

*Everyday
Lives*



2020 CONFERENCE PROGRAM

JANUARY 7-9, 2020

HERSHEY LODGE

325 UNIVERSITY DRIVE
HERSHEY, PA 17033



pennsylvania

DEPARTMENT OF HUMAN SERVICES
OFFICE OF DEVELOPMENTAL PROGRAMS



IMPORTANT INFORMATION

Conference Wifi

Network: Hershey Meetings
Code: everyday2020

Certificates of Attendance

Please stop at the registration desk prior to your departure to turn in your evaluation form and receive your certificate of attendance.



Dear Everyday Lives Conference Attendees,



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Welcome to the 2020 Everyday Lives Conference hosted by the Office of Developmental Programs! Thank you for joining us for what is sure to be a stimulating venture as we share thought-provoking concepts around supporting the everyday lives of individuals with developmental disabilities. I want to emphasize how much we value your participation.

Providing access to quality services for individuals with disabilities is ODP's number one goal. As paradigms continue to shift throughout the service system, we strive to improve services for individuals with disabilities and their families. The 2020 Everyday Lives Conference reflects our commitment to service improvement.

The conference will feature themes aligned with the 12 Everyday Lives recommendations developed by the Information Sharing and Advisory Committee (ISAC). Additionally, this conference, like everything we do, is guided by the foundation of Everyday Lives: Values In Action:

1. We value what is important to people with disabilities and their families, who are striving for an everyday life.
2. People with disabilities have a right to an everyday life; a life that is no different than that of all other citizens.

You will also hear from experts on emerging ODP initiatives such as dual diagnosis, employment, and technology:

- People who have dual diagnoses, face some of the greatest challenges for true inclusion and being connected with their communities. We need to work together to develop best practices and appropriate services and supports.
- Employment is a vital component of community integration, yet only 16% of working age individuals in ODP programs have a job.
- As technology continues to permeate our everyday lives, it is important for us to stay on top of current technological trends to improve supports and promote technological literacy. ODP's Technology Task force has been established to keep up with emerging trends.

We encourage you to approach each session with an open mind and hope you enjoy the opportunity to gain new insights and form new connections.

Please remember to fill out the evaluation form for each day that you attend. When you speak, we listen. The evaluations allow us to improve future conference and training sessions based on your input. We truly appreciate the time take to provide us with your thoughts.

Thank you for joining us!

A handwritten signature in black ink, appearing to read 'Kristin Ahrens'.

Kristin Ahrens

Deputy Secretary
Office of Developmental Programs
Department of Human Services

TUESDAY, JANUARY 7, 2020

REGISTRATION & CONTINENTAL BREAKFAST

8:00 a.m.–9:00 a.m.

INTRODUCTORY REMARKS

Kristin Ahrens

Deputy Secretary

Office of Developmental Programs

9:00 a.m.–9:15 a.m.

FEATURED KEYNOTE

Sharon Lewis

HMA Principal, Disability Policy Expert

9:15 a.m.–10:40 a.m.

BREAK

10:40 a.m.–11:00 a.m.

11:00 a.m.–12:30 p.m.

OR

11:00 a.m.–12:30 p.m.

Dan Dubovsky, MSW

Fetal Alcohol Spectrum Disorders (FASD) in
Individuals with Intellectual Disabilities

Tina Campanella, CEO Quality Trust

Supported Decision-Making:
Who, What, and How?

LUNCH

12:30 p.m. – 1:40 p.m.

provided in Great American Hall

1:40 p.m.–3:10 p.m.

OR

1:40 p.m.–3:10 p.m.

Fetal Alcohol Spectrum Disorders (FASD) in
Individuals with Intellectual Disabilities

CONTINUED

Supported Decision-Making:
Who, What, and How?

CONTINUED

📍 **Session Rooms** are indicated by this icon throughout the program.

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TUESDAY, JANUARY 7, 2020

BREAK

3:10 p.m. – 3:30 p.m.

FEATURED KEYNOTE

Charlene Lane, PhD., LCSW

The Posttraumatic Growth Perspective:

Understanding the culture of individuals with complex needs and their families

3:30 p.m.–5:00 p.m.

Registration Desk Open Until 6:30 p.m.



TUESDAY MORNING KEYNOTE

The ADA Generation: Expecting Great Lives and Real Community Membership

9:15 a.m. – 10:40 a.m.

 **Great American Hall**



WHO SHOULD ATTEND?

ALL AUDIENCES
(individuals, family members/
caregivers and professionals)

Over the past several decades, we have seen incredible change in how people with intellectual and developmental disabilities are supported, celebrated, respected, and contributing to our communities. Federal and state policy and programs have both encouraged these shifts, and sometimes have been slow to address barriers to inclusion. Yet the generation of youth and young adults who have grown up under three decades of the Americans with Disabilities Act have high expectations about full participation, equal opportunity, economic self-sufficiency and independent living (the four goals of the ADA), and their right to community integration as active citizens in reciprocal relationships. Join us for a presentation and discussion focused on how systems are facilitating opportunities for those “everyday lives” in many different ways.

KEYNOTE & FACILITATOR:

Sharon Lewis is a nationally recognized expert in disability policy who works with federal agencies states, providers and advocates to advance opportunities for people with disabilities to fully participate in all aspects of community. She came to HMA after serving for 6 years in presidentially-appointed leadership roles at the U.S. Department of Health and Human Services, where she worked to improve access and quality in integrated HCBS, employment outcomes and supporting families, among other efforts. Her personal passion is ensuring that the perspectives of people with disabilities and their families are central to the development of policies and programs that affect their lives.

TUESDAY BREAKOUT SESSIONS

Please choose **one** of the following Breakout Sessions to attend on Wednesday from **11:00 a.m.–3:10 p.m.**
lunch break provided

Fetal Alcohol Spectrum Disorders (FASD) in Individuals with Intellectual Disabilities

Dan Dubovsky, MSW

When an individual has behaviors that cause difficulty in various settings, we often label the person as being non-compliant, unmotivated, or disruptive. However, their behavior may well be due to brain damage caused by prenatal alcohol exposure, which is much more common than most people suspect. Due to this damage, which spans the intellectual spectrum, evidence based practices that rely on verbal interactions, and reward and consequence systems are often not successful with them and set them up to fail. The majority of those with an FASD are not accurately diagnosed and many have been misdiagnosed. As a result, typical interventions, especially those that involve a reward and consequence approach, are often ineffective and are sometimes contraindicated. This session focuses on the importance of recognizing FASD and understanding how the brain damage caused by prenatal alcohol exposure affects functioning. Part two will focus on the importance of identifying strengths in the individual, the family, providers, and the community as the basis for developing a plan to support a person with an FASD and his or her family.

 **Aztec Room**



WHO SHOULD ATTEND?

PROFESSIONALS who serve persons with an intellectual disability, autism spectrum disorder, or other developmental disability with co-occurring mental health needs

Supported Decision-Making: Who, What, and How?

Tina Campanella, CEO Quality Trust

Supported Decision-Making (SDM) has increasingly become accepted as an option for assisting people with developmental and intellectual disabilities to retain control in their lives and to become better decision-makers over time. The challenge is that support for decision-making will need to be customized for each person's situation, abilities and need for support. This means that while generic strategies and approaches can be generally described, the practice, application and support for will look different for each person. This presentation will explore the application of readily available strategies and tools to support people to make life decisions and become better decision-makers over time. Planning, practice and coaching techniques are typically the foundation for decision making support. The support team works with the person to identify what type of support is required for different decisions and who the person wants support from in each area.

 **Great American Hall**



WHO SHOULD ATTEND?

ALL AUDIENCES
(individuals, family members/
caregivers and professionals)

TUESDAY AFTERNOON KEYNOTE

Post-traumatic Growth Perspective: Understanding the culture of individuals with complex needs and their families.

3:30 p.m. – 5:00 p.m.

 **Great American Hall**



WHO SHOULD ATTEND?

ALL AUDIENCES
(individuals, family members/
caregivers and professionals)

It is time for a paradigm shift in our culture. In an epoch where there is a tendency to examine the pathologies around us, it would be extremely refreshing to assess what is positive, especially in situations that initially present as stressful and overwhelming. The concept of Posttraumatic growth attempts to identify areas of strength, growth and resiliency in seemingly daunting situations. Even though serving individuals with complex needs and providing ongoing support to their families presents unique challenges, there can be positive outcomes.

KEYNOTE & FACILITATOR:

Charlene Lane, PhD., LCSW is a Licensed Clinical Social Worker (in both the states of New York & Pennsylvania) who has over 20 years of clinical as well as administrative experiences. Dr. Lane holds a BA degree in Psychology from York College (CUNY) a Masters in Clinical Social Work from New York University and a Doctorate in Social Work from Adelphi University in Garden City New York. Dr. Lane's post-doc research has focused on the synergy between social work, ageing and the criminal justice system. In addition to her clinical and administrative experiences, Dr. Lane has taught as an adjunct professor since 2004 at Fordham University and Touro College (both in New York). She is currently an Assistant Professor in the Department of Social Work at Messiah College (Mechanicsburg, PA USA). Prior to joining the Messiah family, Dr. Lane served as an Assistant Professor at Shippensburg University, PA. Prior to relocating to Pennsylvania, USA; Dr. Lane was an Instructor and later Assistant Professor at York College (CUNY), New York in the Department of Health, Physical Education & Gerontology.

 **Session Rooms** are indicated by this icon throughout the program.

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WEDNESDAY, JANUARY 8, 2020

CHECK-IN, WALK-IN REGISTRATION & CONTINENTAL BREAKFAST

7:00 a.m.–9:00 a.m.

WELCOME REMARKS

Teresa D. Miller

Secretary of Human Services

9:00 a.m.–9:30 a.m.

FEATURED KEYNOTE

David Hingsburger

“Sexuality: What Teenagers With Intellectual Disabilities Want And Need To Know About Sex”

9:30 a.m.–10:40 a.m.

BREAK

10:40 a.m.–11:00 a.m.

BREAKOUT SESSIONS

11:00 a.m.–12:10 p.m.

LUNCH

12:10 p.m.–1:30 p.m.

provided in Great American Hall

FEATURED KEYNOTE

Tawara D. Goode, Director Georgetown University National Center for Cultural Competence

“Cultural And Linguistic Competence: What It Means In The Everyday Lives Of Individuals With Developmental Disabilities And Their Families”

1:30 p.m.–2:40 p.m.

BREAK

2:40 p.m.–3:00 p.m.

SCHEDULE CONTINUED



WEDNESDAY, JANUARY 8, 2020

Continued

**REPEAT BREAKOUT SESSIONS****3:00 p.m.–4:10 p.m.****PLENARY PANEL**

Exploring the experiences of inclusion, belonging, and intersectionality
from culturally diverse perspectives

4:30–5:40**RECEPTION & POSTER SESSION****6:00 p.m.–7:30 p.m.**

WEDNESDAY MORNING KEYNOTE

Sexuality:

What Teenagers With Intellectual Disabilities Want And Need To Know About Sex

9:30 a.m.–10:40 a.m.

 **Great American Hall**



WHO SHOULD ATTEND?

ALL AUDIENCES
(individuals, family members/
caregivers and professionals)

In over 30 years of working in the field of sexuality and disability, I have been asked many different questions that concern the machinations of love than the mechanics of sex. This Presentation will look at those questions and what the answers mean for teens with disabilities and their view of sexuality.

KEYNOTE & FACILITATOR:

Dave Hingsburger provides direct service to people with intellectual disabilities. He is the director of Clinical and Educational Services for Vita Community Living Services and a primary consultant for the Sexuality Clinic at York Simcoe Behavior Management Services. Dave also works in private practice as a consultant for schools, parents, and agencies in a variety of areas regarding service provision to people with intellectual disabilities, focusing primarily on problematic sexual behavior, understanding problem behavior and abuse prevention. He is a prolific author and has appeared several times on television to speak about disability issues. Dave wrote and narrated the controversial radio documentary "Life, Death and Disability" for the Canadian Broadcasting Corporation.

WEDNESDAY BREAKOUT SESSIONS

Please choose **one** of the following Breakout Sessions to attend on Wednesday from **11:00 a.m.–12:10 p.m.**

Looking Beyond Inclusion: Community Development through the Disability Lens

THIS SESSION REPEATED 3:00 p.m.–4:10 p.m.

Andy Arias, Actor/Advocate and ADA SME

Inclusion is used as a buzzword in the majority of our work but what does it really mean? How does it impact the people we are serving and how can we further extend our understanding of true inclusion? Looking at inclusion as a starting point rather than the end result.

 **Nigerian Room**



WHO SHOULD ATTEND?

ALL AUDIENCES
(individuals, family members/
caregivers and professionals)


Wellness Recovery Action Plan Workshop

THIS SESSION REPEATED 3:00 p.m.–4:10 p.m.

Gina Calhoun - Program Director, Copeland Center;

Lori Young - Program Specialist, Franklin/Fulton MH/IDD/EI

The Wellness Recovery Action Plan (WRAP®) is a personalized wellness and recovery system born out of and rooted in the principle of self-determination. WRAP® is a wellness and recovery approach that helps people to 1) decrease and prevent intrusive or troubling feelings and behaviors; 2) increase personal empowerment; 3) improve quality of life; and 4) achieve their own life goals and dreams. Working with a WRAP® can help individuals to monitor uncomfortable and distressing feelings and behaviors and, through planned responses, reduce, modify, or eliminate those feelings. A WRAP® also includes plans for responses from others when an individual cannot make decisions, take care of him/herself, and/or keep him/herself safe.

 **Trinidad Room**



WHO SHOULD ATTEND?

PROFESSIONALS who
serve persons with an intellectual
disability, autism spectrum disorder
or other developmental disability with
co-occurring mental health needs.

WEDNESDAY BREAKOUT SESSIONS

Continued


The Story of Fred and Leroy: My Mom has Autism

THIS SESSION REPEATED 3:00 p.m.–4:10 p.m.

Wendy Hamilton, Autism Advocate and Chief Development Officer at Girl Scouts Spirit of Nebraska

In a humorous and emotional storytelling format, Wendy Hamilton will share her family's unique perspective on autism spectrum disorders. Wendy will take the audience on her deeply personal journey of having a "different kind of mother," one with ASD. The story ranges from past to present, from her mother's childhood to hers. Now, as her caregiver, Wendy and Moppy work as a team to navigate the complications of aging with autism. Individuals with autism need support throughout their entire lives, not just when they're children. Since receiving her diagnosis, Wendy has discovered that her family's story has a lasting impact on the audience, inspiring them toward action and advocacy. Her overall goal is to change the way we think about, speak about, and advocate for individuals with autism.

 **Aztec Room
AM**

 **Great American Hall
PM**



WHO SHOULD ATTEND?

ALL AUDIENCES
(individuals, family members/
caregivers and professionals)

Future Planning: It's Possible and Necessary

THIS SESSION REPEATED 3:00 p.m.–4:10 p.m.

Liz Mahar, Director of Family & Sibling Initiatives, The Arc of the United States

Nicole Turman, Program Director, The Arc of Pennsylvania

Becoming an adult is about making choices and the plans to move forward. The transition to adulthood is tough for any individual, but for people with intellectual and/or developmental disabilities, there are unique decisions that can be made in advance to encourage independence and success. Experience shows that adults with I/DD make a better transition from the family home when a future plan is in place. It is important to 'think big' and plan for community life – where to live, where to work, where to 'play' and engage with others. This session will provide information, examples, and resources that can help plan for employment and community living. Staff from The Arc of Pennsylvania and The Arc of the United States will provide an overview on how to start planning for the future of your loved one with a disability. You will also learn more about resources that will prepare for the transition to employment and adulthood.

 **Magnolia ABCD**



WHO SHOULD ATTEND?

ALL AUDIENCES
(individuals, family members/
caregivers and professionals)

[MORE SESSIONS](#)



WEDNESDAY BREAKOUT SESSIONS

Continued

Tapping into Your Diva Spirit: Through Self Advocacy, Self-Awareness & Empowerment

THIS SESSION REPEATED 3:00 p.m.–4:10 p.m.

 **Crystal Room**



WHO SHOULD ATTEND?

ALL AUDIENCES
(individuals, family members/
caregivers and professionals)

Donna R. Walton, EdD, Founder and President of The Divas With Disabilities Project

It is believed that our perceptions shape and mold our lives. Our perceptions may influence the way we relate to the world and contribute to the way we cope with ourselves. How we perceive our disability and what we think others perceive of us can significantly impact the way we advocate for ourselves, both inside and outside our community. This workshop will lead participants through a variety of empowerment activities that are aimed at building confidence, strengthening advocacy skills and teaching participants how to embrace their disability “diva” the lies within to create change.

LifeCourse in Action

THIS SESSION REPEATED 3:00 p.m.–4:10 p.m.

 **Wild Rose AB**



WHO SHOULD ATTEND?

ALL AUDIENCES
(individuals, family members/
caregivers and professionals)

PA Family Network

This session will demonstrate how the PA Family Network Advisors have used the Charting the LifeCourse philosophy and tools to help individuals and their families experience transformational change. We will walk our audiences through three actual mentoring experiences starting with the person’s life before LifeCourse, our mentoring approach, profile development, and finally their “after” story. Those attending will leave with realistic ideas and examples on applying the LifeCourse Principals and how to develop portfolios that can help individuals and families plan for an everyday life.

WEDNESDAY BREAKOUT SESSIONS

Continued

Ring of Safety: Teaching People With Disabilities The Skills To Prevent Abuse

THIS SESSION WILL NOT BE REPEATED

David Hingsburger

People with intellectual disabilities are vulnerable to abuse and exploitation. This vulnerability is often attributed to the disability when in fact it's more about education and skills. This presentation will look at the skills people with disabilities need to learn in order to keep themselves safe.

 **Great American Hall**



WHO SHOULD ATTEND?

ALL AUDIENCES
(individuals, family members/
caregivers and professionals)

Building Diverse and Inclusive Communities Through Authentic College Experiences

THIS SESSION REPEATED 3:00 p.m.–4:10 p.m.

PA Inclusive Higher Education Consortium

Three college students (graduate, currently attending, and potential), as self-advocates, share their experiences and desired experiences in attending a fully inclusive curriculum, Integrated Studies, at Millersville University. The discussion encompasses the successes and challenges of an alumni of Integrated Studies, a currently enrolled student, and a perspective college-bound applicant preparing now in high school for her next steps. An overview of Integrated Studies is provided by staff including the aspects of employment, belonging and academics as part of the curriculum and life after graduation. Audience participation is encouraged.

 **Empire ABCD**



WHO SHOULD ATTEND?

ALL AUDIENCES
(individuals, family members/
caregivers and professionals)

WEDNESDAY AFTERNOON KEYNOTE

Cultural And Linguistic Competence: What It Means In The Everyday Lives Of Individuals With Developmental Disabilities And Their Families

1:30 p.m.–2:40 p.m.

 **Great American Hall**



WHO SHOULD ATTEND?

ALL AUDIENCES
(individuals, family members/
caregivers and professionals)

Cultural competence and linguistic competence are essential components of human services and widely recognized as such by policy makers, educators, researchers, health care and social services professionals, and advocates. While the evidence suggests the efficacy of these approaches, developmental disabilities systems continue to struggle with the full integration of cultural and linguistic competence into their policies, structures, practices, and procedures. This presentation is designed to explore the conceptual frameworks of cultural competence and linguistic competence and examine their relevance for the everyday lives of individuals with developmental disabilities, their families, and the system of services and supports in Pennsylvania.

KEYNOTE & FACILITATOR:

Tawara D. Goode, Assistant Professor & Director, Georgetown University National Center for Cultural Competence & University Center for Excellence in Developmental Disabilities

Tawara Goode is an assistant professor in the Department of Pediatrics, Georgetown University Medical Center in Washington, D.C. She has been on the faculty of the Georgetown University Center for Child and Human Development (GUCCHD) for over 30 years. She has degrees in early childhood education, and education and human development. She is the Director of the GUCCHD's University Center for Excellence in Developmental Disabilities and is responsible for short-term and ongoing programs for individuals at-risk for and with developmental and other disabilities and their families. She is also the director of the National Center for Cultural Competence at GUCCHD.

WEDNESDAY PLENARY & RECEPTION

Exploring The Experiences of Inclusion, Belonging, and Intersectionality From Culturally Diverse Perspectives.

4:30 p.m.–5:40 p.m.

 **Great American Hall**



WHO SHOULD ATTEND?

ALL AUDIENCES
(individuals, family members/
caregivers and professionals)

Panelists: Andy Arias, Imani Barbarin, Sandy Ho, Kerry Magro, Donna Walton, Liz Weintraub

Understanding an individual's cultural identity is a vital component of providing quality supports. Join Tawara D. Goode, Director of the Georgetown National Center for Cultural Competence as she speaks with six disability advocacy leaders of diverse backgrounds to unpack the nuances of culture, community, identity, and inclusion through the disability lens..

KEYNOTE &
FACILITATOR:

Tawara D. Goode, Assistant Professor & Director, Georgetown University National Center for Cultural Competence & University Center for Excellence in Developmental Disabilities

RECEPTION & POSTER SESSION

6:00 p.m.-7:30 p.m.

Join the festivities over lite fare, drinks, and live entertainment provided by jazz trio Temple Avenue!

Providers will showcase their innovative service approaches during the Everyday Lives poster session. Visit our vendors and resource tables to learn more about services across the Commonwealth.

Temple Avenue

Jazz Ensemble

Temple Avenue is a jazz group formed eight years ago by Lancaster pianist Colin Mekeel and his friends at Temple University. Today the versatile group plays swing dances, concerts, festivals, church services, receptions and other events, adjusting its size and instrumentation to fit the occasion. Colin, now 25, studies both jazz piano and classical piano. Joining him at the Everyday Lives Conference are singer Calli Graver and bassist Joe Plowman.

THURSDAY, JANUARY 9, 2020

CHECK-IN, WALK-IN REGISTRATION & CONTINENTAL BREAKFAST

7:30 a.m.–9:00 a.m.

FEATURED KEYNOTE

Sara Wolff, Inspirational Speaker

"Promoting a Culture of Awareness & Acceptance"

9:00 a.m.–10:40 a.m.

BREAK

10:40 a.m.–11:00 a.m.

BREAKOUT SESSIONS

11:00 a.m.– 12:10 p.m.

LUNCH

12:10 p.m.–1:30 p.m.

provided in Great American Hall

BREAKOUT SESSIONS

1:30 p.m.– 2:40 p.m.

BREAK

2:40 p.m.–3:00 p.m.

FEATURED KEYNOTE

Sue Swenson, President, Inclusion International

"Pennsylvania in the World"

CLOSING REMARKS

Kristin Ahrens

3:00 p.m.–4:40 p.m.

THURSDAY MORNING KEYNOTE

Promoting a Culture of Awareness & Acceptance

9:00 a.m.–10:30 a.m.

 **Great American Hall**



WHO SHOULD ATTEND?

ALL AUDIENCES
(individuals, family members/
caregivers and professionals)

Sara shares her life experiences to tell the inspirational story of how a small-town girl who happens to have Down Syndrome was able to overcome challenges and attain successes. Sara's journey will inspire, motivate and encourage others to believe that building a culture of awareness and acceptance of all individuals...Leads to achieving lifelong success. Sara believes her message will make a positive change in the hearts and attitudes of others towards individuals with disabilities.

KEYNOTE & FACILITATOR:

Sara Wolff is an amazing young woman and skilled inspirational speaker who happens to have Down Syndrome. An advocate for individuals with Down Syndrome and other intellectual disabilities, Sara actively promotes awareness and understanding through personal appearances and speaking engagements among educators, employers, self-advocates and community professionals. Through the years, Sara has served on the Board of Directors for various organizations including the National Down Syndrome Society, the Arc of Northeastern Pennsylvania in Scranton PA, and the Arc of Pennsylvania in Harrisburg, PA.

THURSDAY BREAKOUT SESSIONS

Please choose **one** of the following Breakout Sessions to attend on Thursday from **11:00 a.m.–12:10 p.m.**

Disability Solidarity: Moving Beyond Inclusion Towards Power

THIS SESSION REPEATED 1:30 p.m.–2:40 p.m.

 **Nigerian Room**



WHO SHOULD ATTEND?

ALL AUDIENCES
(individuals, family members/
caregivers and professionals)

Sandy Ho/Community Organizer, Disability Policy Researcher

In this presentation attendees will explore how disability shapes our social and political lived-experiences, and identities. How do we propel disability discussions beyond inclusion and awareness? Attendees will learn about some fundamental models of disability and how those have informed stereotypes and social perceptions of people with disabilities, and the ways that they present themselves in all of our everyday lived-experiences. This presentation will also delve into broad overviews of the ways that disability intersects with race and ethnicity, sexual orientation, and immigrant status. As we move into the next decade, how will our social and political understandings of disability evolve? What is necessary to move disability beyond awareness? These questions will be posed and guide attendees into the importance of an intersectional framework as we continue to advocate for greater disability rights moving forward.

A Practical Update on Genetic Testing: Diagnosis and Next Generation Treatment Approaches for Persons with Developmental Brain Disorders

THIS SESSION REPEATED 1:30 p.m.–2:40 p.m.

 **Aztec Room**



WHO SHOULD ATTEND?

PROFESSIONALS who
serve persons with an
intellectual disability, autism
spectrum disorder or other
developmental disability with
co-occurring mental health

Brenda Finucane, MS, LGC, Geisinger's Autism & Developmental Medicine Institute, Lewisburg, PA.

Developmental brain disorders (DBD) include a wide range of conditions, including autism, intellectual disability, epilepsy, and schizophrenia, that affect a significant percentage of children and adults in the US. Advances in genetic diagnostic testing have shed new light on the connections among several seemingly unrelated DBD, and these discoveries have practical implications for the way we support individuals living with these conditions. Current practices in genetic evaluation will be described, including information related to specific genetic syndromes and disorders. This training will be of interest to professionals and direct care staff supporting individuals with DBD in school, work, and residential settings.

THURSDAY BREAKOUT SESSIONS

Continued

Navigating the Human Condition

THIS SESSION REPEATED 1:30 p.m.–2:40 p.m.

Dr. Kerry Magro EdD, CAS

The speaker will present on how he survived the education experience growing up being on the spectrum and how his experiences, both good and bad, can help students with disabilities from early childhood to the transition into adulthood. Kerry will present on his experiences with therapies focused on his early development, how he started nurturing self-advocate skills for those impacted by a diagnosis via his Facebook Page A Special Community, his work on 3 best-selling books and much more!

 **Trinidad Room**



WHO SHOULD ATTEND?

ALL AUDIENCES
(individuals, family members/
caregivers and professionals)

Online Social Capital: for Individuals with Disabilities

THIS SESSION REPEATED 1:30 p.m.–2:40 p.m.

Imani Barbarin, Communications Director, Blogger, Disability Activist, Writer

This session will evaluate the ways people with disabilities have used social media to make their presence known for the betterment of the community and explore the ways they're using online platforms to influence language, culture and politics.

 **Crystal Room**



WHO SHOULD ATTEND?

ALL AUDIENCES
(individuals, family members/
caregivers and professionals)

MORE SESSIONS



THURSDAY BREAKOUT SESSIONS

Continued

AAC Interventions:

To support the communication and participation of individuals with complex communication needs

THIS SESSION REPEATED 1:30 p.m.–2:40 p.m.

 **Magnolia ABCD**



WHO SHOULD ATTEND?

PROFESSIONALS who serve persons with an intellectual disability, autism spectrum disorder or other developmental disability with co-occurring mental health needs.

Janice Light, Ph.D.

Many individuals with developmental disabilities have complex communication needs and cannot rely on their natural speech to communicate. Without access to functional speech, they are severely restricted in their participation in all aspects of their lives. This presentation will discuss evidence based AAC interventions to enhance communication, improve language and literacy skills, increase participation, and support the self-determination of individuals with complex communication needs. The presentation will describe the key components of AAC intervention, including innovative AAC technologies; instruction to build linguistic, operational, social, and strategic skills; and intervention to reduce barriers to participation. The session will include a range of case examples to illustrate the impact of AAC intervention on communication, participation, and overall quality of life for individuals with a range of developmental disabilities and their families.

The LifeCourse Tools

THIS SESSION REPEATED 1:30 p.m.–2:40 p.m.

Self Advocates United as 1

Self Advocates United as 1 (SAU1) is a Pennsylvania based self-advocacy group who envision a world where people with developmental disabilities and their families are united to share knowledge, empower others, and use their voices to transform communities. Members of SAU1 will walk audience members through their own experiences with the LifeCourse tools and how LifeCourse can be used by individuals and families to achieve an everyday life.

 **Wild Rose AB**



WHO SHOULD ATTEND?

INDIVIDUALS with an intellectual disability and/or autism, as well as their families and caregivers.

THURSDAY BREAKOUT SESSIONS

Home and Community Based Supports

THIS SESSION REPEATED 1:30 p.m.–2:40 p.m.

Sharon Lewis, HMA Principal

Over the past several decades, we have seen incredible change in how people with intellectual and developmental disabilities are supported, celebrated, respected, and contributing to our communities. Federal and state policy and programs have both encouraged these shifts, and sometimes have been slow to address barriers to inclusion. Yet the generation of youth and young adults who have grown up under three decades of the Americans with Disabilities Act have high expectations about full participation, equal opportunity, economic self-sufficiency and independent living (the four goals of the ADA), and their right to community integration as active citizens in reciprocal relationships. Join us for a presentation and discussion focused on how systems are facilitating opportunities for those “everyday lives” in many ways.

 **Great American Hall**



WHO SHOULD ATTEND?

ALL AUDIENCES
(individuals, family members/
caregivers and professionals)

Technology Supports Panel

THIS SESSION REPEATED 1:30 p.m.–2:40 p.m.

**Panelists: Holly Chakmakjian,
Daniel K. Davies, Nathan Gerhard, Shaleea
Shields**

Technology continuously transforms our lives and shifts paradigms in the blink of an eye. It is important that our service system keep up with the digital age. Hear from four experts in the field of technology supports coordination on how they have developed technology and programs to reflect our changing times. This panel will feature local and national representatives from AbleLink, KenCrest, Keystone Human Services, and Merakey.

 **Empire ABCD**



WHO SHOULD ATTEND?

ALL AUDIENCES
(individuals, family members/
caregivers and professionals)

THURSDAY AFTERNOON KEYNOTE

Pennsylvania in the World

3:00 p.m.–4:40 p.m.

Pennsylvania strives to ensure that her citizens with disabilities have Everyday Lives, but how many Pennsylvanians know about the efforts of people worldwide to do the same thing? Does it matter? Come hear about why your work matters to the whole world -- and why international work matters to you.

 **Great American Hall**



WHO SHOULD ATTEND?

ALL AUDIENCES
(individuals, family members/
caregivers and professionals)

KEYNOTE & FACILITATOR:

Sue Swenson is president of Inclusion International, the international disabled people's organization recognized by the UN to represent people with intellectual disabilities and their families. Sue served the Obama administration in senior roles in the department of education and the Clinton administration in the department of health and human services. Sue has been a Kennedy Fellow and executive director of national non-profits in the disability space. Sue and her husband had three sons, one of whom, Charlie, had disabilities that had a profound effect on his family and his community.

SPEAKER BIOS

Andy Arias has been an advocacy professional for over seven years. He has worked as a System Change Advocate and Program Manager for Orange County & Los Angeles. He is member of many boards and commissions related to creating greater visibility and advancement for diverse communities, especially the disability community. Andy is often hired speak and train at universities, high schools, and for Congressional leaders on ADA compliance and the inclusion of people disabilities and others from diverse backgrounds and communities. He has received several awards for his presentations on LGBTQ diversity and disability equality. Andy's experience and leadership gave him skills to develop and implement a youth programs that served over 150 young adults in Southern California helping them reach their dreams for independence. The curriculum for this program utilized today by specific County agencies. Andy excels in teaching students that nothing can get in the way of their dreams, as long as they use their disabilities as an asset. Andy advocates in the entertainment industry by creating visible pathways as an actor and stand-up comedian. As an actor, Andy has had the pleasure of working with Tom Hanks, Mark Ruffalo and Hilary Swank on projects. He is often asked to consult with producers and directors in create greater media visibility of people with disabilities. He has also produced several small projects that have brought attention to persons with disabilities and the LGBTQ to community. Andy's expertise extends to Federal government and corporate levels. His goal is to marry his policy work with his work in the entertainment industry to create a systemic lasting change.

Imani Barbarin is a disability rights and inclusion activist and speaker who uses her voice and social media platforms to create conversations engaging the disability community. Born with cerebral palsy, Imani often writes and uses her platform to speak from the perspective of a disabled black woman. Imani is from the Philadelphia area and holds a Masters in Global Communications from the American University of Paris. Her published works include those in Forbes, Rewire, Healthline, BitchMedia and more.

Deltilyn Bonal is a student in the Integrated Studies program at Millersville University. Born in Liberia, West Africa she came to US when she was 9 years old. Deltilyn's knowledge of both world and national issues coupled with her desire to be an advocate for people with disabilities gave her a strong desire to use her voice and experiences to effect real and lasting change. By her very nature, she is a change agent and has much to offer through her views and perspectives. Currently, she studies Art and English and her big dream is to become a renowned photographer.

SPEAKER BIOS

Gina Calhoun, after 17 years of back-to-back institutionalization, Gina credits her recovery journey to relationships that chose to focus on “what’s strong”, not “what’s wrong”, as well as meaningful employment. Gina often says, ‘I didn’t get well and go to work. Work was my pathway toward wellness.’ Her full time career began as a member of the PA state leadership team to plan and achieve Medicaid billable peer support services. In this job, she also supported the implementation of the Community Support Planning Process to ensure the voices of people making the hospital to community transition were primary in the development of new services and supports. Gina won the Timothy J. Coakley National Behavioral Health Leadership Award. This award honors peer and family leaders in the behavioral health field whose work is characterized by the highest degree of integrity and a passion for creative approaches for improving the lives of persons living with mental health challenges, especially in the public sector.

Tina Campanella has been the Director and Chief Executive Officer of Quality Trust since its inception in 2002. In over 40 years of experience working on behalf of children and adults with developmental and other disabilities, her work has included providing direct support, administering programs and serving as an expert consultant regarding quality improvement and organizational development throughout the US and abroad. She is recognized as an exceptional thinker and leader with expertise in program development, person-centered approaches and service quality management. Quality Trust advocates for people and families and leads efforts to improve government and community systems and supports.

Daniel Castellanos is a culinary artist and community theater professional who is active in community organizing in Lancaster, PA. Daniel graduated from Millersville University with a major in Career and Life Studies, now known as Integrated Studies. Mr. Castellanos was invited by Millersville’s President to deliver the 2016 Commencement Student Moment of Reflection. Daniel is currently employed as a prep cook and purchaser for a local five-star restaurant in Lancaster, PA. Mr. Castellanos is an active part of a business group developing plans for the establishment of a boutique hotel.

Holly Chakmakjian has been with IndeTech Solutions, LLC since its inception and has been an integral part in its founding and establishment before becoming its Managing Director. Holly has spent over 14 years working with children and adults with disabilities. Starting as a direct support professional, Holly went on to teach early intervention before becoming a special education school leader and then joining KenCrest Services to help develop innovative programs. Holly is proud to work alongside self-advocates, organizations and state leaders nationally to inspire and bring awareness to the Technology First Movement.

SPEAKER BIOS

Daniel K. Davies is the Founder and President of AbleLink Smart Living Technologies, LLC in Colorado Springs. He has been actively involved in research and development of technology for individuals with intellectual and cognitive disabilities for over 25 years. He has been closely associated with issues important to individuals with disabilities and their families, as his oldest brother John lived with severe intellectual and physical disabilities. Mr. Davies has directed over 80 research projects focused on technology and cognitive disabilities consequently in 2006 received the Technology Museum of Innovation's prestigious Katherine M. Swanson Equality award for "pioneering information technology for individuals with cognitive disabilities." He has authored over 100 publications, reports and book chapters related to cognitive technology for individuals with disabilities.

Dan Dubovsky, MSW, has worked for over 40 years in the field of behavioral health. He has worked as a child care worker in residential treatment and as a therapist in residential treatment, inpatient, outpatient, and community settings. Dan has been involved in the field of fetal alcohol spectrum disorders (FASD) for over 20 years. For the past several years, he has focused on the development and implementation of screening to identify those with a probable FASD and modifications of approaches for those who screen positive. He has presented regionally, nationally and internationally on FASD focusing on interventions and prevention for children, adolescents and adults. For this work, his son Bill, who was diagnosed with fetal alcohol syndrome at age 19, has been his mentor and best teacher. In addition to FASD, Dan has developed curricula and provided training and technical assistance for families and professionals working in mental health, developmental disabilities, education, justice, vocational.

Brenda Finucane, MS, LGC, is a licensed genetic counselor and professor at Geisinger's Autism & Developmental Medicine Institute in Lewisburg, PA. Her clinical and research activities have focused on genetic causes of neurodevelopmental disorders. Ms. Finucane has a particular interest in genetic conditions that result in complex intellectual, behavioral, and neuropsychiatric symptoms. Her experience with this population includes young children through adults. Ms. Finucane is widely published and has been in leadership roles in professional and advocacy organizations throughout her career, including a term as president of the National Society of Genetic Counselors.

Nathan Gerhard has worked in Human Services for over 20 years, beginning as a Direct Support Professional at the Western Pennsylvania School for Blind Children residential program. Nathan has gone on to serve in leadership roles in Baltimore, North East Pennsylvania and currently in North Central Pennsylvania with Keystone Human Services. Nathan has piloted innovative remote supports technology at Keystone in both residential services and supported living services that have allowed individuals to gain greater independence in their lives and in the community.

SPEAKER BIOS

Tawara D. Goode is an assistant professor in the Department of Pediatrics, Georgetown University Medical Center in Washington, D.C. She has been on the faculty of the Georgetown University Center for Child and Human Development (GUCCHD) for over 30 years. She has degrees in early childhood education, and education and human development. She is the Director of the GUCCHD's University Center for Excellence in Developmental Disabilities and is responsible for short-term and ongoing programs for individuals at-risk for and with developmental and other disabilities and their families. She is also the director of the National Center for Cultural Competence at GUCCHD.

Wendy Hamilton is the Chief Development Officer at Girl Scouts Spirit of Nebraska. She earned her BA in theatre from Coe College and her MFA from Wayne State University. In 2007, her mother, aka "Moppy," was diagnosed with Autism Spectrum Disorder. Her family's story has been featured in many publications including the book, *Different, Not Less* by Dr. Temple Grandin. Wendy has presented and moderated at many state and national autism conferences as well as TEDxOmaha. Wendy is a passionate disability advocate and currently serves on the National Affiliate Leaders Committee for the Autism Society of America. She is the mom of twin sister greyhounds who are practically perfect except when they're not.

David Hingsburger has worked for over 40 years in a variety of capacities with people with intellectual disabilities. During all that time he has always provided some kind of direct support to those he serves.

Sandy Ho is a disability community-organizer, activist, and disability policy researcher. Currently she is a research associate at the Lurie Institute for Disability Policy at Brandeis University. She is the founder of the Disability & Intersectionality Summit, a biennial national conference organized by disabled activists and centers marginalized disabled people. In 2015 she was recognized as a White House Champion of Change for her work in mentoring for transitional-age disabled women. Sandy is one third of the team behind Access Is Love, a campaign that is co-partnered by Alice Wong and Mia Mingus. Her areas of work include disability justice, racial justice, intersectionality, and disability studies. She is a disabled queer Asian American woman whose writing has been published by Bitch Media online.

Francine Hogan has been involved with the disability community, both professionally and personally for over 17 years. Her advocacy work began when her now 19-year-old son Michael was diagnosed with Autism and Tourette Syndrome. Currently, Francine is the Director of the Pa Family Network for Vision for Equality. She leads a team of 25 Family Advisors and oversees the operations of this statewide initiative, which helps families plan, network, and identify the services and supports their loved one needs to lead an everyday life. In this capacity she also serves as a Statewide Lead for the Pa Community of Practice for Supporting Families throughout the lifespan.

SPEAKER BIOS

Charlene Lane, DSW, prides herself of her Caribbean American Heritage. She was born on the Island of Trinidad & Tobago and spent the majority of her young adult and adult life in New York City prior to relocating to Central Pennsylvania in 2013. Dr. Charlene G. Lane is a Licensed Clinical Social Worker (in both the states of New York & Pennsylvania) who has over 20 years of clinical as well as administrative experiences. Dr. Lane holds a BA degree in Psychology from York College (CUNY) a Masters in Clinical Social Work from New York University and a Doctorate in Social Work from Adelphi University in Garden City New York. Dr. Lane's post-doc research has focused on the synergy between social work, ageing and the criminal justice system. In addition to her clinical and administrative experiences, Dr. Lane has taught as an adjunct professor since 2004 at Fordham University and Touro College (both in New York). She is currently an Assistant Professor in the Department of Social Work at Messiah College (Mechanicsburg, PA USA). Prior to joining the Messiah family, Dr. Lane served as an Assistant Professor at Shippensburg University, PA. Prior to relocating to Pennsylvania, USA; Dr. Lane was an Instructor and later Assistant Professor at York College (CUNY), New York in the Department of Health, Physical Education & Gerontology. Dr. Charlene Lane has presented both nationally and internationally on areas surrounding Post Traumatic Growth & Resiliency, Care give support, Ageing in Place In Prison and The Intersectionality Between Mental Health & the Criminal Justice System and The importance of Cultural competency.

Sharon Lewis is a nationally recognized expert in disability policy who works with federal agencies states, providers and advocates to advance opportunities for people with disabilities to fully participate in all aspects of community. She came to HMA after serving for 6 years in presidentially appointed leadership roles at the U.S. Department of Health and Human Services, where she worked to improve access and quality in integrated HCBS, employment outcomes and supporting families, among other efforts. Her personal passion is ensuring that the perspectives of people with disabilities and their families are central to the development of policies and programs that affect their lives.

Janice Light, Ph.D., holds the Hintz Family Endowed Chair in the Department of Communication Sciences and Disorders at Penn State University. She is actively involved in research, teaching, service delivery, and outreach to support the communication and participation of individuals with complex communication needs who require AAC. She is currently the Principal Investigator of the federally-funded research and training center in AAC (The RERC on AAC). Her contributions have been recognized through numerous awards including the Faculty Medal for Outstanding Achievement in Social & Behavioral Sciences, Distinguished Research Career Award, and Fellow of the International Society for AAC.

SPEAKER BIOS

Kerry Magro is an award-winning professional speaker and best-selling author who is on the autism spectrum. Kerry runs the popular Facebook Page A Special Community. He regularly speaks at schools, businesses, parent groups, nonprofit organizations and other special events on topics ranging from but not limited to disability, innovation, school bullying, the power of communication, diversity, workplace bullying, servant leadership and much more. For his efforts, Kerry has been featured in major media and worked with amazing brands including The Today Show, CBS News, Inside Edition, Upworthy and Huffington Post among others. You can contact Kerry at Kerrymagro@gmail.com

Liz Mahar is the Director of Family and Sibling Initiatives at The Arc of the United States. Before joining The Arc, Liz was a Managing Supervisor for Fleishman-Hillard, managing stakeholder relations for government-funded public health campaigns on topics including binge drinking, drug abuse, and chronic diseases. She brings social policy expertise from five years of working on Capitol Hill. Liz graduated from the George Washington University and is the sibling of a younger sister with I/DD.

Thomas Neuville is a Professor of Special Education & Disability Studies at Millersville University. He has more than 40 years' experience in education, community, and organizational development. Dr. Neuville centers on designing coherent models of planning and program development within the systems of Education. Specifically, he works with teacher candidates to develop strategies founded on social justice and focused on true personalization. He serves as founder and Advisor of Integrated Studies, an inclusive post-secondary curriculum at Millersville. Dr. Neuville is the Principal Investigator for The Model Comprehensive Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSID) in PA.

Shaleea Shields, Technology and Innovation Manager, has been with Merakey for fifteen years. Shaleea has held several positions during her time with Merakey. Currently she serves as policy chairperson for the committee writing policy for the IDD Division within Merakey, heads the Merakey AVS Career Enhancement Program, and is serving as a project manager on several technology initiatives. Implemented projects consist of: two smart homes, communication technology, transportation technology and a project focused on improving quality and services through a nursing model change.

Sue Swenson is president of Inclusion International, the international disabled people's organization recognized by the UN to represent people with intellectual disabilities and their families. Sue served the Obama administration in senior roles in the department of education and the Clinton administration in the department of health and human services. Sue has been a Kennedy Fellow and executive director of national non-profits in the disability space. Sue and her husband had three sons, one of whom, Charlie, had disabilities that had a profound effect on his family and his community.

Nicole Turman is the Program Director of The Arc of Pennsylvania's ADEPT (Arc Discovery Employment Transitions) program and Include Me school age consulting program. She is also a Discovery/Customized Employment Program Specialist, nationally certified in Discovery and Customized Employment through Marc Gold & Associates (MG&A).

SPEAKER BIOS

Donna Walton, EdD has made an enormous impact in the disability and women of color communities as a hub for thoughtful discussion and shaping the perception of what “disability” looks like. Her work has increased access and inclusion opportunities in countless industries that have traditionally marginalized the participation minorities with disabilities. Walton is the author of her newly released book *Shattered Dreams, Broken Pieces*, an eye-opening tale of reinvention that chronicles the decades she spent working to rebuild her world after bone cancer and the amputation of her left leg above the knee.

Liz Weintraub has a long history of leadership in self advocacy, and has held many board and advisory positions at state and national organizations. She is a full-time member of the AUCD’s policy team and also the host of *Tuesdays With Liz: Disability Policy For All*, where she attempts to make policies in accessible language so policy is accessible to all. In the Spring of 2018, Liz served as a Fellow for Senator Casey of Pennsylvania, working in his DC Office where she helped lead the way on disability policy by helping the Senator hold the administration accountable for disability stakeholder input into key programs; calling attention to the need for accessible supports and services for students and employees with disabilities on college campuses who have been sexually assaulted, which resulted in a S.2530; and helped organize a first of its kind Pennsylvania Disability Employment Summit with over 250 participants. Said Senator Casey, “Liz has shown the Senate how important it is to have staff members who have developmental and intellectual disabilities. She’s helped reshape the culture of the Senate.”

Sara Wolff is an amazing young woman and skilled inspirational speaker who happens to have Down Syndrome. An advocate for individuals with Down Syndrome and other intellectual disabilities, Sara actively promotes awareness and understanding through personal appearances and speaking engagements among educators, employers, self-advocates and community professionals. Through the years, Sara has served on the Board of Directors for various organizations including the National Down Syndrome Society, the Arc of Northeastern Pennsylvania in Scranton PA, and the Arc of Pennsylvania in Harrisburg, PA.

CONFERENCE MAP

Key

Great American Hall
Cocoa Ballroom
Chocolate Ballroom
Monarch Ballroom
Tower Suites

Offices
Restaurants
Prefunction Areas
Guest Registration
and Lobby
Wall Dividers

Tower Level

Main Level

KEY	
BC	Business Center
♂ ♀	Restrooms
☎	Telephone
Ⓐ	ATM

**GENERAL SESSIONS,
BREAKFAST & LUNCH**

**PHOTO BOOTH,
QUILTING AREA,
AND EXHIBITORS**

**BREAKOUT
SESSIONS**

**WEDNESDAY
EVENING
RECEPTION
& POSTER
SESSION**

**WALK-IN REGISTRATION
& PAYMENT**

**CONFERENCE
REGISTRATION**

📍 **Session Rooms**
are indicated
by this icon
throughout the
program.

Confection Hall Level

**BREAKOUT
SESSIONS**

**RELAXATION
ROOM**

