

**2024 SYMPOSIUM ON CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS (CYSHCN)**  
*Better Systems of Care, Better Tomorrow*  
**May 21, 2024 – IN-PERSON, Best Western, Harrisburg**

**AGENDA**

**TUESDAY, MAY 21, 2024**

**OPENING PLENARY SESSION**

<b>8–9:00 AM</b>	<i>In-person registration open for check-in (Ballroom Lobby); breakfast in Ballroom A/B/C</i>
<b>9:00 AM</b> <b>Ballroom A/B/C</b>	<b>WELCOME AND OPENING REMARKS</b> -Tara Trego, Director, Bureau of Family Health, PA Department of Health -Cindy Findley, Deputy Secretary, PA Department of Health
<b>9:15 AM</b> <b>Ballroom A/B/C</b>  <b>BLUEPRINT:</b>  <b>Health Equity</b>  <b>Access to Care</b>  <b>Quality of Life</b>  <b>Financial</b>	<b>CHANGING A SYSTEM: HOW VISION AND PRINCIPLES DRIVE THE BLUEPRINT FOR CHANGE FOR CYSHCN</b> - Dennis Kuo, M.D., M.H.S., FAAP University of Rochester Medical Center How does one change a system? What role does any individual play in changing a system? The Blueprint for Change for CYSHCN has four focus areas – access, equity, quality of life, and finance – AND the Blueprint was built on several key assumptions about the health and wellness of CYSHCN that drive the principles and strategies for change. In this session, attendees will get an overview of how the Blueprint was formed, why the Blueprint starts with key assumptions, and how we draw on lived experiences, human-centered design, and empathy to change a system. Attendees will learn these key assumptions, principles, and strategies that underpin the four focus areas of the Blueprint, and understand how the principles and strategies influence their own work in changing systems of care.  <b>BIO:</b> Dr. Kuo is the Purcell Family Distinguished Professor of Pediatrics and Chief of Developmental and Behavioral Pediatrics at the University of Rochester Medical Center/Golisano Children’s Hospital. Dr. Kuo has a longstanding interest in the care of children with disabilities and medical complexity, including systems of care, early childhood, and health equity. His work has focused on defining family-identified needs of children with medical complexity and neurodevelopmental disabilities, and designing the systems of care needed to address the life course needs of children and families. Dr. Kuo has served on numerous state and national work groups as an expert in the care of children with disabilities and medical complexity, and he is the Immediate Past Chair of the AAP Council on Children With Disabilities.
<b>BREAK: 10:15 – 10:30 AM</b>	
<b>10:30 AM</b> <b>Breakout A</b>  <b>Ballroom E</b>  <b>BLUEPRINT:</b>  <b>Access to Care</b>	<b>TACKLING ACCESS BARRIERS FOR CYSHCN</b> -Jacquelyn White, Community Relations Coordinator, The PEAL Center -Carmen Roman, Family Resource Specialist-Bilingual, The PEAL Center This session will explore obstructions and access barriers from a family perspective. Families experience challenges accessing information, supports and services, lack knowledge of systems, as well as other barriers that cause needs to go unaddressed. Considering these variables and how family engagement can serve to identify and tackle challenges in our service delivery, while meeting family and patient needs, can help position us to toward closing the gaps.  <b>BIOS:</b> Jackie White is the Coordinator of Community Relations and Executive Support for the PEAL Center. As the mom of 3 children with disabilities she has extensive personal experience in advocating for the rights of children with disabilities. She is a graduate of CUNY School of Professional Studies with a Bachelor of Arts degree in Disability Studies and is a current MPH student at Temple University. Additionally, she has completed C2P2 through the Temple Institute on Disabilities and loves being able to use her lived experience in her work. Advocating for Children and Youth with special needs in the healthcare capacity is of particular interest.

	<p>Carmen Roman is a strong parent advocate and agent of change through her initiatives raising awareness through the state of PA, utilizing her communication platforms and training experience to “build bridges for families to connect with professional alliances.” Her journey began as a parent advocate when her daughter was diagnosed and struggled to navigate the complex Special Needs systems. She has been an accomplished bilingual advocate, healthcare and community leader for the past 23 years. She has also served as commissioner and board member for different organizations. She is a faculty member for a local college, certified and licensed in various fields: healthcare, finances, insurance, diversity, inclusion, drug and alcohol. She believes in empowering families to create the best environment for their children to thrive.</p>
<p><b>10:30 AM Breakout B</b></p> <p><b>Cameron Room</b></p> <p><b>BLUEPRINT:</b></p> <p><b>Financial</b></p>	<p><b>TEMPLE UNIVERSITY'S TECH OWL PROGRAM: A COMMUNITY RESOURCE FOR INDIVIDUALS WITH DISABILITIES</b></p> <p><b>-Marci Walborn, Director of Childhood and Ancillary Services, United Cerebral Palsy of Central PA</b></p> <p><b>-Jacqueline Wardle, Assistive Technology Specialist</b></p> <p>TechOWL is Pennsylvania’s Assistive Technology Act program. TechOWL has 9 regional centers across the Commonwealth of Pennsylvania to help people with disabilities explore the tools and technology they need to be independent. Learn more about the resources available through TechOWL and how to access these resources.</p> <p><b>BIOS:</b> As Director of Childhood and Ancillary Services, Marci Walborn provides strategic direction and oversight of several inter-related UCP service lines, including Early Intervention, Family Support, and Assistive Technology/Independent Living Technology. She is responsible for fiscal oversight, regulatory compliance, continuous staff development, and ongoing evaluation of each service. With over 20 years of hands-on experience in Early Intervention—and as a testament to her commitment to the successful early development of all children—Marci continues to support a small caseload as an Occupational Therapist. She also lends her Occupational Therapy knowledge and expertise to other UCP divisions as needed.</p> <p>Jacqueline Wardle has a BS in Special Education and an MS in Education of the Hearing Impaired. She began working in UCP’s Assistive Technology Program in 1991, where she was a part of the team completing assistive technology evaluations. She has extensive knowledge of a variety of assistive technology. Jackie helped establish and build UCP’s Changing Hands equipment reuse program and is integral in implementing the TechOWL initiatives at UCP Central PA, providing device demonstrations, overseeing short term equipment loans, and providing support to individuals with obtaining adapted phones from Pennsylvania’s Free Special Phone Program.</p>
<p><b>10:30 AM Breakout C</b></p> <p><b>Keystone Room</b></p> <p><b>BLUEPRINT:</b></p> <p><b>Health Equity</b></p> <p><b>Access to Care</b></p>	<p><b>PEDIATRIC TO ADULT CARE TRANSITIONS</b></p> <p><b>-Mary Stephens, MD, Jefferson FAB Center for Complex Care</b></p> <p><b>-Karin Roseman, LCSW, Jefferson FAB Center for Complex Care</b></p> <p>The American Academy of Pediatrics acknowledges “Optimal health care is achieved when each person, at every age, receives medically and developmentally appropriate care. The goal of a planned health care transition is to maximize lifelong functioning and well-being for all youth, including those who have special health care needs and those who do not.” The Jefferson FAB (For Adolescents and Beyond) Center is a primary care medical home for adolescents and adults with complex childhood-onset conditions located in Philadelphia, PA and is part of the Department of Family and Community Medicine at Jefferson Health. The speakers will discuss the barriers this medically underserved population faces when transitioning to adult care, and successes they have had with planned health care transitions.</p> <p><b>BIOS:</b> Dr. Mary Stephens is an Associate Professor in Family and Community Medicine at Thomas Jefferson University in Philadelphia, PA. In 2019 she helped launch the Jefferson Continuing Care Program, a new primary care practice for teens and adults with complex childhood onset conditions. In 2023, JCCP became the Jefferson FAB Center for Complex Care, directed by Dr. Stephens and Karin Roseman, LCSW. She is actively involved in student and resident education at Jefferson and regularly volunteers with Camp PALS, Special Olympics PA, and Special Olympics USA. Additionally, Dr. Stephens serves on the Board of Directors of the Down Syndrome Medical Interest Group (DSMIG) and is a member of the volunteer committee for the Global Down Syndrome Foundation's adult healthcare guidelines.</p> <p>Karin Roseman, MSW, LCSW is a Licensed Clinical Social Worker in the Department of Family and Community Medicine at Thomas Jefferson University in Philadelphia, PA. She is the co-director, alongside Dr. Mary Stephens, of the Jefferson FAB Center for Complex Care, a primary care practice for teens and adults with complex childhood onset conditions. Karin holds a Bachelor of Science in Therapeutic Recreation and a Master of Social Work both</p>

	<p>from Temple University in Philadelphia, PA and has over a decade of experience working with children and adults with complex healthcare needs, Intellectual and Developmental disabilities. At the FAB Center she helps to provide psychosocial education and support to patients and their caregivers, educate students from various disciplines on working with this complex population, support growth of the program through research and grants, and support the overall expansion and direction of the program.</p>
<p><b>10:30 AM Breakout D</b></p> <p><b>Ballroom D</b></p> <p><b>BLUEPRINT:</b></p> <p><b>Health Equity</b></p> <p><b>Access to Care</b></p>	<p><b><i>ACHIEVING HEALTH EQUITY THROUGH PARTNERSHIPS, INNOVATION AND TECHNOLOGY</i></b></p> <p><b>-Andrea Matthews, Founder, Children’s Sickle Cell Foundation, Inc.</b></p> <p><b>-Michael Matthews, Executive Director, Children’s Sickle Cell Foundation, Inc.</b></p> <p>CSCF works with both UPMC Children’s Hospital of Pittsburgh Pediatric and UPMC Adult Sickle Cell Programs on several programs designed to eliminate health disparities and improve health outcomes. Whether establishing a rubric for direct financial assistance distributed according to household size vs. a particular amount for every family or improving access for families living in rural Pennsylvania by launching statewide toll-free care line or through the Introduction to Being a Physician Program, where first year medical students interact with persons living with sickle cell disease. These programs have a profound impact on achieving health equity across systems.</p> <p><b>BIOS:</b> Andrea Matthews is the Executive Director of The Brashear Association, and the founder of the Children’s Sickle Cell Foundation, Inc., where she served as Executive Director for 13 years. From there, she served as Public Health Analyst with the Health Resources and Services Administration in the Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs. With more than 20 years of experience in the non-profit sector, Andrea believes in the power of innovation and change. “Your Voice can change the world.” is a message that she shares with emerging leaders. She is an author and transformative leader, wife and mother of a young adult living with SCD, who passionately weaves all her experiences into inspiring messages of hope for everyone living with sickle cell disease and those who care for them.</p> <p>Michael Matthews is the Executive Director of the Children’s Sickle Cell Foundation, Inc., whose mission is to provide quality programs for children with sickle cell disease and their families to help them face the educational, social and economic challenges caused by the (SCD) through an integrated system of community and hospital partners. He formerly served as the Program Director, responsible for the development, implementation and evaluation of all CSCF programs including the flagship, Educational Support Program, which serves school aged children through college. Michael’s passion for innovation and experience in quality improvement has resulted in steady organizational growth and impact for families with sickle cell across Pennsylvania. CSCF is the state lead for the PA Living Well with Sickle Cell Program, Sickle Cell Disease Newborn Screening Follow-Up Program, and the Pennsylvania Sickle Cell Providers Network, and formerly served as Lead for the regional SiNERGe Project ECHO for Community Based Organizations.</p>
<p><b>LUNCH: 11:45 AM – 12:45 PM</b></p>	
<p><b>AFTERNOON PLENARY SESSION</b></p>	
<p><b>12:45 – 1:45 PM</b></p> <p><b>Ballroom A/B/C</b></p> <p><b>BLUEPRINT:</b></p> <p><b>Access to Care</b></p> <p><b>Quality of Life</b></p>	<p><b><i>Resilient Leadership: Leading Organizations Where People Want to Work</i></b></p> <p><b>-Caitlin Bailey, PhD, Co-Director, National Leadership Consortium</b></p> <p><b>-Kristen Loomis, MBA, Co-Director, National Leadership Consortium</b></p> <p>Leaders are busier and more stressed out than ever. Through our work, the National Leadership Consortium has consistently heard about challenges related to staff shortages, employee engagement, and organizational culture. The pandemic made these challenges worse despite leaders showing incredible resilience (ability to adapt and be flexible). We can learn from leaders who have focused on healing, recognition, building trust, and hope. During this session, the National Leadership Consortium will share lessons learned from leaders and other strategies and practices that leaders can use to build sustainability, engagement, and connection within their teams to make their organization a place where people want to work. Attendees will leave this session with strategies, ideas, and resources they can use in their organizations and teams.</p> <p><b>BIOS:</b> Caitlin Bailey is the Co-Director of the National Leadership Consortium. In her role, she leads the development and coordination of all research and evaluation projects and technical assistance and support to organizations and disability sector leaders as well as strategic planning initiatives for the Consortium. Caitlin brings significant knowledge and experience in research, evaluation, training, development, and facilitation of leadership development programs for the disability service sector and the Federal government. Caitlin has served</p>

	<p>on the Boards of Directors for the National Alliance for Direct Support Professionals, the Alliance for Citizen Directed Supports, and the advisory committee for NAQ.</p> <p>Kristen Loomis is the Co-Director of the National Leadership Consortium programs, services, products, and activities. Kristen has worked with the National Leadership Consortium since 2012. Her work has focused on developing and coordinating training and technical assistance for leaders across the intellectual and developmental disabilities field. Kristen received her Bachelor of Science degree in Human Services and her Master of Business Administration with a concentration in Strategic Leadership from the University of Delaware.</p>
	<b>BREAK: 1:45 – 2:00 PM</b>
<p><b>2:00 PM</b> <b>Breakout E</b></p> <p><b>Ballroom E</b></p> <p><b>BLUEPRINT:</b></p> <p><b>Health Equity</b></p> <p><b>Access to Care</b></p> <p><b>Financial</b></p>	<p><b><i>TRANSITION AGE NAVIGATION GUIDE FOR YOUTH WITH AUTISM</i></b>  <b>-John Lees, Member &amp; Family Advocate, Magellan of Pennsylvania</b>  <b>-Kristen Scalise, LCSW, Manager, Clinical Care Services, Magellan of Pennsylvania</b></p> <p>The Autism Action Committee, with the support of Magellan Behavioral Health of Pennsylvania, created this guide to help young people, families, teachers, counselors, and other professionals and volunteers who work with neurodiverse youth. Our guide helps support and prepare youth with autism to be successful in adulthood. This session will provide an overview of this resource.</p> <p><b>BIOS:</b> John Lees has been the Member &amp; Family Advocate at Magellan of PA since 2016. John’s role as the Member &amp; Family Advocate is to help Magellan members and their families in Lehigh and Northampton counties. As a licensed social worker for over 23 years, John has experience working in a variety of settings, including outpatient behavioral health, residential treatment facilities, crisis intervention, juvenile detention, and schools. This experience provides him with a well-rounded approach to members’ and providers’ needs. John has been with Magellan of PA since 2004 working in a variety of roles including Clinical Care Management Supervisor and Director of Training. As the Member &amp; Family Advocate, John acts as a point of connection between Magellan and members, their families, and other support individuals. John can also help to educate members about Magellan, advocate to meet their treatment needs, and help them navigate services. John is also the Chairman of the Magellan Autism Action Committee and Host of the new “Behavioral Health Matters Podcast” by Magellan of PA.</p> <p>Kristen Scalise holds a master’s degree in social work from Rutgers University and a bachelor’s degree in community health. In her 25 years in the field, her experience varies from an HIV/AIDS Case Manager and Sexuality Educator for Planned Parenthood to specific roles in supporting youth and adults within their mental and behavioral health recovery. Kristen has worked for Magellan Behavioral Health for almost 15 years initially as a Clinical Care Manager and now a Clinical Manager. Her primary role is to support the Care Managers who oversee and members/families who access any children’s community based services funded by Magellan. Kristen has also been heavily involved with the Autism Action Committee at Magellan since its inception. She enjoys working with the providers and members to ensure quality treatment for those in need.</p>
<p><b>2:00 PM</b> <b>Breakout F</b></p> <p><b>Cameron Room</b></p> <p><b>BLUEPRINT:</b></p> <p><b>Financial</b></p>	<p><b><i>PA NAVIGATE: A STATE-WIDE APPROACH TO ADDRESSING HEALTH RELATED SOCIAL NEEDS</i></b>  <b>-Keith Cromwell, M.Ed., Program Director, Central PA Connect Health Information Exchange</b>  <b>-Bill Marella, MBA, MMI, VP Value Based Care &amp; Analytics, Health Share Exchange</b></p> <p>The session will highlight the private-public partnership in the Commonwealth of Pennsylvania, created to address health related social needs for the citizens of the state. Working together the Pennsylvania Department of Human Services and 4 state certified health information exchanges have created a state-wide closed loop resource and referral tool, known as PA Navigate. The panel will discuss the funding streams used, the procurement journey that ultimately led to the selection of FindHelp as the vendor, as well as the interoperability successes and challenges connecting health care providers, payers and community based organizations into a common state-wide solution. The panel will also discuss how they engaged with Community Action Partnership of Pennsylvania to help augment the solution and provide community engagement and call center services as part of the PA Navigate program. The speakers will also share how members of the audience can get engaged with PA Navigate and leverage the platform to improve social care coordination across the Commonwealth.</p>

	<p><b>BIOS:</b> Keith Cromwell is the Program Director at Central PA Connect Health Information Exchange, where he leads the effort to connect the South Central Pennsylvania region and beyond both regionally and to the state based HIE network. In addition to his role at Central PA Connect HIE, Keith also serves as the Director of Ambulatory Applications and Epic Connect at Penn Medicine. Keith has been in healthcare IT for over 27 years and has worked in the health data exchange space for the past 15 years. Always focusing on creating systems that strive to deliver the appropriate clinical information into the hands of clinicians at the right time. Keith received a Master of Education from Pennsylvania State University and a Bachelor of Science in Computer Science from Millersville University. He currently serves as a member of the Epic CareEverywhere Governing Council, HIMSS Interoperability Committee, HIMSS SDOH Committee and the Pennsylvania HIE Trust Community Committee.</p> <p>Bill Marella is Vice President, Value Based Care and Analytics, at HealthShare Exchange (HSX) the healthcare data aggregator for the Greater Philadelphia region. Covering southeastern PA, southern NJ, and northern DE, HSX synthesizes clinical data from more than 500 healthcare providers and over 40 electronic medical record platforms. With over 14 million patients in its clinical data repository, HSX has one of the most complete repositories of healthcare data and outcomes for people living in this region. At HSX, Mr. Marella is responsible for ensuring the data's usability for programs in population health, public health, healthcare quality measurement; he is also responsible for overall data quality. He leads HSX's Data Aggregator Validation (DAV) certification from the National Committee for Quality Assurance (NCQA) as well as HSX's participation in developing PA Navigate, a statewide program for connecting people with resources to address social needs.</p>
<p><b>2:00 PM</b> <b>Breakout G</b></p> <p><b>Ballroom D</b></p> <p><b>BLUEPRINT:</b></p> <p><b>Access to Care</b></p> <p><b>Quality of Life</b></p>	<p><b><i>EQUITABLE FAMILY ENGAGEMENT: CRITICAL TO WELL-FUNCTIONING SYSTEMS</i></b></p> <p><b>-Sadia Batool, Early Childhood Family Lead for Early Childhood Comprehensive Systems, Departments of Education and Human Services, Office of Child Development and Early Learning</b></p> <p><b>-Christina Harris, Early Childhood Lead for Early Childhood Comprehensive Systems Project, Departments of Education and Human Services, Office of Child Development and Early Learning</b></p> <p><b>-Family Members: Melissa Egan Kerr; Drew Whelan; Maggie Parke</b></p> <p>This session will highlight equitable family engagement practices vital to implementing the Blueprint for Change through a diverse panel of families of CYSHCN who will share their experiences as advocates and vital partners to improving systems for a better tomorrow.</p> <p><b>BIOS:</b> Sadia Batool, born and raised in Dubai is a physician by qualification with a current focus on supporting families and professionals in the Early Childhood Systems. Her passion for Early Childhood field stems from her personal experience of receiving life-changing Early Intervention services for her daughter. Sadia is a graduate of the Pennsylvania Office of Child Development and Early Learning Policy Fellowship and the 2023 National Prenatal to Three Leaders Fellowship from the Rockwood Leadership Institute. She currently serves as a family and professional representative on a variety of local, state-wide, and national organizations serving families and children including serving as the Governor appointed parent Co-chair to the Pennsylvania State Interagency Coordinating Council. Sadia is committed to enhancing family engagement and leadership across maternal and early childhood systems. In 2021, she joined the Pennsylvania Office of Child Development and Early Learning as the Early Childhood Family Lead for Early Childhood Comprehensive Systems (ECCS) Health Integration Prenatal-to-age Three Project, a Federal grant Pennsylvania received to focus on cross-sector collaboration and partnership, health system transformation, state-level policy and fiscal innovation, family leadership, and advancing equity.</p> <p>Christina Harris is the Early Childhood Lead for Early Childhood Comprehensive Systems Project through the Pennsylvania Office of Child Development and Early Learning (OCDEL). Christina has a BS from Indiana University of Pennsylvania in Exercise Science and Physiology with a minor in Nutrition, and a MS from California University of Pennsylvania in Health Promotion. Christina is passionate about her work within OCDEL because it allows for collaboration on initiatives to create a brighter future for Pennsylvania</p> <p>Melissa Egan Kerr is the parent of two young children, one of whom has a rare neuromuscular disorder called Joubert Syndrome. Feeling isolated and overwhelmed by the unique challenges of raising a child with medical complexities, Melissa sought out training and support programs for guidance and community. These family leadership experiences proved transformative, enhancing her ability to support her son, connect with other families, and advocate for systemic change. Last year, she completed Pennsylvania's Partners in Policymaking, Competence and Confidence for Families of Children in Early Intervention (C2P2 EI) and attended the Division of</p>



	<p>Early Childhood International Conference as a family leader. Melissa is passionate about challenging and unlearning ableist perceptions, improving support systems for siblings of children with disabilities, and championing accessibility and inclusion within the arts. Professionally, she works as a grant writer for a regional theatre.</p> <p>Drew Whelan is the father of four-year-old twin girls, one of whom was born with congenital heart defects. She spent her first eight months at the Children’s Hospital of Philadelphia, primarily in the Cardiac Intensive Care Unit and was on the heart transplant list for a large percentage of this time. Since birth, she has undergone five open heart surgeries as well as other procedures on her heart. She takes numerous medications daily and all of her feeding is through a G-Tube. At age three, she was diagnosed with moderate to severe autism and is currently non-verbal. Being the father of a child with such needs, Drew sought out training and support. Drew recently completed the Pennsylvania’s Partners in Policymaking, Competence and Confidence for Families of Children in Early Intervention (C2P2 EI). Drew is passionate about getting fathers more involved in the overall care and support of their children who have physical and/or mental difficulties. Drew currently serves as a member of Early Childhood Comprehensive Systems Advisory Committee; a cross sector advisory committee working to better coordinate and align Pennsylvania’s maternal and early childhood systems.</p> <p>Maggie Parke is a dedicated and compassionate individual with over 25 years of experience as a peer supporter for Parent to Parent of PA. As the South-Central Regional Coordinator for Parent to Parent of PA, Maggie champions the needs of families with varying special needs, drawing from her personal experience as a parent of four adult children with special needs. Her leadership extends to serving as the Board Chair of PA Families Inc, demonstrating her commitment to making a positive impact in the lives of others.</p>
<p><b>2:00 PM</b> <b>Breakout H</b></p> <p><b>Keystone Room</b></p> <p><b>BLUEPRINT:</b></p> <p><b>Health Equity</b></p> <p><b>Access to Care</b></p> <p><b>Quality of Life</b></p>	<p><b><i>IMPROVING SUPPORTS FOR CYSHCN THROUGH CAREGIVER WELLBEING</i></b></p> <p><b>-Meghann Luczkowski, MS Ed., Community Network Navigator &amp; Family Caregiver, Technology Assisted Children's Home Program</b></p> <p><b>-Erin Johnson, MPH, Program Coordinator &amp; Public Health Nurse, Technology Assisted Children’s Home Program</b></p> <p>Families of CYSHCN tell us that the current system of services is not working for their children, leaving their caregivers to fill in those gaps. While it is known that 85% of CYSHCN still do not receive services via a well-functioning system, the profound and various impacts on the wellbeing of their caregivers and the function of their families is still not being accounted for. If we are not doing our best for the whole family, then we are not doing our best for a child with special health care needs. As family caregivers of CYSHCN working in a program that directly supports technology dependent children, we combine our personal and professional experience to spotlight this gap and explore how all stakeholders supporting CYSHCN can address it.</p> <p><b>BIOS:</b> Meghann Luczkowski serves technology assisted children and their families as a Community Network Navigator for TACHP. Meghann graduated from Arcadia University with a degree in Psychology and earned her M.S. in Education from the University of Pennsylvania. She is a certified special educator and the parent of children with disabilities. Meghann combines her professional and personal experiences to improve systems of care for all children and families. She is proud to serve as an appointee of the Medical Assistance Advisory Council's Consumer Subcommittee, as well as Board Secretary of Partnership for Community Supports, Program Consultant for Vision for Equality, and Steering Committee member of the Imagine Different Coalition.</p> <p>Erin Johnson is currently the Program Coordinator and a Registered Nurse for the Technology Assisted Children’s Home Program (TACHP), Health Promotion Council. TACHP is a home visiting and telehealth program serving families of children who are technology-assisted in 31 counties of Pennsylvania. Erin is also part of the Imagine Different Nursing Shortage Workgroup coalition and created the first iteration of the Shift Check app, a mobile application for family caregivers. Erin gained relevant experience for this position after navigating her daughter's diagnosis and treatment for an uncommon type of infant Acute Lymphoblastic Leukemia (ALL). Previously Erin was Assistant Clinical Professor at the College of Nursing &amp; Health Professions at Drexel University where she taught population health courses for pre and post-licensure nurses. Ms. Johnson holds a Bachelors of the Arts in Environmental Studies (BA), Bachelor of Nursing (BSN), a Master of Science in Nursing, Health Leadership (MSN), and a Master of Public Health (MPH).</p>
<p><b>BREAK: 3:00 – 3:30 PM</b></p>	

<p><b>3:30 PM Breakout I</b></p> <p><b>Ballroom E</b></p> <p><b>BLUEPRINT:</b></p> <p><b>Health Equity</b></p> <p><b>Access to Care</b></p> <p><b>Quality of Life</b></p> <p><b>Financial</b></p>	<p><b><i>POLICIES IMPACTING CARE ACCESS FOR CYSHCN AND WELLBEING OF PARENTS</i></b></p> <p><b>-Douglas Strane, MPH, Research Scientist, Children’s Hospital of Philadelphia</b>  <b>-Asiya Validova, PhD, Postdoctoral Research Fellow, Children’s Hospital of Philadelphia</b>  <b>- Aditi Vasan, MD, MSHP, Pediatric Hospitalist and Health Services Researcher</b></p> <p>Researchers will share how policies related to health insurance, care coordination support, and family medical leave can affect parents of CYSCHN, including their wellbeing, the care they are able to provide, and the care their children can access. Presenters will conclude with a discussion of potential policy solutions.</p> <p><b>BIOS:</b> Doug Strane is a research scientist at PolicyLab at Children’s Hospital of Philadelphia (CHOP). Mr. Strane is experienced in mixed methods program evaluation and analysis of administrative data for observational study designs related to child and family health. His research interests include the ways in which health systems can address social determinants of health; the changing health insurance landscape for families; and the intersection of parenting and substance use disorder. He also serves as the Senior Evaluation Manager at CHOP's Center for Health Equity. Mr. Strane received his Master of Public Health in Epidemiology from the University of Michigan School of Public Health. He is a former Centers for Disease Control and Prevention Public Health Associate Program fellow.</p> <p>Asiya Validova is a postdoctoral research fellow at PolicyLab. She joined the team of Dr. Meredith Matone to take part in policy-oriented health services research. Dr. Validova is involved in several research projects in maternal and child health including the study of mental/behavioral healthcare utilization and the impact of underinsurance on children’s ability to access care and on their health status. Asiya Validova received her PhD in Applied Demography from University of Texas at San Antonio where she conducted research in such fields of public health and demography as children's and adolescents' health, income inequality and population health, fertility behavior in low-fertility countries. Asiya’s current research interests include socio-economic inequalities and their health consequences, health disparities in children's health, and immigrant adolescents' mental health.</p> <p>Aditi Vasan is a faculty member at PolicyLab and an attending physician with the Division of General Pediatrics at Children’s Hospital of Philadelphia (CHOP) and the Perelman School of Medicine at the University of Pennsylvania. She also serves as the faculty lead for PolicyLab's Health Equity Portfolio. Dr. Vasan is passionate about health equity, and her research is centered on improving health outcomes for children and families living in poverty. Her current work is focused on understanding and addressing the impact of social determinants of health on child health outcomes, implementing and evaluating social needs screening and referral programs, alleviating families' barriers to government benefit program participation, and exploring the relationship between childhood food insecurity, government nutrition benefit program participation, and children's health care utilization and expenditures.</p>
<p><b>3:30 PM Breakout J</b></p> <p><b>Ballroom D</b></p> <p><b>BLUEPRINT:</b></p> <p><b>Health Equity</b></p> <p><b>Access to Care</b></p> <p><b>Quality of Life</b></p>	<p><b><i>FAMILY IMPACT INITIATIVE</i></b></p> <p><b>-Mary Glazer Smyth, MPH, CYSHCN Program Manager, Philadelphia Department of Public Health</b>  <b>-Danielle Rhodes, Public Health Program Administrator, PA Department of Health</b></p> <p>This presentation will cover the implementation and current goals of the systems change initiative, FII, which focus is an improved system of care for CYSHCN. FII is a formalized partnership between local health departments, local community partners and healthcare providers who serve CYSHCN, and families of CYSHCN as leaders improving the system of care for CYSHCN.</p> <p><b>BIOS:</b> Mary Glazer Smyth is the CYSHCN Program Manager in the Division of Maternal, Child, and Family Health at the Philadelphia Department of Public Health. She leads the Family Impact Initiative, a systems change program focused on improving the lives of CYSHCN by increasing access to resources and availability/cultural sensitivity of services. She also leads the Philadelphia Special Needs Consortium and oversees the administration of grants to Community Based Organizations serving CYSHCN. She is committed to improving health equity for all people with disabilities in Philadelphia.</p> <p>Danielle Rhodes is a Public Health Program Administrator in the Bureau of Family Health at the Pennsylvania Department of Health. Danielle’s responsibilities in the bureau consist of answering the Special Kids Network helpline to provide information and resources to families across PA who have a child with special health care</p>

	needs (CYSHCN) as well as administering the home visiting program for CYSHCN, Community to Home, and the newly implemented system change initiative, Family Impact Initiative. Danielle has served children and families in need at both the local and state levels for almost 15 years in various systems of care.
<b>3:30 PM Breakout K</b>  <b>Cameron Room</b>  <b>BLUEPRINT:</b>  <b>Financial</b>	<p><b>PROMOTING FINANCIAL INDEPENDENCE WITH PA ABLE &amp; KEYSTONE SCHOLAR</b>  <b>-Larry Booker, Central PA Regional Program Manager, PA Department of Treasury</b></p> <p>A PA ABLE Savings Program account encourages eligible individuals to save private funds to support health, independence and quality of life. PA ABLE gives individuals with qualified disabilities and their families and friends a way to save for a wide range of disability-related expenses while maintaining government benefits. PA ABLE accounts are free to open. Investment options are state and federal tax free. During this session, you will learn what PA ABLE is and who is eligible; learn about the wide variety of qualified expenses; and, understand how PA ABLE accounts interact with current benefits. Keystone Scholars account funds can be used for qualified higher education expenses including tuition, fees, books, and more at a vocational or technical school, apprenticeships, community college, or four-year university anywhere in the country and at many schools abroad. This session will also provide detailed information on the Keystone Scholars program.</p> <p><b>Bio:</b> Larry Booker is PA Treasury’s Central Pennsylvania Relationship Program Manager. He has over 15 years of experience in financial services and client relations. Prior to joining PA Treasury, he was supervisor at the Pennsylvania Higher Education Assistance Agency where he managed a team of Guarantor/Insurer Relations representatives. Larry previously worked as a customer service representative with the Pennsylvania Department of Treasury’s Consumer Programs division, advising investment options and assisting with account maintenance. Larry’s career has centered around helping families prepare for the future teaching the importance of financial literacy and planning. He is a strong believer in the principle that “every dollar saved is a dollar you don’t have to borrow.”</p>
<b>3:30 PM Breakout L</b>  <b>Keystone Room</b>  <b>BLUEPRINT:</b>  <b>Health Equity</b>	<p><b>Disability Justice and Title V: Operationalizing the CYSHCN Blueprint in Pennsylvania</b>  <b>-Paige Falion, MS, AMCHP</b></p> <p>This session will equip attendees with skills to build stronger systems to support individuals with special health care needs and disabilities that will not only improve their circumstances but will create better, more coordinated systems for all. This session will address how to infuse disability equity into public health programs, policies, and practices by demonstrating a model for including all voices, especially those with lived experience, in decision making and program design. Participants will learn foundational concepts of disability equity and participate in an interactive exercise to apply the concepts to actual CYSHCN-focused programs and services in Pennsylvania, exploring ways to make their work more accessible and inclusive.</p> <p><b>Bio:</b> Paige (Bussanich) Falion, MS, is the Associate Director for Child Health and CYSHCN at the Association of Maternal and Child Health Programs (AMCHP). Ms. Falion has over 10 years of extensive experience in working with individuals with disabilities in research, evaluation, and outreach settings and is passionate about disability justice and community-based participatory research. She leads AMCHP’s Child &amp; Adolescent Health team in the tracking, analysis, and reporting on federal and state programs impacting child, adolescent, and CYSHCN health and in strengthening the capacity of state-level efforts related to CYSHCN. She received her bachelor’s degree in psychology from the University of Alabama and received her Master of Science in Human Development &amp; Family Studies at the University of Wisconsin-Madison School of Human Ecology, where her research was focused on parental attributions for positive behaviors in children with autism spectrum disorder.</p>
<b>TURN IN EVALUATION FORMS /CLOSE OF SYMPOSIUM: 4:30 – 4:45 PM</b>	