

# Disability Health Action Summit

  
**The Arc**  
Pennsylvania



**Beyond Barriers,  
Toward Solutions**

**Camp Hill, PA  
May 19-20, 2026**

# Tuesday, May 19, 2026

Registration will be open from 12:00 - 4:45.  
Sponsor exhibits open. Vendor exhibits closed.  
All sessions to be in the [Grand Ballroom](#).

**1:00 - 1:10**

## Welcome

Sherri Landis, The Arc of Pennsylvania

**1:10 - 1:30**

## Keynote: You Don't Use Them Anyway: What Healthcare Still Gets Wrong About Disability

Theotis W. Braddy, MSW, Executive Director, National Council on Independent Living

**1:30 - 2:15**

## Legal Access as Disability Health Justice: Scalable Models for Breaking Systemic Barriers

Sherry Thomas, Legal Clinic for the Disabled

**2:15 - 2:30**

## Break & Exhibits

**2:30 - 3:15**

## Panel: Emergency Preparedness

Kohei Akiba, Public Health Management Corporation (PHMC) - Research & Evaluation (R&E) Group; Maria Brandt, The Arc of Blair County; Jason Rechtman, PerformCare  
*Moderator:* Sherri Landis, The Arc of Pennsylvania

**3:15 - 4:00**

## Beyond the Diagnosis

Dr. Josie Badger, J Badger Consulting & Susan Tachau, Project Beyond the Diagnosis

**4:00 - 4:45**

## Panel: Policy Outlooks

Dr. Josie Badger, J Badger Consulting; Jennifer Garman, Disability Rights Pennsylvania; Mary Hartley, The Arc of Greater Pittsburgh (Achieva)  
*Moderator:* Sherri Landis, The Arc of Pennsylvania

# Wednesday, May 20, 2026

Registration will be open from 12:00 - 4:45.

Sponsor exhibits open. Vendor exhibits closed.

All sessions, except Breakouts, to be in the [Grand Ballroom](#).

**8:00 - 8:50**      **Breakfast & Exhibits**

**8:50 - 9:00**      **Welcome**

Sherri Landis, The Arc of Pennsylvania

**9:00 - 9:20**      **Keynote: Valerie A. Arkoosh, MD, MPH**

Secretary, Pennsylvania Department of Human Services

**9:20 - 10:05**      **Effectively Partnering with Healthcare Professionals through CARE Down Syndrome**

Dana Sciullo, National Down Syndrome Society (NDSS) & Anthony Sciullo

**10:05 - 10:50**      **Bridging the Data Gap: Disability Inclusion in Community Health Assessments**

Makhari Dysart & Hannah Wells, Institute on Disabilities at Temple University

**10:50 - 11:20**      **Break & Exhibits**

**11:20 - 12:05**      **Breakout Sessions**

**Keystone A: Breaking the Silence: Building Accessible Mental Health Services for Deaf, Hard of Hearing, and Deafblind Communities**

Neil McDevitt, Deaf-Hearing Communication Centre

**Keystone B: The Impact of Self-Advocate Storytelling on the Development of Disability Education Resources for Healthcare Providers**

Karin Roseman, MSW, LCSW, Jefferson University FAB Center for Complex Care

**Keystone C: Empowerment Through Technology: Accessible, Affordable, Life-Enhancing Tech; Real Tools, Real Lives, Real Independence**

Diana Petschauer, M.Ed., ATP & Travis Fiem, ETIS, AHS Smart Living Tech, Arc Human Services

# Wednesday, May 20, 2026

**12:05 - 1:15**      **Lunch & Exhibits**

**1:15 - 2:00**      **Breakout Sessions**

**Keystone B: Partnering with Caregivers to Promote Optimal Oral Health for People with ID/A**

Saumya Ayyagari, MSN, MPH & Kelly Parker, RDH, Special Outreach Services

**Keystone C: Designing for Neurodiversity: Building Inclusive Spaces for Health Equity**

Sabra Townsend, MS & Wendy J. Ross, MD, FAAP, Jefferson Health

**2:00 - 2:45**      **Breakout Sessions**

**Keystone A: Preparing for Clinical Encounters with Individuals with Intellectual/Developmental Disabilities**

Alyssa Siegel, MD, Children's Hospital of Philadelphia (CHOP)

**Keystone B: Integrating ADEPT-CARE for Youth with Intellectual and Developmental Disabilities into a Medical School Curriculum**

Cailey Bozic, Zekiel Factor & Meghan Hartman, Penn State College of Medicine

**Keystone C: The Community Supported Care Model: A Whole Person Health Solution for Pennsylvania**

Charles Hooker & Nancy Murray, William Penn Human Services

Shane Spotts, Deon Health

**2:45 - 3:00**      **Break & Exhibits**

**3:00 - 3:45**      **Panel: Self-Advocate Insights**

Michael Anderson, Raquel Ross, & Monica Albert Still, BSN, RN

*Moderator:* Shane Janick, The Arc of Philadelphia

**3:45 - 4:00**      **Closing Remarks**

Sherri Landis, The Arc of Pennsylvania

**4:00 - 4:30**      **Exit & Exhibits**

Tuesday, May 19, 2026

1:10 - 1:30

## Keynote Speaker

# Theotis W. Braddy, MSW

Executive Director  
*National Council on Independent Living*



Theo Braddy is a nationally recognized disability rights leader with more than four decades of experience advancing civil rights, community integration, and independent living for people with disabilities. He currently serves as Executive Director of the National Council on Independent Living (NCIL), where he leads national advocacy efforts and represents a network of Centers for Independent Living across the United States and Statewide Independent Living Councils.

Prior to NCIL, Braddy founded and served for over 30 years as CEO of the Center for Independent Living of Central Pennsylvania, building a model organization that expanded access to services and strengthened community-based supports. He is a Presidential appointee to the National Council on Disability and serves on multiple advisory councils focused on healthcare access and disability inclusion.

A social worker, educator, and author, Braddy is committed to strengthening the Independent Living movement, advancing disability health equity, and mentoring the next generation of leaders.

Tuesday, May 19, 2026

1:30 - 2:15

# Legal Access as Disability Health Justice: Scalable Models for Breaking Systemic Barriers

## Abstract

People with disabilities face persistent structural barriers that undermine their health, safety, and well-being. Disparities in access to housing, healthcare, education, employment, and public services are often rooted in discriminatory systems that remain unchallenged due to limited access to legal recourse. This presentation reframes legal access as a foundational element of disability health justice—not simply a matter of individual rights, but a critical strategy for advancing population-level health equity. By examining scalable, community-informed models that integrate legal advocacy into healthcare and social service settings, this session explores how legal empowerment can address upstream drivers of health inequity. These include Medical-Legal Partnerships (MLPs), community disability law clinics, and peer-led advocacy initiatives that embed legal services directly into the daily environments of disabled people. The presentation highlights how these models not only help individuals enforce their rights but also create systemic change by disrupting institutional cycles of exclusion and poverty. Drawing on case studies and implementation data this session will identify best practices and core design principles—such as cross-sector collaboration, accessibility, and participatory governance—that enable these legal-health interventions to scale effectively and equitably. Emphasis will be placed on the role of disabled leadership in shaping these efforts, ensuring they reflect the lived realities and priorities of the communities they serve. Participants will leave with concrete strategies for building or expanding integrated legal access programs in their own work, along with a deeper understanding of how legal infrastructure can serve as a tool for disability justice and public health transformation. This presentation makes the case that dismantling legal barriers is not only a civil rights imperative—it is a public health necessity.

## About the Speaker

**Sherry Thomas** joined Legal Clinic for the Disabled in 2011, and today, she heads up the work of LCD's Housing Initiative. Sherry manages a team of attorneys and paralegals to provide direct representation in landlord/tenant matters and to further LCD's work in tenant's rights, defense and eviction prevention. Sherry also works on collaborative advocacy with partners in the Philadelphia Eviction Prevention Project. Sherry was born in India, but grew up in Philadelphia. She received a B.A. in International Relations from University of Pennsylvania, and a J.D. from Temple University School of Law. Sherry loves that the work she does aims to support people going through some of the worst times of their lives. She appreciates being able to use her education and training to stand with LCD's clients, especially when they don't have anyone else to stand with them.



Tuesday, May 19, 2026

2:30 - 3:15

## Panel: Emergency Preparedness

### About the Panelists



**Kohei Akiba** is a project manager who works for the Research & Evaluation Group at the Public Health Management Corporation. He currently resides in the Philadelphia area and has worked in the public health space for the past 5 years, mainly conducting and assisting on evaluation projects covering topics such as disability inclusion, health equity, and tobacco cessation.



**Maria Brandt** has been the Executive Director of The Arc of Blair County for 22 years. Maria is a member of several boards, committees and advisory councils including: Altoona Sunrise Rotary Club where she has received the prestigious Paul Harris Fellow several times and Rotarian of the Year several times; UPMC Behavioral Health Advisory Committee; and Skills of Central Pennsylvania Board of Directors. Maria has chaired the Emergency Management Planning Committee for Persons with Disabilities for several years. This committee partners with businesses, Blair County Emergency Service agencies and schools, agencies and families serving people who have a disability. She has been bestowed the distinct honors of WISE Women of Blair County and the Blair County Chamber of Commerce Athena Award. Maria was the first recipient of Forever Media's ""Famous Hometown Friends"" and has been featured in several articles in the Altoona Mirror newspaper. She has been nominated and received recognition in the Pennsylvania Business Magazine on multiple occasions as one of Women in Business' Top Nonprofit Female Leaders, including, most recently, in April of 2026.



**Jason Rechtman** is a volunteer for the Medical Reserve Corps and member of their leadership committee who has brought his knowledge and experience from working in the I/DD field for over 20 years. By combining these experiences, Jason is focused on improving health outcomes for people with I/DD during emergencies. Jason is also a Licensed Professional Counselor who has extensive experience in crisis prevention and intervention and has provided countless trainings on this and many other subjects related to the dually diagnosed as well.

Tuesday, May 19, 2026

3:15 - 4:00

# Beyond the Diagnosis: Advancing Equitable Access to Services for People with Developmental Disabilities

## Abstract

This session will highlight key findings from Beyond Diagnosis, including results from a multi state review of Home and Community Based Services (HCBS) waivers and policy efforts such as Pennsylvania House Resolution 134. Participants will gain insight into how reimagining eligibility criteria can strengthen service systems, promote dignity and independence, and ensure all people with developmental disabilities are supported to live full lives in their communities.

## About the Speakers



**Dr. Josie Badger** received her Bachelor's degree from Geneva College in Disability Law and Advocacy, a Master's from the University of Pittsburgh in Rehabilitation Counseling, and a Doctorate from Duquesne University in Healthcare Ethics. In 2012, Dr. Badger was crowned Ms. Wheelchair America. In 2014 Josie founded J Badger Consulting Inc. where she provides youth development and disability consulting services. She is the National Transition Director for SPAN Parent Advocacy Network, working with RAISE and the National Healthcare Transition Center for Youth with ID/DD. She is the lead Field Organizer and co-chair for the Family Care Act that supports paid family and medical leave, and is the developer of SAIL, a statewide advocacy and lobbying training program. She also works on the Beyond Diagnosis project. She serves on the ACHIEVA board. Josie also founded PEACOCK a nonprofit that will further support the needs of the disability community. Recently she was contracted by the FISA Foundation to lead their Health Care Access initiatives.



**Susan Tachau** is the manager of Project Beyond Diagnosis. Now in its fourth year, this project focuses its work on addressing service gaps and barriers for people with developmental disabilities who live in the community. Susan serves on several Boards of Directors and advisory councils including Appalachian Assistive Technology Loan Fund, the Pennsylvania Employment First Oversight Commission, the Pennsylvania Statewide Independent Living Council, and Montgomery County's Office of Senior Services. Susan received her B.A. from Colorado College before receiving an M.A. from the Eagleton Institute of Politics at Rutgers University. Susan and her husband are the parents of an adult son who is enrolled in Community HealthChoices, and who lives in his own home and works part-time.

Tuesday, May 19, 2026

4:00 - 4:45

## Panel: Policy Outlooks

### About the Panelists

**Dr. Josie Badger** - learn more about her on page 8.



**Jennifer Garman** has nearly 20 years of experience in disability advocacy. She began her career at DRP as a staff attorney and most recently served for 9 years as the Director of Government Affairs, where she spearheaded policy initiatives that significantly improved independence and inclusion for people with disabilities. Her leadership has been marked by a commitment to empowering individuals and communities, fostering collaboration, and driving impactful change. Previously, Jennifer was the Project Director for the Protection and Advocacy of Beneficiaries of Social Security Project, addressing both individual and systemic barriers to employment for people with disabilities and the duties of employers under the ADA. Jennifer received her J.D. from Widener University School of Law and her B.A. from Pennsylvania State University.



**Mary Anderson Hartley** is a parent advocate who began as a volunteer on the Pittsburgh Local Task Force on the Right to Education. She began her professional career in 2007, working at Achieva on the Disability Healthcare Initiative. Prior to returning to Achieva as the President of The Arc of Greater Pittsburgh, Mary was the Executive Director of the PEAL (Parent Education & Advocacy Leadership) Center and developed the work of United Way of Allegheny County's 21 and Able Initiative. Most notably, she directed #IWantToWork, a self-advocacy social media campaign, increasing employment and financial freedom through three successive efforts that resulted in legislative wins. As a consultant, she also served as Project Director for the Western Pennsylvania Disability History and Action Consortium (WPDHAC). Governor Wolf appointed Hartley to serve on the Employment First Oversight Commission, where she was the inaugural Chair. She is the 2023 recipient of the Richard Meritzer (Pittsburgh) City-(Allegheny) County Task Force on Disabilities/Reel Abilities Award and, in 2018, received Achieva's Excellence in Advocacy Award.

Wednesday, May 20, 2026

9:00 - 9:20

## Keynote Speaker

# Valerie A. Arkoosh, MD, MPH

Secretary

*Pennsylvania Department of Human Services*



Valerie A. Arkoosh, MD, MPH, was appointed to lead the Pennsylvania Department of Human Services by Governor Josh Shapiro on January 17, 2023. Prior to this role, she served on the Montgomery County Board of Commissioners for eight years, serving as Commission Chair from November 2016 through January 2023. As a physician and public health professional, Dr. Arkoosh was at the center of Montgomery County's efforts to combat the COVID-19 pandemic, leading a data- and science-driven approach to the unprecedented challenge.

Dr. Arkoosh's leadership was praised during the county's response, especially her transparency and public communication throughout the pandemic. Upon obtaining her Master of Public Health in 2007, she became deeply engaged in the national effort to achieve comprehensive health care reform.

She led the National Physicians Alliance, a national non-profit organization of physicians, who, putting their patients before profits, joined a broad-based nation-wide coalition for reform. During this time, she developed policy and legislative strategy, and promoted public engagement in Washington, D.C., Pennsylvania, and throughout the country. Dr. Arkoosh maintains comprehensive knowledge of the implementation of the Patient Protection and Affordable Care Act and its impact on individuals and the health care system.

Wednesday, May 20, 2026

9:20 - 10:05

# Effectively Partnering with Healthcare Professionals through CARE Down Syndrome

## Abstract

Navigating the healthcare system can feel overwhelming for many adults with Down syndrome and their families. Medical appointments are often brief, and many healthcare professionals receive limited training on the unique health considerations associated with Down syndrome. As a result, families and self-advocates may find themselves needing to explain health differences, raise concerns that may be unfamiliar to clinicians, or advocate for appropriate screening and care. While clinicians want to provide the best possible care, they may not always have access to the most current information about the health needs of individuals with Down syndrome. The presenter will introduce CARE Down Syndrome, a free, online, clinical education and resource hub created by the National Down Syndrome Society and Dr. Brian Chicoine that provides evidence-informed training for healthcare professionals. Participants will also be introduced to additional trusted resources that can be shared with clinicians in a respectful and collaborative way.

## About the Speakers



**Anthony Sciuolo** is 33 years old and lives with his parents in Pennsylvania. He works at a local auto shop. Anthony loves the outdoors, photography, watching the Pittsburgh Penguins, working out at the gym, and traveling. Hockey and football are his favorite sports to watch on TV. He is happy to have his sister, Dana, around to spend time with him. They do lots of fun things such as go on family vacations, play games, and make meals together. They make happy memories and support each other. Anthony looks forward to taking photography classes at the local community college.



**Dana Sciuolo** engages in outreach, education, and advocacy activities in support of NDSS' health programs. Dana is a licensed and registered occupational therapist with a background in pediatric care. Dana strives to improve the health and wellness of the Down syndrome community by bringing together researchers, medical professionals, and families to learn from each other. She facilitates this by sharing resources, hosting webinars, organizing and attending conference sessions, and supporting health and wellness programming. Dana also manages the NDSS Scientific and Clinical Advisory Board which is a group of researchers and medical professionals who advise NDSS on health-related initiatives. Dana holds two degrees from the University of Pittsburgh.

Wednesday, May 20, 2026

10:05 - 10:50

# Bridging the Data Gap: Disability Inclusion in Community Health Assessments

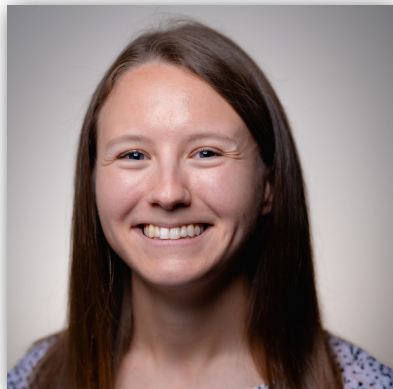
## Abstract

Health departments and non-profit hospitals are required to conduct Community Health Needs Assessments (CHNAs) or Community Health Assessments (CHAs) every three years to maintain accreditation and tax-exempt status. They are intended to reflect the communities served and prioritize medically underserved populations experiencing health disparities. Yet, despite people with disabilities representing the largest population facing such disparities, research shows major gaps in how CHAs address disability and health equity. This project conducted a statewide evaluation of disability inclusion across CHAs and CHNAs in Pennsylvania. Our analysis examined the inclusion of disability-related data, the inclusion of the disability community as a priority interest group, the models of disability represented, and the representation of disability partner organizations on CHNA and CHA steering committees. By assessing current practices, we aim to advocate for the recognition of the disability community as a population experiencing health disparities. This can pave the way for sustained funding and initiatives to address social determinants of health and accessibility barriers experienced by the disability community. Additionally, hospitals' mandated improvement plans based on CHNA findings offer a clear pathway to promote and implement enhanced accessibility practices statewide. By targeting existing processes, this approach offers a scalable, sustainable model to embed disability inclusion into healthcare planning, setting the stage for broader future efforts and resource development.

## About the Speakers



As a Health Equity Program Manager, **Makhari Dysart** is responsible for creating programs that highlight the diversity of perspectives in the disabled community. While completing her education at the University of Pennsylvania, Makhari worked in both research and advocacy for several universities and non-profit organizations with a focus on policy, writing, and community engagement. Her experience in health equity ranges from advocating for greater inclusion of disability justice principles to documenting the adverse health effects of socioeconomic marginalization, leading to policy change for historically excluded communities.



**Hannah Wells** (She/Her) is a Health Equity Project Manager with the Institute on Disabilities. Before joining the IOD, Hannah worked with adults experiencing significant mental health challenges and substance use disorders, as well as folks with Intellectual and Developmental Disabilities. Hannah received her master's degree in Parks, Recreation, and Tourism Management with a focus on Recreational Therapy from Clemson University.

Wednesday, May 20, 2026  
11:20 - 12:05 --- Keystone A

# Breaking the Silence: Building Accessible Mental Health Services for Deaf, Hard of Hearing, and Deafblind Communities

## Abstract

Mental health care remains one of the most critical yet inaccessible services for individuals who are Deaf, Hard of Hearing, and Deafblind. Systemic barriers—such as communication mismatches, lack of culturally and linguistically competent providers, and limited access to interpreters or adaptive technologies—continue to prevent equitable care. This session moves beyond barriers by presenting actionable, sustainable solutions to make mental health services fully accessible and inclusive for all. Participants will examine the intersection of language, culture, and access within mental health systems, exploring how traditional service models often overlook the unique needs of people who communicate through American Sign Language (ASL), tactile sign, or other non-visual modalities. The session will highlight effective practices in provider training, trauma-informed care, and collaborative service delivery that center Deaf, Hard of Hearing, and Deafblind individuals as partners in care—not simply recipients. Through real-world examples, case studies, and discussion, attendees will gain practical tools to adapt mental health services using accessible communication strategies, assistive technology, and cross-sector collaboration. Emphasis will be placed on community-driven solutions that are sustainable, replicable, and measurable—bridging policy, practice, and lived experience. By moving Beyond Barriers, Toward Solutions, this session empowers practitioners, policymakers, and advocates to reimagine mental health care systems that honor linguistic diversity, ensure access, and promote true equity for all individuals—regardless of hearing or vision level.

## About the Speaker

**Neil McDevitt** is the Executive Director for the Deaf-Hearing Communication Centre in Swarthmore, PA. Neil is also the Mayor for North Wales Borough in Suburban Philadelphia. He is the first Deaf person to be directly elected to this office in the country and was recently sworn in for his second term in office. In this role, Mayor McDevitt was the first person to introduce a sitting United States President in ASL at the White House, introducing President Biden at Disability Pride in September 2024 (<https://www.youtube.com/watch?v=cbNDDVxMgME>).

Neil served at the Federal Emergency Management Agency in their Office of Disability Integration and Coordination. As the first person to be the agency's Disability Integration Communications Specialist, Neil took a lead role in crafting inclusive messaging for the first nationwide EAS test in 2011. As a former volunteer firefighter in suburban Philadelphia, Neil was one of a handful of emergency responders in the country who are also profoundly deaf. He used that experience to lead a national training program bringing together emergency responders and people with disabilities to facilitate discussions on how they can help each other prepare for and respond to disasters. He graduated from Gallaudet University in 1996 with a degree in Government.



Wednesday, May 20, 2026  
11:20 - 12:05 --- Keystone B

# The Impact of Self-Advocate Storytelling on the Development of Disability Education Resources for Healthcare Providers

## Abstract

Graduate medical education in the United States does not require intellectual and developmental disability (IDD) education. Our team designed a set of online, asynchronous learning modules about providing quality healthcare for people with IDD to support integration of these topics into medical education and beyond. The project is co-designed by a Community Advisory Board (CAB) of patients and family members with lived experience of disability. The CAB has been a crucial part of the project development in providing topics to cover, input on the patient experience in all learning materials, telling stories and creating videos about their own experiences in healthcare, and providing continuous feedback. Learners who engage with the created content reflect that the patient stories are the most compelling pieces and make the materials easy to engage with and add meaning to the content. Our presentation will focus on the impact of our CAB in the development of our learning materials, provide opportunities for discussion to hear from CAB members on their experiences, and discuss ways to utilize a CAB and the value of self-advocates in practice when creating content or learning materials about disability topics. This project is sustainable as the online resources can be easily updated over time and are free to access because of funding provided by the Pennsylvania Developmental Disabilities Council. The materials are designed with Pennsylvania community supports identified, however could be scaled and changed for other states to utilize the resources. The reception of our project has been overwhelmingly positive since launch and is being integrated into the curriculum of different healthcare professions including medical resident and nurse practitioner programs, and the Thomas Jefferson University Community Health Worker training program. We are collecting feedback and meeting with interested individuals across the state and nationwide about the implementation of the learning materials.

## About the Speaker



**Karin Roseman**, MSW, LCSW is the co-director of the Jefferson FAB (For Adolescents and Beyond) Center for Complex Care, a primary care medical home for patients with complex childhood-onset conditions. She has been recognized within and beyond the Jefferson network for outstanding work in interprofessional care.

Wednesday, May 20, 2026  
11:20 - 12:05 --- Keystone C

# Empowerment Through Technology: Accessible, Affordable, Life-Enhancing Tech; Real Tools, Real Lives, Real Independence

## Abstract

For many people with disabilities, technology can open doors to independence, health, and everyday success—but the path to finding the right tools can often feel costly, complicated, or out of reach. This engaging, hands-on session will show that the power to live more independently may already be in your pocket, home, or workplace. Join ATP and ETIS experts from AHS Smart Living (Arc Human Services) to explore how free and low-cost assistive technologies, built-in accessibility features, and statewide Smart Living Technology Labs and tech resources can transform daily living. Learn how to access funding and equipment through waiver-based programs, assistive technology assessments, and device loan programs—and walk away with actionable strategies you can start using immediately. Participants will experience live demonstrations of everyday devices supporting literacy, organization, health, safety, communication and independence—plus discover local and statewide resources that make a Technology-First approach achievable for all. This presentation moves beyond gadgets—it's about empowerment, advocacy, and inclusion, showing how technology supports individuals to live, learn, work, and thrive on their own terms. Together, we'll go Beyond Barriers, Toward Solutions—making independence possible through technology that fits each person's goals, needs, and dreams.

## About the Speakers



**Travis Fiem** is an Enabling Technology Implementation Specialist at Arc Human Services, bringing hands-on expertise to the design, deployment, and training of smart home and assistive technologies that support independence, safety, and self-direction in everyday life. With more than a decade of experience, Travis works at the intersection of direct support, technology, and systems innovation. His work includes integrating AT with electronic health records, leading pilot initiatives for the use of robotics in direct care, and implementing the rollout of medication dispensing technologies to improve safety and promote greater independence in medication management.



**Diana Petschauer** is a highly experienced Assistive Technology Professional and Tech Integration Specialist with over 25 years of expertise supporting individuals across all stages of life and in varied settings. She has held leadership roles including Executive Director, Senior Consultant, and AT & Accessibility Coordinator, consistently championing tech-first approaches to accessibility & inclusion. A recognized national and local speaker, Diana has served on numerous boards & committees, contributing to the development of best practices in the field. Her work is deeply informed by both personal experience and the lived experience of those she supports.

Wednesday, May 20, 2026

1:15 - 2:00 --- Keystone B

# Partnering with Caregivers to Promote Optimal Oral Health for People with ID/A

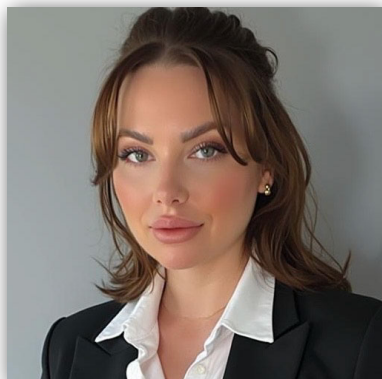
## Abstract

People with intellectual and developmental disabilities and/or autism (ID/A) tend to have poor oral health outcomes due to challenges with daily oral hygiene regimens and barriers to accessing oral health care. Direct support professionals (DSPs) are responsible for all care related to the health and wellbeing of their clients with ID/A. DSPs are responsible for the oral hygiene care of people with ID/A, and they often have trusting relationships with their clients. DSPs frequently do not have access to robust training and support to overcome barriers to daily oral hygiene regimens unique to their clients. Special Outreach Services (SOS) provides continuous, hands-on individualized support and education about oral health and hygiene for DSPs who care for people with ID/A at eight service provider facilities in the Greater Philadelphia Area. The SOS program's efforts have led to improvements in oral health outcomes among residents of the facilities whose staff participated in the education program. The SOS program continues to seek opportunities to scale up through partnerships with additional service providers who care for people with disabilities to support more caregivers. SOS educates parent and family caregivers of people with ID/A through free online virtual oral health education and question and answer sessions. This presentation will provide an overview of the structure and function of Special Outreach Services (SOS) as well as the impact of the SOS program in supporting caregivers to improve oral health outcomes for people with ID/A.

## About the Speakers



**Saumya Ayyagari** provides direction and management of SOS. She participates directly in delivering SOS programs to facilities and families. She has worked in nursing and public health since 2015, most recently with the Pennsylvania Action Coalition and Nurse Family Partnership. A Registered Nurse, Ms. Ayyagari attended the University of Pennsylvania: Bachelor of Science in Nursing, Master of Science in Nursing Health Leadership, and Master of Public Health. She earned a Bachelor of Arts in International Studies from the University of North Carolina. Ms. Ayyagari currently volunteers as a Board Member for Children First and previously served on an Advisory Committee for the Mid-Atlantic Center for Children's Health and the Environment.



**Kelly Parker** was Clinical Manager at Special Smiles, Ltd., where she worked directly with people with intellectual disabilities patients for before joining the SOS team as Outreach Hygienist. Ms. Parker educates caregivers on proper oral healthcare and works with each patient to help the person cooperate with oral hygiene practices specifically tailored to their needs. Ms. Parker also works as an adjunct instructor in the Dental Assisting Program at the Community College of Philadelphia, from which she earned an Associate's Degree in Dental Hygiene with high honors and won the Johnson & Johnson award for highest clinical grades. Ms. Parker earned a Bachelor's Degree in Journalism from Temple University and worked in finance.

Wednesday, May 20, 2026

1:15 - 2:00 --- Keystone C

# Designing for Neurodiversity: Building Inclusive Spaces for Health Equity

## Abstract

The built environment includes our homes, clinics, schools, workplaces, and public spaces. These places have a powerful impact on health. For neurodivergent people, many everyday spaces are not designed with their needs in mind. This session explores how the design of physical spaces affects health equity for neurodivergent people and what we can do about it. We will move beyond just identifying barriers to highlighting real-world solutions that center neurodiverse experiences. Participants will learn how small environmental changes can reduce stress, support communication, and increase safety and dignity not only for neurodivergent individuals, but for everyone. Drawing on interdisciplinary research and lived experience, this session highlights how sensory-sensitive spaces, clear wayfinding, predictable spatial layouts, and flexible environments can reduce overstimulation and cognitive fatigue while enhancing autonomy and comfort. We will also look at how self-advocates, providers, behavioral health professionals, policymakers, and caregivers can advocate for and implement these changes in clinical settings, homes, and communities. To achieve health equity, we must recognize the built environment as a tool for either exclusion or belonging. We can create environments that don't just accommodate neurodivergent people but truly support their belonging as equal participants in health and community life.

## About the Speakers



**Sabra Townsend** works in Community Operations at Jefferson Health's Center for Autism and Neurodiversity. She is responsible for program management, training, and consultations that create neurodiverse friendly environments in clinical and community settings across the lifespan. For individuals with intellectual and developmental disabilities, she directed an AmeriCorps national service program, managed medical and nursing students, and provided training to both parents and professionals. Sabra holds a BS degree in industrial engineering with a concentration in Operations Management from Lehigh University and an MS in Architecture and Design Research from Thomas Jefferson University.



**Wendy Ross, MD, FAAP**, is a clinical professor, developmental pediatrician, and the inaugural director of Jefferson Health's Center for Autism and Neurodiversity. She graduated from Mt. Sinai School of Medicine and completed Pediatrics residency at Yale and Developmental and Behavioral Pediatrics fellowship at Harvard. In her clinical practice, she works with children, integrating medical, educational and therapeutic plans into a cohesive approach. She was named a Top 10 CNN Hero for her groundbreaking Phillies program, her efforts to make air travel inclusive and her leadership in research on individuals with intellectual and developmental disabilities during the COVID-19 crisis.

Wednesday, May 20, 2026

2:00 - 2:45 --- Keystone A

# Preparing for Clinical Encounters with Individuals with Intellectual/Developmental Disabilities

## About the Speaker

**Dr. Alyssa Siegel** is an attending physician at Children's Hospital of Philadelphia (CHOP) and Clinical Director of the New Jersey Transition to Adult Coordinated Care program. A nationally recognized pediatrician and advocate for individuals with intellectual and developmental disabilities, she specializes in transition planning, complex healthcare needs, and helping youth move successfully from pediatric to adult healthcare systems. Dr. Siegel earned her medical degree from the State University of New York at Stony Brook and completed her pediatric residency at St. Christopher's Hospital for Children. She is a Clinical Associate Professor of Pediatrics at the Perelman School of Medicine at the University of Pennsylvania and has been recognized as a Philadelphia Magazine "Top Doctor" in Pediatrics. Throughout her career, Dr. Siegel has focused on improving healthcare access and coordinated care for people with disabilities and complex medical needs. She has received honors including the New Jersey Public Health Innovator Award and recognition as a Healthcare Provider of the Year finalist by NJBIZ.



Wednesday, May 20, 2026

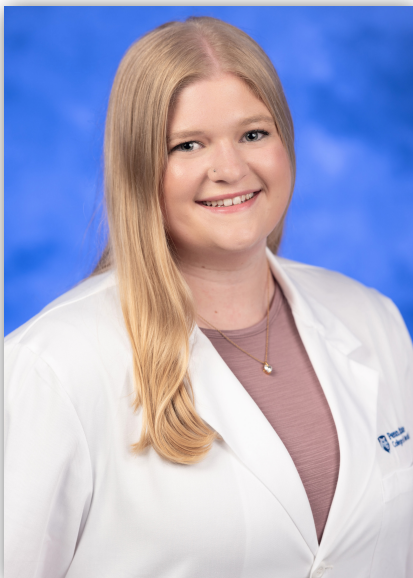
2:00 - 2:45 --- Keystone B

# Integrating ADEPT-CARE for Youth with Intellectual and Developmental Disabilities into a Medical School Curriculum

## Abstract

People with intellectual and developmental disabilities (IDDs) are an underserved patient population, yet medical education has historically provided limited training in disability-related care. This has contributed to ongoing health disparities for patients with IDDs. In addition, providers express discomfort caring for people with IDDs. Recent curricular innovations demonstrate that structured educational interventions and direct engagement with individuals with disabilities can significantly improve medical students' attitudes, empathy, and preparedness to care for this population. The ADEPT-CARE curriculum at Penn State College of Medicine seeks to expose medical students to key techniques for providing high-quality care to people with IDDs early in their training. This is meant to build confidence and empower future physicians to improve healthcare quality and accessibility for this population. The ADEPT-CARE model is a comprehensive approach to clinical evaluation (history taking and physical exam) tailored to account for the diverse needs of youth with IDDs, including mobility, sensory, cognitive, communication, and behavioral factors. This model includes four components: a didactic session on model implementation in clinical practice, a Q&A with a panel of advocates with disabilities sharing their experiences, a session on ethical considerations, and Objective Structured Clinical Examinations (OSCEs) with members of the local community with IDDs and their support persons as Standardized Patients in simulated clinical encounters to practice implementation of ADEPT-CARE. This program at PSCOM is the first in the country which provides medical students with early exposure and guidance for working with children with IDDs. It also provides an avenue for direct advocacy within the healthcare system for youth and young adults with IDDs and their families/caregivers, allowing students to learn from their insights.

## About the Speakers



**Cailey Bozic** is a third-year medical student at Penn State College of Medicine and a student leader in the implementation of ADEPT-CARE. Her work aims to better prepare future physicians to deliver equitable and informed care for patients with disabilities by embedding disability perspectives throughout medical training. Cailey earned her Bachelor of Science in Neuroscience with a focus in Cognition from Johns Hopkins University, where she developed a strong foundation in understanding the neural and cognitive processes that shape human experience and behavior. In addition to her leadership within medical education, Cailey serves as a coach for the AllStarz Adaptive Field Hockey Team, where she works with athletes of all abilities to promote inclusion, empowerment, and adaptive recreation. Her commitment to accessibility and patient partnership informs both her teaching and her approach to medicine.

Wednesday, May 20, 2026

2:00 - 2:45 --- Keystone B



**Meghan Hartman** is a third-year medical student at Penn State College of Medicine and a student facilitator of the ADEPT-CARE curriculum. Her interests center on advancing inclusive care through curricula development. She previously earned a degree in biology and a minor in education from Bucknell University. She has been an active member of both her undergraduate and medical school tutoring programs, holding leadership positions that allow her to identify barriers and promote inclusive and equitable education. Meghan also volunteers with the hospital's Child Life program, where she helps create a supportive environment for hospitalized pediatric patients. She also serves as a field hockey coach for the PA Rev All Starz adaptive team, working with athletes of all abilities to promote confidence, teamwork, and accessible recreation. Through her clinical training and community engagement, she is committed to advocating for inclusive practices and curricula that improve health outcomes for diverse patient populations.



**Zekiel Factor** is an MD/PhD student and coordinator of the ADEPT-CARE curriculum at Penn State College of Medicine, which brings medical students together with community members with disabilities to improve clinical skills for inclusive healthcare. They first got involved as an autistic self-advocate in high school, initially focusing on anti-ableist educational reform. Since college their advocacy work has focused on healthcare and medical ethics, such as improving accessible mental health services and supporting patient autonomy for people with intellectual and developmental disabilities. After graduating, they worked with children with developmental disabilities and their families throughout the diagnostic and service coordination process. During medical school, they have also served as president of the Disability and Deafness Advocacy Coalition and as a peer mentor for Medical Students with Disabilities and Chronic Illnesses National. Zekiel is dedicated to integrating advocacy with science and medicine to foster disability-inclusive clinical and research practices.

Wednesday, May 20, 2026

2:00 - 2:45 --- Keystone C

# The Community Supported Care Model: A Whole Person Health Solution for Pennsylvania

## Abstract

William Penn Human Services (WPHS) was created by more than 40 of Pennsylvania's leading intellectual disability and autism (ID/A) providers and is encouraging the Shapiro Administration to develop an integrated system of care, the Community Supported Care Model (CSCM), for individuals with intellectual disabilities/autism and their families. This model provides whole person health by integrating physical and behavioral health, dental, pharmacy, long term services, Medicaid waiver services and services that address social determinants of health such as food insecurity, housing and employment. The CSCM is grounded in a strong quality framework based on person-centered outcomes with governance that intentionally includes people with lived experience. The model has developed service navigation provided by highly skilled teams of service navigators and multi-disciplinary care teams who coordinate all healthcare, waiver and social services. It also preserves provider choice by ensuring individuals can remain with their current ID/A service providers while expanding access to a broader, integrated network of care. During this session, the WPHS team will discuss how the CSCM will reform current policies within Pennsylvania's Department of Human Services to better provide whole person integrated services for people with ID/A and their families.

## About the Speakers

**Nancy Murray** is a recently retired SVP at Achieva, President of The Arc of Greater Pittsburgh. She has more than 40 years of experience in the disability field in the areas of public policy, advocacy, family support, supports coordination, health care, and state government serving people with disabilities and their families. Nancy's primary areas of interest and study are the resilience of families of children and adults with disabilities and family caregiving. Nancy and her husband have three adult children with Down syndrome.

Nancy is the founder and Project Director of Achieva's Disability Healthcare Initiative and was one of the founders and first Director of the Down Syndrome Center at Children's Hospital (UPMC) of Pittsburgh. She has served as the President of the Board of Directors of the Pennsylvania Assistive Technology Foundation, a member of the Pennsylvania Medical Assistance Advisory Council, numerous committees through the Pennsylvania Office of Developmental Programs, numerous committees of The Arc US, and the National Council of Executives of The Arc, a member of the Pennsylvania Waiting List Campaign, Co-chair of the federal RAISE Family Caregiving Council, a member of the Pennsylvania Adult Protective Services Advisory Council, a member of the Pennsylvania Governor's Council on Reform and a member of the Advisory Council for the University of Pittsburgh's Center for Research, Training and Dissemination of Family Support for People with Disabilities Across the Life Course.



Wednesday, May 20, 2026

2:00 - 2:45 --- Keystone C



**Charles J. Hooker, III** is the President of William Penn Human Services (WPHS). Previously, as President and CEO Keystone Human Services and later a consultant to the organization, Mr. Hooker led a global provider of services and supports for children and adults with disability and an advocate for inclusion. Throughout his 48 years of professional experience in human services, Mr. Hooker has been a strong voice of support for vulnerable people to live full, meaningful lives within their communities. His experiences in developing human services include developing systems of care in the United States, the Republic of Moldova, the Russian Federation (prior to Putin's invasion of Ukraine), and India.



**Shane Spotts** is the President and Founder of Deon Health, a purpose-built, specialty managed care organization designed exclusively to serve people with intellectual and developmental disabilities (I/DD). As an expert in Medicaid and I/DD policy, Shane designed Deon's model of care to transform systemic healthcare practices, align incentives, and maintain a focus on community-based, person-centered care. Most recently, Shane served as a principal at Health Management Associates (HMA), where he led national consulting teams and worked with states, providers, and advocacy organizations on I/DD policy and Medicaid redesign. Before this role, Shane was the Medicaid Growth Director at Anthem and the Interim CEO of Summit Community Care in Arkansas, where he played a significant role in launching the state's Provider-Led Shared Savings Entity (PASSE) model to coordinate care for complex behavioral health and I/DD populations. Earlier in his career, Shane served as the Director of the Indiana Division of Disability and Rehabilitative Services (DDRS), overseeing the state's I/DD service system and two instrumental lifespan-focused programs: First Steps and Vocational Rehabilitation. Here, he supervised a legislatively mandated evaluation and overhaul of a waiver program, resulting in reduced waiting lists and improved resource allocation. Shane credits this experience as the initial inspiration for Deon Health. Shane earned a Bachelor of Science in Public Affairs and Economics from Indiana University.

Wednesday, May 20, 2026

3:00 - 3:45

## Panel: Self-Advocate Insights

### About the Panelists



**Shane Janick** is the Executive Director at The Arc of Philadelphia where his passion advocating for, and with, the community with IDD has grown from having an older brother with a variety of complex disabilities. He has previously coordinated the Adult Advocacy and Healthcare Advocacy programs at The Arc of Philadelphia and worked as a Teaching and Research Assistant at Temple University where he earned a Master of Public Health.



**Michael Anderson** is the legislative advocate for The Arc of Philadelphia. He has been working at The Arc for eight years and works with government officials to discuss matters pertaining to the disability communities to shape local, state, and federal policies. He graduated from Edinboro State University in 2007 with an Associate's degree in Journalism. Michael is an active member in Philadelphia's disability community and helps set up conferences and resource fairs for populations with disabilities.



**Monica Albert Still**, RN, BSN, is a registered nurse, disability advocate, and community leader committed to advancing equitable, accessible, and person-centered healthcare. Grounded in both professional nursing practice and lived experience, she works to bridge healthcare systems and the disability community through respect, clear communication, and medical literacy. Monica is actively engaged in advocacy and advisory roles, contributing to policy and organizational efforts that center on disabled voices and promote practical, system-level change. Monica champions a healthcare system where disabled people are respected as experts in their own lives and supported to live fully, independently, and well.



**Raquel A. Ross**, prior to retiring to care for her daughter, founded Raquel Ross Law, L.L.C., a law firm with an emphasis on Guardianships, and Special Education Law, and represented children in several counties as a Guardian Ad Litem. She served as President of the Centre Region Down Syndrome Society, Policy Advisor for the Pennsylvania Down Syndrome Advocacy Coalition, and currently serves as a Board Member for The Arc of Pennsylvania. Nationally, Raquel remains an active member of the National Down Syndrome Advocacy Coalition. She earned her Juris Doctor from The University of Connecticut School of Law.

# Special Thanks

The 2026 Disability Health Action Summit was made possible by a grant from the **Pennsylvania Disability Advocacy Fund**, a fund of **The Foundation for Enhancing Communities**.

The Arc of Pennsylvania is grateful for this opportunity to carry out the vision of assuring the rights and entitlements of persons with disabilities in receiving access to healthcare.

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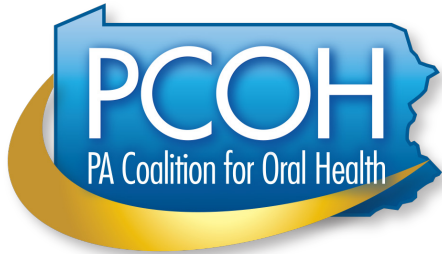


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**To learn more about the sessions and speakers, visit our website to view the full program and additional resources.**

**<https://thearcpa.org/2026DHASResources>**



**We want your feedback! Tell us about your experience at this year's Disability Health Action Summit.**

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## **Continuing the Work**

The Disability Health Action Network (DHAN) is a statewide collaborative initiative by The Arc of Pennsylvania, committed to addressing inequities in the disability community and advancing the health and wellbeing of individuals with disabilities in Pennsylvania.

DHAN's key objectives are to promote equitable access to quality healthcare, foster effective communication between stakeholders, and enhance overall health outcomes for people with disabilities.

Learn more and stay connected by visiting DHAN's website.

**<https://dhanpa.org/>**

