

Disability Health Action Summit

"Advancing Health Equity for People with Disabilities"





March 19, 2025

Sheraton Hershey Harrisburg Hotel-Harrisburg, PA

Summit Schedule - Wednesday, March 19, 2025

All general sessions and lunch will be held in Salon A&B.

8:00 - 8:30 AM **REGISTRATION**

8:30 - 8:45 AM Welcome

Sherri Landis, The Arc of Pennsylvania

8:45 - 9:00 AM Keynote Speaker

Disability Oral Healthcare in 2025 and Beyond

Dr. Mark Wolff, Dean of the University of Pennsylvania School

of Dental Medicine

9:00 - 10:00 AM Breakout Sessions

Session A - A Far Cry from Fair (Elm/Fir Room)

Dr. Jessica Jarvis, University of Pittsburgh

Session B - <u>Creating Planes of Equity: Our Journeys to Wellness</u> (Chestnut/Dogwood Room)
Jim Sharp, Rehabilitation & Community Providers
Association (RCPA)

10:00 - 10:30 AM BREAK & Time to Visit Vendors

10:30 - 11:30 AM General Sessions

Breaking Barriers: Advancing Disability and Health Equity

David Saunders, Pennsylvania Department of Health

Children with Complex Care Needs Should Live with Their

Families

Mary Hartley, Achieva

Summit Schedule - Wednesday, March 19, 2025

All general sessions and lunch will be held in Salon A&B.

11:30 - 1:00 PM LUNCH & Time to Visit Vendors

1:00 - 2:00 PM Breakout Sessions

Session C - <u>U.S. v. Maine: A Win for Community-Based</u> <u>Healthcare</u> (Elm/Fir Room) Vanessa Rastović, Achieva

➤ Session D - Introduction to the Special Olympics

Rosemary Collaboratory Initiative in Pennsylvania
(Chestnut/Dogwood Room)

Andrea Lowe, The Social Impact Consulting, LLC
Chelsea Hammell, Special Olympics Pennsylvania
Chloe Phillips, Special Olympics Pennsylvania

2:00 - 2:15 PM BREAK & Time to Visit Vendors

2:15 - 3:30 PM Panel Discussion

Experiences in Healthcare

Moderator: Shane Janick, The Arc of Philadelphia

Panelists: Karin Roseman, Michael Anderson, Steve Zuccarini,

and Yvonne Hughes

3:30 - 3:45 PM Closing Remarks

Sherri Landis, The Arc of Pennsylvania

Session Descriptions

Disability Oral Healthcare in 2025 and Beyond - Dr. Mark Wolff

This presentation will examine the current state of oral healthcare for individuals with disabilities and the potential impacts of the evolving healthcare landscape within today's economic and political climate. Since the early 1990s, significant progress has been made in various aspects of healthcare for people with disabilities. However, ongoing national changes may result in varying access to oral healthcare across states and shifting priorities within the research community. The discussion will highlight the progress achieved, identify existing gaps that require attention, and explore the steps needed to ensure equitable healthcare both within the Commonwealth and across the nation. Additionally, the presentation will reflect on Dr. Wolff's personal journey that led to a deep commitment to advocating for oral healthcare and how those experiences can help shape a pathway toward improved oral healthcare for all.

A Far Cry from Fair - Dr. Jessica Jarvis

During this session, presenters will review the methods and results of the FISA Foundation's new report, A Far Cry from Fair: Health-Care Access for People with Disabilities.

Creating Planes of Equity: Our Journeys to Wellness - Jim Sharp

The presentation will explore the evolving landscape of understanding and acceptance of mental health within communities and its role in daily life. It will examine the systems, resources, challenges, and opportunities within the current mental health system, as well as the personal interests that shape individual journeys to wellness. Additionally, the session will address advocacy strategies to ensure sustainable access to care in Pennsylvania.

Breaking Barriers: Advancing Disability and Health Equity - David Saunders

This presentation will examine the critical intersection of disability and health equity, exploring the systemic barriers that have historically marginalized disabled communities. It will highlight innovative strategies and actionable steps for advancing inclusivity in healthcare. Key topics include:

- ➤ Understanding Barriers: Analyzing social, economic, and structural obstacles that hinder health equity for people with disabilities.
- Innovative Approaches: Showcasing cutting-edge initiatives and technologies that are bridging gaps in healthcare for disabled individuals.
- Actionable Solutions: Providing practical recommendations for healthcare professionals, policymakers, and advocates to drive positive change.

Session Descriptions

<u>Children with Complex Care Needs Should Live with Their Families</u> - Mary Hartley

All children—including those who need skilled nursing care—deserve to live with their families. The national nursing shortage has made that impossible for some Pennsylvania children and threatened the homelives of others. In this session, you will learn about potential legislation to allow family members the choice to provide paid care to their children; and ensure rate increases and changes to the system to provide adequate professional nursing care.

U.S. V. Maine: A Win for Community-Based Healthcare - Vanessa Rastović In late November 2024, the Department of Justice sued the State of Maine for failing to adequately invest in community-level healthcare for children with behavioral health conditions. The lack of accessible behavioral healthcare in the community resulted in unnecessary institutionalization and prolonged confinement due to the absence of local care options, with institutions serving as the only readily available sources of treatment. The DOJ investigation and subsequent lawsuit against Maine alleged that this failure to invest in community-based behavioral healthcare violated the Americans with Disabilities Act (ADA) as interpreted by the Supreme Court in Olmstead. Rather than contesting the suit, the state opted for an immediate settlement.

This session will explore why this outcome represents a victory for people with disabilities and how a Medically Underserved Population designation would enable states to make necessary investments in community-level care. Additionally, it will examine the reintroduction of the HEADs UP Act in the 2025-26 session of Congress.

Introduction to the Special Olympics Rosemary Collaboratory Initiative in Pennsylvania - Andrea Lowe, Chelsea Hammell, & Chloe Phillips

The Rosemary Collaboratory Initiative is a multi-level collaboration between Special Olympics International and Special Olympics organizations across 8 countries and 3 U.S. states. Its vision is to accomplish health system reform that ultimately improves the health outcomes of people with intellectual and developmental disabilities. The initiative plans to accomplish this through assessment and additional data gathering, as well as identifying and utilizing policy levers to achieve this vision in partnership with local communities, organizations, and self-advocates. Our presentation will focus on the initial assessment phase of the Rosemary Collaboratory and feature future opportunities for this initiative in Pennsylvania.

Keynote Speaker

Mark Wolff, DDS, PhD



Dr. Wolff is the Morton Amsterdam Dean of the University of Pennsylvania School of Dental Medicine and a Professor in the Department of Preventative and Restorative Dentistry. Formerly, he was a Professor and Chair of the Department of Cariology and Comprehensive Care and Associate Dean for Predoctoral Clinical Education and Associate Dean for Development and Alumni Relations at the New York University College of Dentistry. He has designed, developed, and implemented an extensive curriculum in caries risk assessment and has designed dental information systems to assist dental schools in monitoring the risk of the entire dental patient population.

Dr. Wolff has completed numerous national and international research and oral health assessment programs. He started his dental career as a private practitioner, creating a family practice that focused on the medically compromised and disabled patients of all ages. He has been a lifelong advocate and educator for individuals with physical, intellectual, and developmental disabilities through the lifespan. Dr. Wolff received his DDS degree and PhD in Oral Biology and Pathology from Stony Brook University. He has served as the principal or co-principal investigator on multiple bench top and clinical research projects investigating dental caries, novel remineralizing agents, dental erosion, periodontal disease, dental materials and dentinal hypersensitivity. He has co-authored over 100 scientific papers, text chapters and edited multiple textbooks. Dr. Wolff lectures world-wide and is a frequent consultant to industry. He has been the principal or co-principal investigator on more than \$9.0 million in industrial and National Institute of Health funded research. Prior to joining the NYU College of Dentistry in 2005, he served as Associate Dean at Stony Brook University School of Dental Medicine, where he helped develop and implement the first completely computerized dental record. Under his leadership, Penn Dental Medicine implemented extensive clinical programs of caries and health risk assessments, minimal intervention dentistry, tobacco cessation, evidence-based dental education, community-based dentistry and dental care for all patients through the life-cycle. He frequently serves as a media source for information on consumer issues and hosted an annual radio series on dental issues on satellite radio.



Jessica Jarvis, PhD, MT-BC, is an Assistant Professor of Physical Medicine & Rehabilitation at the University of Pittsburgh School of Medicine. A health services researcher and board-certified music therapist, Dr. Jarvis is committed to improving the equity and effectiveness of pediatric rehabilitation services. She uses mixed methodologies to develop nonpharmacologic interventions for the pediatric intensive care unit and to evaluate equitable access to care across the continuum, ensuring that every child has the opportunity to achieve their best possible health and functioning.



Jim Sharp is the Chief Operating Officer and Director of Mental Health Services for the Behavioral Health Division at RCPA. He is responsible for overseeing all policy and regulatory matters related to children's services and advancing members' vision and goals through collaboration with key system stakeholders. With 30 years of crosssystems advocacy, organizational leadership, and strategic planning experience, Jim has held several key positions throughout his career. He previously served as Chief Juvenile Probation Officer at Philadelphia Family Court and as a director of child welfare residential services. He began his career at Montgomery County Juvenile Probation. Jim has contributed to numerous state and national committees focused on child welfare policy and system reform, including initiatives with the MacArthur and Pew Foundations. He holds a bachelor's degree from Mount Saint Mary's University and graduated magna cum laude from Shippensburg University with a Master of Administration.



David Saunders joined the Pennsylvania Department of Health in 2016 as the Director of Health Equity. In addition to more than 30 years of non-profit management experience, David brings with him extensive knowledge in the fields of education, public health, disparities and youth development. He has collaborated on health disparity reduction initiatives, developed cutting-edge programs targeting underserved communities, and established state training institutes, collaborating with state, county and local officials.



Mary Hartley is a parent advocate who began as a volunteer on the Pittsburgh Local Task Force on the Right to Education. Prior to her role at Achieva as the President of The Arc of Greater Pittsburgh, she was Executive Director of the PEAL Center and led the United Way of Southwestern Pennsylvania's 21 and Able initiative. Mary directed #IWantToWork, a self-advocacy social media campaign, increasing employment and financial freedom through three successive efforts that resulted in legislative wins. She is a recipient of the 2023 Richard Meritzer Award and the 2018 Excellence in Advocacy Award from Achieva. She has served on the Board of Disability Rights Pennsylvania and is past Chair of UPMC's Disability Resource Council.



Vanessa Rastović is an accomplished attorney and person who experiences disabilities. As a National Science Foundation awardee and Law Review member, Vanessa spearheaded public relations efforts for a non-profit focused on eradicating abuse, while her tenure at Legal Aid saw her providing crucial legal support to refugees, older adults, and people with disabilities. Vanessa is an active member of the American Bar Association, including its Health and Administrative Law sections, and the American Society of Law, Medicine, and Ethics. She serves on the American Academy of Developmental Medicine and Dentistry's Presidents' Workgroup and is appointed to the City-County Task Force on Disabilities.



Andrea Lowe leads the Social Impact Studio Consulting, LLC and is a strategic policy and program management expert and community builder. Her consulting practice works with small-to-midsize health and human services agencies to build equitable policies, practices, and strategies at the local, state and national level. Prior to starting her business in 2022, Andrea spent 13 years supporting policy, advocacy, and strategic initiatives for local, state, and national governments, non-profit, and private sector entities, most notably addressing systemic barriers to service delivery.



Chelsea Hammell is Vice President of Mission Integration at Special Olympics Pennsylvania, where she drives impactful initiatives that empower athletes to reach their full potential. She leads the development of an organization-wide strategy to improve the overall health and fitness of athletes and has mentored over 200 athletes to become leaders through the innovative Athlete Leadership program. Chelsea and her team are dedicated to enhancing the athlete and volunteer experience, ensuring their needs are met and their journeys are fulfilling. With 10 years of experience at Special Olympics Pennsylvania, Chelsea's passion for the mission is deeply ingrained as she strives to create a more inclusive and empowering environment for all. In her free time, Chelsea enjoys hiking and camping with her family.



Chloe Phillips' smile greets everyone with warmth. She is a young lady determined to spread the word of acceptance and understanding of those with intellectual disabilities. As an athlete in Special Olympics Pennsylvania since 2009, Chloe participates in bowling, snowshoeing, powerlifting and her main passion, swimming. Chloe's role in Special Olympics Pennsylvania has developed beyond that of athlete, becoming a Global Messenger, speaking about the importance of Special Olympics Pennsylvania to schools and community organizations. She is also an athlete representative, empowering her to be a voice in her local program. She has recently taken on new leadership roles by serving as a committee member for both the Summer and Indoor Winter games. Besides being a dedicated athlete and speaker, Chloe is an assistant coach for the Special Olympics Pennsylvania Unified track program at her former high school. A registered USA triathlete, Chloe has completed 7 super sprint triathlons and is looking forward to her first sprint triathlon this June. She is a proud employee of the YMCA, working in the maintenance department. When she has a few moments of rest, she enjoys being with her two cats, Fritz and BB.



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.



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 of the Jefferson FAB (For Adolescents and Beyond) 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 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 center.



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.



Steve Zuccarini has been active in the dental field for 12 years and has spent the last 8 years with Special Smiles, Ltd., where he currently serves as the Chief Operating Officer. Steve has a passion to see patients have a positive experience when going to the dentist.



Yvonne Hughes is a self-advocate and community leader whose dedication has made a significant impact in Philadelphia, Pennsylvania. In 2023, Yvonne launched Showing Community Other Perimeters of Education (SCOPE), a series of summits designed to educate senior citizens about government programs, health services, and non-profit resources. Her advocacy has gained recognition at the state level with her appointment by Governor Shapiro to the Special Education Advisory Panel (SEAP) in 2024, where she contributes to family engagement resources. She also participates in the Mid-Atlantic ADA Center's leadership program, known for her ability to mobilize community members for various initiatives. Yvonne has also been involved with the Mayor's Commission for People with Disabilities (MCPD), Equal Partners in Change (EPIC), and Bridgeway. Her passion for empowering others continues to inspire her community, demonstrating that perseverance and dedication can create lasting change.

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The 2025 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.

For information about **The Arc of PA's Health Initiatives**, including the "Barriers" and "Recommended Solutions" reports, scan the QR code or go to:



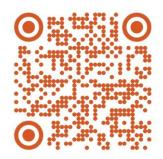
https://thearcpa.org/healthcare-initiatives/

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https://thearcpa.org/2025Feedback



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