

The Future of
Disability:
a Big Ideas event!



Saturday, February 23, 2019
8:00 am - 6:00 pm

PROGRAM

The Inn at Opryland
2401 Music Valley Drive
Nashville, TN 37214

The Future of Disability: a Big Ideas event!



Schedule of Activities at a Glance

8:00am - 4:00pm - Registration

8:00am - 9:00am - Registration, Coffee & Tea, Networking

9:00am -10:30am - McGavock Ballroom

Welcome - Jeremy Norden-Paul

Presentations:

- John Shouse - Setting the Stage
- Wanda Willis & Friends - DD Act: All About the Journey
- Dave Griffin - One More Friend
- Sam Hutchins and Laurie Sain - Won't You Be My Neighbor?

10:30am-11:00am - Break & Networking with Speakers

11:00am - 12:30pm - McGavock Ballroom

Presentations:

- Waverly Ann Harris - Blended Families: Ingredients for a Good Mix
- Joe Macbeth - Direct Support Professionals and Supporting Choice
- Dr. Jamie Ho - Beyond 20/20: Visionary Vision Rehabilitation

Performance - Crescent Club Quartet

12:30pm - 1:15pm Mediterranean Buffet Lunch - Atrium

1:15pm - 2:30pm - McGavock Ballroom

Presentations:

- Tammy Hearon - Keys to Building Relationships for Success
- Stephen E. Morris - The Next Generation of Integrated Living
- Martha Summa-Chadwick - N.O.T.E.S. of the Neural Tango

2:30pm - 3:00pm - Break & Networking with Speakers

3:00 - 4:30 pm - Sessions - McGavock Ballroom

Presentations:

- Melissa J. Hogan - When Treatment Causes Trauma
- Joe Macbeth - The Changing Roles and Increasing Expectations of Direct Support Workforce
- Heather Dawn & Sarah Edwards - Advocacy Through the Arts

Performance - Crescent Club Quartet

Closing Thoughts - Jeremy Norden-Paul

4:30pm - 5:30pm Closing Reception and Networking with Speakers - Atrium

<http://www.thearctn.org/Big-Ideas.php>

Presentation Details

9:00am -10:30am - McGavock Ballroom

Welcome - Jeremy Norden-Paul

Setting the Stage - John Shouse

DD Act: all about the journey - Wanda Willis & Friends

The Developmental Disabilities Act, first enacted in 1963, created a fundamentally different vision of what it means to live with a developmental disability. The DD Act promoted a vision rooted in this belief: "disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities." One of the most profound and impactful laws affecting individuals with developmental disabilities and their families, the DD Act created 3 programs in each state: University Centers for Excellence in Developmental Disabilities, Protection and Advocacy Centers and State Councils on Developmental Disabilities. The mission of the DD Act and its programs remain as relevant today as when they were created by family members years ago. The term 'developmental disability' was first used in the Act, a change from the use of clinical terms for various conditions that resulted in a disability. The Act promoted comprehensive community-based services, employment, self-advocacy, research and training and protection of rights. The Act created State Councils as a forum for cross-communication, comprehensive review and analysis of state systems and strategic planning to improve systems of support and implement. The executive directors of Tennessee's DD Act programs join together to explain the wisdom of the Act and why it remains so relevant today.

One More Friend - Dave Griffin

Won't You be My Neighbor? - Sam Hutchins and Laurie Sain

'Won't you be my neighbor' is such an invitational phrase. One important assumption of this phrase by Mr. Rogers is that we have something to offer our neighbor and our neighbor has something important to offer us. At Lipscomb University we are fortunate to have students with disabilities who live on campus. They have and are neighbors to many. Our presentation seeks to share important lessons learned in our residential program and provide commentary on the way we understand and teach concepts of community and social life.

11:00am - 12:30pm - McGavock Ballroom

Blended Families: ingredients for a good mix - Waverly Ann Harris

Blended families are often the norm rather than the exception in today's society. How does this impact individuals with special needs as they enter in to a new family system? What advantages do blended families offer? How can we better support step-family members and what can they teach us about inclusion? Each member of the family brings a unique perspective. Newly blended families are at high risk for conflict as each person enters in to a setting that is unknown and unfamiliar. Yet, the makeup of the family can also bring fresh energy, open communication, clear expectations, and the willingness to try new ideas.

Direct Support Professionals & Supporting Choice - Joe Macbeth

In embracing a person-centered approach and supporting self-direction, people receiving supports need to be empowered to make their own choices. These ideals and practices of informed decision making are embedded into the NADSP Code of Ethics. Whether it involves relationships, privacy,

sexuality, well-being, or other areas, people with intellectual and developmental disabilities should be supported in making informed decisions, while understanding the associated risks and responsibilities that are tied to those decisions.

Beyond 20/20: Visionary Vision Rehabilitation - Dr. Jamie Ho

Over 50% of the brains' surface is dedicated to vision, eye movement control, and visual perception. Vision also integrates with other sensory systems to direct eye-hand coordination, balance, and orientation. Visual system deficiencies (including blur, double vision, light sensitivity, headaches, dizziness, or difficulties functioning in crowded environments) can be rehabilitated. Lenses, prism glasses, filters, and therapeutic exercises can help develop more efficient eye movements, improve visual processing, and enables effective integration with other sensory systems. Dr. Ho will share some extraordinary cases of how vision rehabilitation helped symptomatic patients recover and better handle the functional challenges of a visual-spatial world.

Performance by the Crescent Club Quarter

Tyler - Trumpet

Edward - Electric Bass

Mitch - Drums

Paul - Saxophone

1:15pm - 2:30pm - McGavock Ballroom

Keys to Building Relationships for Success - Tammy Hearon

The Next Generation of Integrated Living - Stephen E. Morris

Connecticut's Specialty Housing apartments will offer a combination of affordable rents, enhanced accessibility features, a smart-apartment technology system, common social spaces, and healthy prepared meal delivery. This along with 24/7 on-site staff supports will create a setting where residents with variable and complex needs can move out of more expensive congregate settings and age-in-place in a fully integrated community-based setting. This next generation residential living option is intended to be a demonstration project that if successful, can be replicated around the state and across the country. Anticipated occupancy date: February 2020

N.O.T.E.S. of the Neural Tango - Martha Summa-Chadwick

This presentation will provide an overview of the remarkable benefits of music in the brain when applied therapeutically for persons with motor, speech, and cognition challenges. Biomedical music protocols are scientifically researched and evidence-based; they have opened a new paradigm of how music can improve the lives of persons with intellectual or developmental disabilities in the home, classroom, or inclusive community. Videos will be shown of children with autism that demonstrate positive therapeutic outcomes with gait issues, attention focus, and speech challenges. A hands-on demonstration of the attention focus protocol will also be included for audience members wishing to participate.

3:00 - 4:30 pm - Sessions - McGavock Ballroom

When Treatment Causes Trauma - Melissa J. Hogan

Side effects of medications are on labels and in commercials. Risks of surgeries are shared in informed consent discussions. But few know or talk about a potential side effect and risk of medical appointments, treatments, and procedures: medical trauma. Advocate and rare disease parent Melissa Hogan explains why understanding medical trauma and how to prevent and manage it is so important for parents, health care providers, and institutions, and offers a few strategies to build on.

The Changing Roles and Increasing Expectations of Direct Support Workforce - Joe Macbeth

This discussion offers a chance to reflect on the current direct support workforce challenges and the evolving roles and expectations of Direct Support Professionals. Many of these changes are driven by people with disabilities, their families and funders who are demanding more from the current systems approach. This is a radical departure from which we are accustomed and will ultimately create an emphasis on 'personal autonomy,' greater access to 'integrated settings,' and helping people to make 'informed choices'

Advocacy Through the Arts - Heather Dawn & Sarah Edwards

If you have the opportunity to share something about yourself with the public, what would it be and what would it look like? That is the question that was asked to ten self-advocates. Over the course of a year, they will learn different modalities of art in order to communicate their self-advocacy piece. Using film, performance, dance, poetry, visual arts, music, script, projection and more, these self-advocates will communicate with confidence and creativity to the larger community. Heather and Sarah facilitate a creative process that allows individuals to express themselves no matter their background or abilities. Community volunteers who specialize in specific art forms support the self-advocates in their projects. Each participant grows in their own creative expression and in better understanding of themselves as individuals.

Performance by the Crescent Club Quarter

Tyler - Trumpet

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Closing Thoughts - Jeremy Norden-Paul

Our Speakers



Joseph Macbeth

Joseph M. Macbeth is the Executive Director at the National Alliance for Direct Support Professionals (NADSP) and has worked in the field of intellectual and developmental disabilities for 35 years - beginning as a Direct Support Professional. Macbeth is recognized as a national leader in the advocacy & movement to recognize direct support as a profession and is a highly sought after speaker on the workforce challenges that affect the disability system. Macbeth has co-authored the Report to the President: America's Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities and the U.S. Economy for the President's Committee for People with Intellectual Disabilities (PCPID, 2017), he was the Issue Editor for Impact: The Direct Support Workforce and People with Intellectual, Developmental, and Other Disabilities (University of Minnesota, 2018) and produced an award winning Realistic Job

Preview titled "Working as a Direct Support Professional: We Get It Done" (NYSACRA 2011). While working in New York, Macbeth partnered with the State University of New York (SUNY) by assisting more than 500 direct support professionals advance their college education through the "Disability Studies Certificate". He currently sits on the board of directors for The Council on Quality and Leadership (CQL), The Learning Community for Person Centered Practices (TLCPCP) and the College of Direct Support's National Advisory Board. In 2016, Macbeth was appointed by New York Governor Andrew Cuomo as a Member of the Advisory Council for the New York State Justice Center for the Protection of People with Special Needs. He lives in Albany, NY.

Heather Dawn

Heather Dawn joined Friends Life Community's staff as Visual Arts Specialist in 2016. She holds a bachelor's degree in Fine Arts from Watkins College of Art, specializing in printmaking, performance, fiber art and sculpture. Heather has developed and grown the visual arts program and supports over 25 artists with IDD throughout the year. In 2018 the Visual Arts program displayed over 500 original works of art in two galleries, produced over 250 handmade products, and started a new collaboration with artists at Friends Life and in the community to debut a self-advocacy project lead by the artists in Spring 2019. Heather's specialty is understanding an individual beyond what words can express and facilitating the process of that person being able to communicate it through art.



Sarah Edwards, M.A., RDT

Sarah Edwards joined Friends Life Community in 2012. After receiving her Bachelor of Fine Arts degree in Theatre Education, Sarah spent two years incorporating theatre, puppetry, and dance into Friends Life Community's Day Program to increase social and life skills. In 2015, Sarah graduated with her master's degree in Drama Therapy from Kansas State University and is a Registered Drama Therapist with the North American Drama Therapy Association. Sarah developed the Performing Arts Program at Friends Life. In 2018 the program wrote and performed an original play to over 400 community members, piloted an arts program in rural Tennessee, learned two choreographed dances and performed flash mobs throughout the community, wrote an original screenplay for a short film and started filming, and is collaborating with the Visual Arts program for Arts Advocacy. Sarah has the imagination and the ability to use theatre to

help individuals realize their potential and feel empowered to live it out.



Waverly Ann Harris, M.S.ABA

Waverly Ann Harris joined Friends Life Community in 2011 as the first Program Director in order to develop and grow the Day Program, for adults with IDD to grow personally, develop socially, and increase community inclusion, and became Executive Director in 2016. Waverly Ann has worked with over 100 individuals with IDD and their families through Friends Life and has a Master's degree in Applied Behavior Analysis. Her primary work focuses on systems design to support all individuals around common goals, this includes individuals, families, work places, and organizations.

Dr. Jamie Ho

Dr. Jamie Ho graduated from the Illinois College of Optometry and a residency with The New England College of Optometry and Beth Israel Deaconess, a Harvard teaching hospital in Boston. She is a Fellow of the American Academy of Optometry and an Associate of the College of Optometrists in Vision Development (COVD) and Neuro Optometric Rehabilitation Association (NORA). Ho Vision Group offers comprehensive vision rehabilitation services and innovative solutions for visual problems from missing visual fields to various vision problems due to eye diseases, brain injury, and stroke. She is one of the few hundred neuro-developmental optometrists in the United States.



Melissa Hogan

Melissa Hogan is a lawyer by training, a writer by passion, and an advocate by necessity. At two years old, her son was diagnosed with the rare disease Hunter Syndrome, plunging them into a world of specialists, therapies, and clinical trials. She is now the President of Project Alive, the world's leading Hunter Syndrome research and advocacy foundation. Because of her son's medical experiences, she is passionate about preventing and managing medical trauma in children and is currently co-writing a book for parents on the topic with one of the leading researchers in the field, Meghan Marsac, PhD.

Sam Hutchins and Lorie Sain

Sam is the IDEAL Residential Coordinator at Lipscomb University and Laurie is the Associate Dean of Student Life who oversees all of the Resident Hall Directors. In conjunction with other Student Life and IDEAL program team members, they have overseen the installation and expansion of the residential program at Lipscomb. Laurie has 19 years of experience in Student Life and Residence Life and has been a strong advocate for the IDEAL program. This is Sam's third year in this position and has worked directly with students to promote a holistic independent living.



Steve Morris

Steve started working in the field of Intellectual and Development Disabilities as a Job Coach in 1987. Currently, he is the Executive Director the Arc of the Farmington Valley, Inc. (Favah) in Canton, CT. He was formerly Executive Director of Sarah, Inc. (Arc Affiliate) in Guilford, CT. Steve has degrees from the University of Rhode Island, University of Connecticut and additional formal education from Harvard Kennedy School. He is the founder of Summit Hiking & Camping: an outdoor integrated adventure club for people of all abilities. Steve lives in Burlington, CT with his wife Cherie and their dog Reggie.



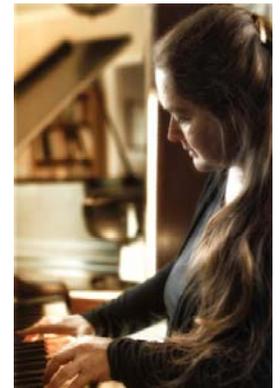
John Shouse

John Shouse and his wife Janet are parents to three children, including a young adult son with autism. John served as the president of the Autism Society of Middle Tennessee (now Autism Tennessee) for 6 years, and for nearly 4 years as a Vice Chair of the national board of the Autism Society of America. He is currently serving as Past President of The Arc Tennessee. A graduate of Partners In Policymaking, John has been an engaged and active advocate for enhanced services and supports for people with disabilities. He has been a frequent speaker at national and regional conferences on the special issues faced by fathers of children with autism and other disabilities. John was one of three finalists in 2008 for the Center for Nonprofit Management's "Board Member of the Year" award. He is co-author, with Paula Kluth, of *The Autism Checklist: A Practical Reference for Parents and Teachers*, John Wiley & Sons, 2009.



Martha Summa-Chadwick, DMA

Martha Summa-Chadwick DMA, is a concert pianist, educator, and advocate for the use of music in therapy. Dr. Summa-Chadwick frequently presents at regional and national conferences as a promoter of medical music therapy into healthcare and education. She is on the faculty of the Cadek Conservatory in Chattanooga and is the Executive Director of the nonprofit organization Music Therapy Gateway In Communications (MTGIC). MTGIC's current projects include a unique performance series designed to disseminate information about music and the brain, development of inclusive music class curriculum, and a groundbreaking project to automate biomedical music techniques into apps for mobile devices.



Crescent Club Quartet

Tyler Benson

Tyler, age 29, was born in Chattanooga, TN. He was diagnosed with Asperger's in 2017. Tyler graduated from a private Christian high school and went on to attend Lee University. At 19, Tyler was an International Teen Talent Winner with his church, playing trumpet. He has played at various churches and functions. He also plays piano, bass guitar, and sings lead and harmony.



Edward Newton

Edward, age 25, was born in Hartford, CT. He was diagnosed with autism when he was 28 months old. Edward graduated from Hixson High School. Edward began playing the electric bass when he received one for his 22nd birthday. He currently works at The America's Thrift Store.

Mitch Newton

Mitch, age 20, was born in Hartford, CT. He was diagnosed with autism and central auditory processing disorder at 21 months. Mitch was part of Hixson High School's marching and jazz bands until he graduated in December 2017. Mitch plays drums, piano and electric guitar. He is currently enrolled in the Siskin Community Reentry Program.



Paul Newton

Paul, age 16, was born in Chattanooga, TN. When 15 months old, he began attending the ACHIEVE pre-K for deaf and hard of hearing toddlers. He was diagnosed with autism on his second birthday. Paul is a junior at Hixson High School where he plays in the Orchestra, Jazz Band, Marching Band, and Concert Band. He plays saxophone, violin acoustic guitar, and piano. Paul is currently working toward his Eagle Scout rank in the BSA.

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