2 Profound Autism Sumit Sparking Collaboration Advancing Treatment

April 5, 2024 Boston Marriott, Burlington





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Profound Autism Summit Sparking Collaboration | Advancing Treatment

Friday, April 5, 2024









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After the Summit...

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BOSTON 2024

REGISTRATION

On-Site Check-in and Registration begins at 7:15 AM Lobby

MORNING PROGRAM

Opening Remarks 8:45 - 9:00 am Salon A-E LIZ MARTINEAU

Building a Life: Applied Behavior Analysis and the Development of Meaningful Goals for Individuals with Profound Autism

9:00 - 9:50 am Salon A-E 1 CE PETER GERHARDT AND SHANNA BAHRY

Echo Autism Intense Behavior: Moving Knowledge, Not People

10:00-10:50 am Envision KRISTIN SOHL

AAC is for Everyone – Evidence-based Communication Interventions to Support All

Learners

10:00-10:50 am Salon A-E 1 CE JENNIFER ALBIS NEAL

LifeSpan Panel

11:00-11:50 am Envision MAURA SULLIVAN, CATHERINE BOYLE Safety Panel: Elopement 11:00 am -12:15 pm Salon A-E 1.5 CEs NATHAN CALL, KATE MOVIUS, WILLIAM CANNATA

LUNCH

11:50 am -12:50 pm Salon F, Collaborate, Patios

AFTERNOON PROGRAM

"In a Different Key" Presentation

12:55 - 1:10pm Salon A-E CAREN ZUCKER, JOHN DONOVAN

A Compassionate Approach to Treating Severe Problem Behavior

1:10 - 2:00 pm Salon A-E 1 CE GREGORY HANLEY

Long-term Effectiveness and Generality of Skill-Based Treatment

2:10 - 3:00 pm Salon A-E 1 CE JESSICA SLATON

The Science of Profound Autism

2:10 - 3:00 pm Envision ALYCIA HALLADAY

The representation wars: media portrayals, language debates, and advocacy in the autism community

3:10 - 4:00 pm Envision AMY LUTZ

Psychopharmacology of Autism Spectrum Disorder

3:10 - 4:00 pm Salon A-E CHRIS MCDOUGLE **Family Life Panel** 4:10 pm -5:00 pm Envision EILEEN LAMB, CHERYL RYAN CHAN, TERRI FARRELL

Advocacy Panel 4:10 pm -5:00 pm Salon A-E 1 CE NAN LEONARD, JUDITH URSITTI, MAURA SULLIVAN, SEAN GARBALLEY

POST-SUMMIT EVENT (separate registration required)

In a Different Key

5:30 - 8:00 pm Envision This is a free event, but seating is limited. Please register separately at <u>www.profoundautism.org/in-a-different-key/</u>.

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Dr. Nate Call

Nate Call is a Professor of Pediatrics and Associate Chief of the Division of Autism & Related Disorders in the Emory University School of Medicine. He has worked at Marcus Autism Center since 2006, where he has held many positions as a researcher, clinician, and leader of clinical programs. He currently serves as the Vice President for Children's Healthcare of Atlanta overseeing the center. In this role he oversees all clinical activities and works with providers and other center leaders to develop new clinical innovations. Dr. Call has an active research agenda and has published over

seventy papers and book chapters on the treatment of challenging behavior exhibited by individuals with autism or developmental disabilities.



Captain William A. Cannata, Jr. (Retired)

Bill was a member of the fire service for 35 years. Bill had been an officer with the Westwood Fire Department for fifteen years. He was also a Massachusetts Fire Academy instructor for 15 years. Bill became a member of Autism and Law Enforcement Education Coalition (ALEC) in November 2003. In January of 2006, he became the statewide coordinator of ALEC. ALEC currently educates first responders across the state of Massachusetts and through out the world about Autism Spectrum Disorder and how to better understand a person who is on the spectrum. ALEC has trained over

55,000 first responders throughout the United States.

Bill is also the parent of a child with Profound Autism.



Cheryl Ryan Chan

Cheryl Ryan Chan is a professional facilitator with nearly 10 years of experience providing person-centered planning as well as training in personcentered practices to individuals, families, groups and organizations across Massachusetts, in Missouri, Minnesota, Maryland, Wisconsin, New York and California. She is a parent of a young adult with profound intellectual disabilities and autism. Cheryl is a well-known leader and advocate within the disability community, and regularly presents at conferences on topics affecting the disability community and caregiving for people with disabilities.



Dr. Shanna Bahry

Dr. Bahry is a board-certified, doctoral-level behavior analyst (BCBA-D), certified progressive autism professional (CPBA-AP), and licensed behavior analyst in Massachusetts (LABA) and Rhode Island (LBA). She has been working with individuals with autism spectrum and related disorders for over 15 years, across a wide range of ages, abilities, and severity of challenging behavior, in a variety of settings. Dr. Bahry received her PhD in applied behavior analysis from Endicott College, under the advisement of Dr. Peter Gerhardt. She has authored several publications and presented nationally

and internationally within her focus areas of adaptive behavior programming leading to optimal outcomes in adulthood, including teaching practitioners the skills needed to target meaningful goals with effective and efficient teaching methodologies. Dr. Bahry currently serves as the Executive Director of Meaningful HOPE, an agency committed to helping practitioners and families best support individuals with disabilities in preparing for a meaningful life in adulthood. She is also an Adjunct Professor in the master's and doctoral programs at Endicott College's Institute for Applied Behavioral Sciences.



Catherine Boyle

Catherine Boyle is a commissioner of the Winchester Housing Authority, a member of the Winchester Housing Partnership Board, and has completed over 60 hours of housing counseling training through HUD-approved intermediaries. She is the recipient of two Margaret L. Bauman Awards: one for her work with Autism Housing Pathways, and another for the development of the St. Mary's Curriculum for Students with Autism, a religious education curriculum. A former Foreign Service Officer, Catherine is a graduate of Dartmouth College. She holds a certificate of graduate

studies from UMASS Boston in adapting curriculum and a certificate in ADRC (Aging and Disability Resource Centers) Options Counseling from the Center for Aging & Disability Education & Research at Boston University's School of Social Work.

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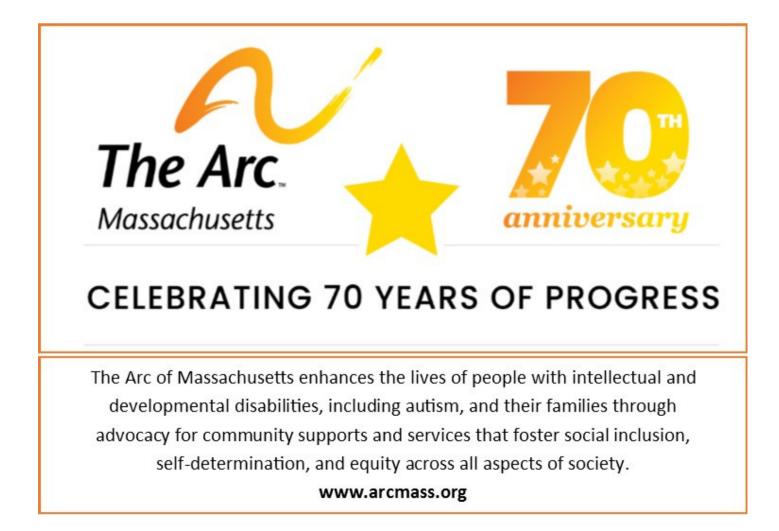




Terri Farrell

Terri is the Project Director of the Insurance Resource Center for Autism and Behavioral Health of Massachusetts. The resource center is housed in the Shriver Center of UMass Medical School in Worcester, MA. The IRC provides technical assistance to families, providers and agencies in need of information related to both public (MassHealth) and private insurance. Terri was appointed the chair of AFAM's (Advocates for Autism of Massachusetts) Government Affairs Committee in 2013. AFAM is the leading Massachusetts autism advocacy non-profit promoting budgetary and legislative initiatives at

the state level. Terri plans AFAM's annual Autism Awareness and Acceptance Day held at the State House. Terri has presented at local conferences focusing on autism insurance, transition and issues affecting homeless youth with ASD. She has presented at SPEDPACS throughout the Commonwealth on the ARICA law and accessing ABA coverage through MassHealth. Terri is the parent of a 25 year old autistic adult.





Representative Sean Garballey

Representative Garballey has been dedicated to the autism community since he began in the Massachusetts legislature in 2008. He is currently the lead sponsor on multiple bills that support people with profound autism including a bill to strengthen and expand the Abuser Registry (Nicky's Law) and Hospital Autism training bill, and several others. The Representative has been instrumental in budget Advocacy and has been a tireless voice for individuals with autism and other intellectual disabilities turning 22 and transitioning into adult services. Rep Garballey is a two time Advocates for Autism (AFAM) Legislator of the Year Champion.



Dr. Peter Gerhardt

is the Executive Director of the EPIC Programs in Paramus, NJ. The EPIC Programs provide comprehensive and individualized behavior analytic supports and interventions to children and adults with autism. He also serves as an Affiliate Professor and doctoral advisor at Endicott College's Institute for Applied Behavioral Sciences. Dr. Gerhardt has nearly 40 years of experience utilizing the principles of applied behavior analysis in support of adolescents and adults with autism spectrum disorders in educational, employment, residential, and community-based settings. He is the author,

co-author, or editor of a number of articles, chapters, and books on the needs of adolescents and adults with autism spectrum disorder. He is a highly regarded speaker, frequently sought out to present nationally and internationally on his areas of expertise. Dr. Gerhardt serves as Founding Chair of the Scientific Council for the Organization for Autism Research, which to this date has funded more than \$4 million in applied research grants. He is on numerous professional advisory boards and is a trustee of the Cambridge Center for Behavioral Studies. Dr. Gerhardt also serves as a reviewer for several behavior-analytic and autism-specific journals. He received his doctorate from Rutgers, The State University of New Jersey's Graduate School of Education.

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Dr. Alycia Halladay

Alycia Halladay is the Chief Science Officer for the Autism Science Foundation, where she oversees all of the scientific activities, grant programs, funding projects and scientific initiatives of ASF. This includes a weekly podcast and a year end summary of research for families. Prior to joining ASF in 2014, she served as the Senior Director of Clinical and Environmental Sciences at Autism Speaks. She has authored over two dozen peer-reviewed papers in science journals around autism spectrum disorder, with a focus on the needs of the underserved and

underrepresented in scientific research. Alycia also serves on Board of Directors for the Phelan McDermid Syndrome Foundation and the Interagency Autism Coordinating Committee. She is on the editorial boards of Neurotoxicology and Frontiers in Pediatrics. She received a PhD in biopsychology from Rutgers in 2001 and completed a postdoctoral fellowship in pharmacology and toxicology at the University of Medicine and Dentistry of NJ in 2004. She still holds a faculty appointment at Rutgers. She is the parent to a 13 year old daughter with ASD.



Dr. Greg Hanley

Dr. Hanley has been applying the principles of learning to improve socially important behaviors of children and adults with and without disabilities for 35 years. He worked and trained at the Kennedy Krieger Institute, was degreed at the University of Florida, was tenured at the University of Kansas, and directed the Behavior Analysis Doctoral Program and Life Skills Clinic at Western New England University (WNEU). Dr. Hanley has published over 100 book chapters and articles in peer-reviewed journals in areas such as the assessment and prevention of problem behavior, skill development,

and evidence-based values. Dr. Hanley is a Fellow of the American Psychological Association (Div. 25), past Associate Editor of The Behavior Analyst, and past Editor of the Journal of Applied Behavior Analysis and of Behavior Analysis in Practice. He currently serves as a Research Professor at WNEU, and CEO of FTF Behavioral, an international training and consulting group based in Worcester Massachusetts.



Eileen Lamb

Eileen Lamb, founder of The Autism Cafe, shares life experiences, anecdotes, and a wealth of information and resources to those experiencing or parenting children with autism in her upcoming photography and essay collection, All Across The Spectrum. As the mother of a son with severe nonverbal autism, and as someone living with high-functioning autism herself, Eileen's unique perspective, coupled with her stunning collection of photography, aims to raise autism awareness and help readers better understand the many facets of autism.



Nan Leonard

Nan is a Board Member at Nashoba Learning Group and practiced corporate law at Palmer & Dodge until the birth of her triplets, one of whom has a severe developmental disability. She became interested in finding more effective treatments to help people with developmental disabilities and completed a graduate program in Applied Behavior Analysis at Simmons College, receiving an Ed.S. degree in 2003 and qualifying as a Board Certified Behavior Analyst. In 2006-2007 she was a LEND fellow at the Eunice Kennedy Shriver Center studying public policy change in disabilities

and received a Masters in Healthcare Administration from Suffolk University. She drafted the ARICA legislation which requires private health insurers to pay for ABA treatment. Her advocacy to extend access to ABA treatment to adults with profound developmental disabilities with Medicaid continues. Nan received her JD from Boston College Law School where she was an editor of the Law Review and her AB from Harvard University.



Dr. Amy Lutz

Amy S.F. Lutz, PhD is a historian of medicine at the University of Pennsylvania, the Vice-President of the National Council on Severe Autism (NCSA), and the parent of a profoundly autistic son, Jonah, 25. She has written about profound autism for many platforms, including The Atlantic, The Washington Post, Psychology Today, Spectrum, and Slate. Her most recent book is Chasing the Intact Mind: How the Severely Autistic and Intellectually Disabled Were Excluded from the Debates that Affect Them Most (2023); she is also the author of We Walk: Life with Severe Autism

(2020) and Each Day I Like It Better: Autism, ECT, and the Treatment of Our Most Impaired Children (2014). She lives outside of Philadelphia with her husband and whichever of her five kids happen to be home at the time.



Liz Martineau

Liz Martineau is the Founder and CEO of Nashoba Learning Group (NLG), which has operated a School since 2003 and an Adult Program since 2013, and now serves 200 individuals with Profound Autism. NLG provides comprehensive and individualized behavior analytic support, in partnership with the family, and focused on meeting each individual's unique needs in a loving, compassionate environment. Liz earned her BCBA certification in 2001 and her Ed.S in Behavioral Education from Simmons. Prior to NLG, Liz was a strategy consultant and partner at Monitor Company. She earned an

MBA from Harvard Business School and an AB in Economics from Williams College. She and her husband are the parents of five grown children, including a son with Profound Autism.

Liz, with her NLG colleague Katherine Johnson, conceived of the Profound Autism Summit, and serves as Committee Chair with Katherine and Judith Ursitti.



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Dr. Christopher McDougle

Christopher McDougle, MD, received a B.A. in Chemistry from Valparaiso University in 1981 (with Highest Distinction) and an M.D. from Indiana University School of Medicine in 1986 (with Highest Distinction). He subsequently completed a residency in psychiatry at Yale University School of Medicine (1990) and a fellowship in child and adolescent psychiatry at the Yale Child Study Center (1995). After seven years on the faculty at Yale, Dr. McDougle joined the Indiana University School of Medicine (IUSM) in 1997 as the Raymond E. Houk Professor of Psychiatry and Director of the Section

of Child and Adolescent Psychiatry. In September of 2000, Dr. McDougle was named the Albert Eugene Sterne Professor of Psychiatry and Chairman of the Department of Psychiatry at the IUSM. He continued on as Director of the Section of Child and Adolescent Psychiatry, as well. In the fall of 2011, Dr. McDougle became the Director of the Lurie Center for Autism and the Nancy Lurie Marks Professor in the Field of Autism at Harvard Medical School.

Dr. McDougle was elected to the American College of Neuropsychopharmacology in 1995, and is now a fellow. He was twice chosen as Teacher of the Year by the Yale Psychiatry Residents. In 2002, Dr. McDougle was selected as a recipient of the 12th Annual Nancy C.A. Roeske, M.D. Certificate of Recognition for Excellence in Medical Student Education from the American Psychiatric Association, and in 2007 he was selected as a recipient of the Annual Irma Bland Award for Excellence in Teaching Residents, also by the American Psychiatric Association. Dr. McDougle was awarded the Frank J. Menolascino Award from the American Psychiatric Association in 2009 and the George Tarjan Award from the American Academy of Child and Adolescent Psychiatry in 2012. In 2003, he was appointed Associate Editor of the Journal of Autism and Developmental Disorders.

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Kate Movius

Kate Movius is the founder of Autism Interaction Solutions, whose mission is to provide effective training in autism identification, safety and communication tactics for first responders. For over a decade, Kate has trained multiple police departments and other key county agencies. For the past 7 years, along with her autistic co-trainers, Kate has been the key disability trainer for the LA Sheriff's Department – the nation's largest. Kate's work has been profiled by CBS, ABC, FOX and the LA Times. She is a frequent spokesperson about special needs issues and has been a contributing writer for The LA Times and Los Angeles Magazine. Kate serves

on the LA Found Task Force, working with the Los Angeles Board of Supervisors to establish a strategic plan to minimize the risks of wandering for people with Alzheimer's and autism. She is also a member of the Autism Society of America Safety Task Force. Kate is the proud mom of two sons, one of whom has autism.



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Dr. Jennifer Albis Neal

Dr. Neal is a Speech-Language Pathologist and a Board Certified Behavior Analyst. She is the Director of Therapy Services for the Evergreen Center, where she helps to integrate knowledge and interventions from a variety of disciplines into the educational and residential programming for students with disabilities.

Jen studied Speech-Language Pathology at Boston University and MGH Institute of Health Professions, and studied Applied Behavior Analysis at Simmons College. She completed her doctorate in Speech-Language

Pathology through Northwestern University. Her research focuses on indirect service delivery models within Allied Health fields and how to ensure students receive the most effective and efficient evidence-based interventions.

With over two decades of experience, Jen has taught communication and life-skills in a variety of settings, including schools and early intervention. In addition to her work at the Evergreen Center, Jen also teaches graduate-level special education and early intervention courses through Cambridge College. She is passionate about integrating knowledge from a variety of fields to empower families and educators and to improve services for individuals with Autism and related disorders.



Dr. Jessica Slaton

Dr. Slaton has worked in the fields of applied behavior analysis and special education for almost 20 years. She is the Director of Applied Research at Nashoba Learning Group, a day school and adult program for autistic individuals, and also serves as adjunct faculty in the Applied Behavior Analysis master's program at Regis College. She received an M.S.Ed. in Behavioral Education at Simmons University in 2006, and Ph.D. in Behavior Analysis from Western New England University in 2016. She specializes in working with autistic children with intellectual disabilities who engage in

severe problem behavior. Dr. Slaton has shared her work at local, national, and international conferences over the last decade, has published several articles in peer-reviewed journals, and currently serves on the Board of Editors of the Journal of Applied Behavior Analysis.



Dr. Kristin Sohl

Dr. Sohl is a pediatrician with extensive experience in medical diagnosis, evaluation and treatment of children with a concern of autism and other neurodevelopmental disorders. She is an expert in quality and process improvement for comprehensive autism diagnostic and longitudinal services.

Dr. Sohl is the site principal investigator for the Autism Intervention Research for Physical Health/Autism Treatment Network (AIRP/ATN) and serves in national leadership roles with each program. She is also founder of

ECHO Autism, an innovative framework to increase community capacity to care for children with autism and other developmental/behavioral concerns. ECHO Autism is considered a national model for expanding autism diagnosis and treatment to underserved and rural populations. Her team has established partnerships with health care entities in more than 15 states and five countries.

Dr. Sohl's research focuses on systems change to improve health care and services for individuals with autism and also focuses on understanding underlying medical conditions in individuals with autism.

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Maura Sullivan

Maura Sullivan is the Senior Director of Government Affairs and Health Policy for The Arc of Massachusetts and Advocates for Autism of MA. She is also the Director of Operation House Call, a training program and partnership between The Arc and all major Massachusetts Medical Schools.

Maura's advocacy work includes passing priority legislation for the autism community, such as Nicky's Law, Police Training in Autism and Operation House Call. Her work at the State House focuses on increasing funding for the DDS budget, the workforce, and MassHealth.

Maura is an advisor to Drexel University's Autism Transition Project and Harvard Medical School. Maura is a two-time Margaret Bauman advocacy award recipient, sits on the advisory board for Nashoba Learning Group and the Governor's Autism Commission for Healthcare. She is a national public speaker on health equity and a former LEND Fellow with a master's degree in public administration from Suffolk University. Maura is also the mother of three, her two sons have profound autism.



Judith Ursitti

Judith Ursitti is Co-Founder and President of the Profound Autism Alliance. A CPA by training, she spent a decade working in tax accounting. She became immersed in the world of autism advocacy when her son, Jack, was diagnosed at age 2. Since his diagnosis, she has worked on the passage, implementation, and enforcement of autism-related legislation nationwide. She worked for Autism Speaks as their director of state government affairs for thirteen years and, most recently, at the Council of Autism Service Providers as their vice president of government affairs. Judith and her husband Andy are parents to two adult children, Amy, and Jack, who has profound autism.

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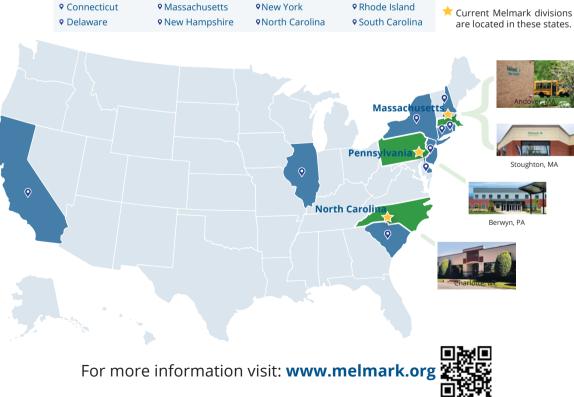
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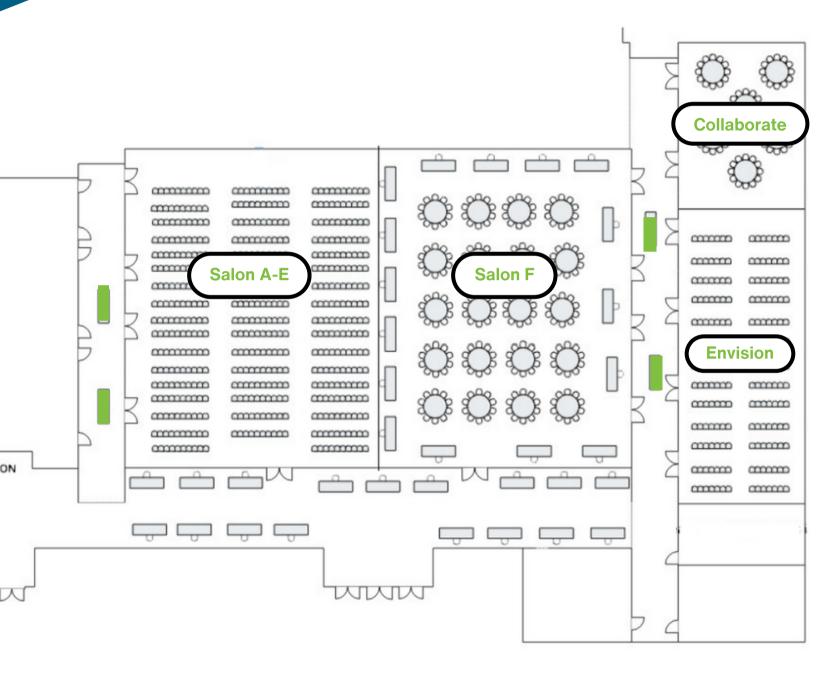
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