Waisman Center in Madison, WI as a Community Outreach Specialist helping bridge the gap between the university, professionals, and communities. Ida is a leader in her community and cares about what happens and decisions are made in her community.

Panel: Cultural Perspectives on Sustainability**June 14, 2023, 10:30 – 11:30 pm****Barbara Leach*****Family Support Specialist and Special Projects Coordinator, Family Support Program, UNC School of Social Work***

Barbara Leach is a Family Support Specialist and Special Projects Coordinator. She joined the Family Support Program in 2005. She has over 30 years of experience as a child and family advocate for families with children who have mental illnesses, developmental disabilities, and other special needs.

In addition to providing information and referral for families and providers, Ms. Leach serves as a family advisor on multiple state and national committees that work collaboratively to transform systems so that they better meet the needs of children with disabilities and their families. She presents extensively on topics relating to supporting families, family advocacy, family engagement, family/provider partnership, cultural competence, and systems change.

Mariela Maldonado***Senior Hispanic Outreach & Support Coordinator, Autism Society of North Carolina (ASNC)***

Mariela Maldonado has been the leader of the Hispanic Outreach & Support Department since 2007 and provides resources, organizes and offers workshops/webinars, leads regional Hispanic Support Groups, and develops autism awareness campaigns across the NC State. As a Peruvian-American immigrant mother of a young adult with autism, she coaches families to advocate in their own culture. Mariela is a conference and university speaker on effective communication to reach diverse cultures. She has a degree in Social Communication from the University of Lima-Peru and an NC license of CBRS - Developmental Therapy for Early Intervention. She provides CBRS-Development Therapy for children from born to 3 years old.

Mariela has had the experience of working as a counselor and case manager for Hispanic families seeking resources in various areas such as domestic violence, sexual abuse, and early childhood education. In addition, Mariela is a member of the Steering Committee and Community Advisor for study and research projects of universities dedicated to Hispanic children and adults in the areas of autism evaluations, impact on siblings, transition to adulthood and the culture shock facing the Hispanic families in understanding autism and resources. She is the mother of a 28-year-old young adult with autism and other neurological conditions. She currently lives in Raleigh, NC with her 3 adult children.

Felicia Williams Brown***Connection & Resource Specialist, Autism Society of North Carolina (ASNC)***

Felicia Williams Brown's work involves supporting families and people with autism on social media by connecting them to services and helping with system navigation. She is a certified Community Health Worker, a Charting the LifeCourse Framework Ambassador, a certified trainer for Adult Mental Health First Aid, a Sexuality Educator for Individuals with IDD, a certified facilitator for the Wellness Recovery Action Plan (WRAP), a certified instructor for HealthMatters and a certified facilitator for QPR Suicide Prevention. She serves on various Steering Committees, has been involved with numerous community projects and is a UNC LEND fellow; a prestigious leadership program for North Carolina Leadership Education in Neurodevelopmental and Related Disabilities (LEND) at the CIDD that provides interdisciplinary leadership training at undergraduate, graduate, and postdoctoral levels, as well as interdisciplinary services and care.

Candy Ross***Family Services Manager, Qualla Boundary Head Start / Early Head Start***

My name is Candy Ross. I am a Native American from the Eastern Band of Cherokee Indians in Cherokee, NC. I am married to my wonderful husband Mark and we are raising 5 awesome children. I am the Family Services Manager at the Qualla Boundary Head Start / Early Head Start. My job duties include overseeing enrollment, providing resources to families within our service area, tracking needs and providing support to vulnerable families, and advocating for families in need. I serve on several committees on the Qualla Boundary. I recently completed a certification as an Autism Support Specialist through the Autism Society of North Carolina. Currently there are not any services for families in Cherokee, NC to support families with children who have Autism. I am excited to start the journey of learning how to help parents and children become more aware and informed of the challenges of Autism and to let them know they have support. I will share my personal experiences, challenges, and successes with others.



Shagun Gaur
Autism Resource Specialist, Autism Society of North Carolina (ASNC)

Shagun Gaur has been working as an Autism Resource Specialist with the Autism Society of North Carolina for 5 years. In her current role, she provides resources to individuals, their families throughout Charlotte area which includes 10 counties around. She also delivers presentations, workshops, and is an active member of CFAC-Alliance committee and Diversity Committee at the Autism Society.