



Massachusetts Down Syndrome Congress (MDSC) 33rd Annual Conference

MDSC 33rd Annual Conference
Saturday, March 25, 2017

DCU Center, Worcester MA



Join us for a day of learning and celebration!



Detailed Workshop Description & Speaker Bios

Each spring, over 600 people with Down syndrome, their family members, health care professionals and educators from across New England attend our Annual Conference on Down syndrome. Participants gather to hear the latest research findings and timely information from national and local experts on a range of topics related to Down syndrome. They also share stories, celebrate victories, advocate for acceptance and inclusion, and reunite with other MDSC families. The conference features presentations that will appeal to families with young children through adulthood and families with children who have complex medical needs and autism. In addition, there will be presentations that will appeal to educators, medical professionals, and siblings of individuals with Down syndrome.

Looking for a team mate to play with at school? "Count Me In!"

Looking for a friend who will not judge you? "Count Me In!"

Looking for someone who will stand up for what's right? "Count Me In!"

Interviewing candidates for a job opportunity? "Count Me In!"

Changing the world with a can-do attitude? "Count Me In!"

For 2017, the theme for the MDSC and our Down syndrome community in Massachusetts is - you guessed it - **COUNT ME IN!**

Our community includes individuals with the full spectrum of interests and abilities, people of all different cultures and backgrounds, individuals with unique viewpoints and personalities. What ties us together? Ultimately, all people with Down syndrome and their families want to be **COUNTED** and deserve to be **INCLUDED**.

So **COUNT US IN!**

We are positive. We are diverse. We are accepting. Help us bring our 2017 theme to life this year:

- Make your voice **COUNT**
- Let your friends, neighbors, teachers know that we're **COUNTING** on them
- Help us **COUNT** the progress we've made over the years (and consider how much further we have to go)
- Join us as we **COUNT** up to our 33rd Annual Conference, our 4th Annual Advocacy Day, our 21st Buddy Walk & Family Festival, etc.

And together, we'll help the world understand the math that really COUNTS - that the 3rd copy of the 21st chromosome that defines Down syndrome adds up to a better world for everyone.

Annual Meeting

8:00 AM – 8:45 AM

At the Annual Meeting you will meet with our Board of Directors and Executive Director to hear about the progress the MDSC made this past year and also vote on our new slate of Board members. The meeting is open to all MDSC members. A continental breakfast will be served.

BREAKOUT SESSION I
9:00 AM - 10:30 AM (Choose one)
GENERAL SESSIONS

In lieu of specific tracks this year, we have formatted our program to offer our membership a variety of workshops. We want our attendees to choose any topic that may interest them. We have provided a recommended target audience for each workshop to support you as you choose your sessions for the day.

Key:

Related to Children ages 0-5	Related to Children ages 5-12	Related to Teenagers	Related to Young Adults	Related to Adults	Related to ASD	Related to Complex Needs	Related to Education
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1. New Parents: Sharing Our Stories - Sarah Cullen, Family Support Director, MDSC; Angela Lombardo, Program Coordinator, Down Syndrome Program at Boston Children's Hospital; Melanie Perkins McLaughlin, MDSC Prenatal First Call parent and Disability Advocate

Related to Children ages 0-5

We invite new parents to come and hear the stories from experienced parents and share their own stories, meet other new parents, learn about helpful resources and/or just listen and relax in the warm community of other new families.

Sarah Cullen is the Family Support Director for MDSC. She oversees the Parents' First Call program, supporting both new and expectant parents. The MDSC First Call program has been replicated in 15 Down syndrome organizations across the country in 13 states. Sarah is the parent of three children, including Matthew, who is 20 and has Down syndrome.

Angela Lombardo is the Program Coordinator for the Down Syndrome Program at Children's Hospital in Boston. She is also Family Faculty for both the Leadership Education in Neurodevelopmental and Related Disabilities Program and the Institute for Professionalism and Ethical Practices. In addition to those three roles, she also serves as the coordinator for Linking Hands, a program at Children's where medical staff go to the homes of children with special health care needs to learn directly from families outside of the clinical setting. Angela's biggest and most important job is being the single mom of a 21 year old son, Isaiah, who has Down syndrome.

Melanie Perkins McLaughlin is a documentary filmmaker, a disability rights advocate, public speaker and the mother of three children, the youngest of whom has Down syndrome.

In 2007 Perkins McLaughlin independently produced film, "Have You Seen Andy?", the personal story of the search for answers to the disappearance of her childhood friend, was broadcast on HBO winning a National Emmy Award for Best Investigative Journalism. That same year Perkins McLaughlin received a prenatal diagnosis: her third child had Trisomy 21 and a congenital heart defect.

Since her daughter's birth Perkins-McLaughlin has become a public spokesperson on disability and civil rights issues. She has been interviewed nationally by TIME magazine, CBS News, USA Today, HBO, ABC, Japanese Public Broadcasting (NHK), National Public Radio, Fox News and the BBC. She has presented on prenatal ethics and

disability awareness issues with Harvard University Medical School, Tufts Medical School, Boston University School of Medicine and Brandeis University.

Perkins-McLaughlin was the commencement speaker at Fitchburg State University (her alma mater) where she received an honorary doctorate degree. She is currently a First Call parent volunteer with the Mass Down Syndrome Congress where she offers a unique and non-judgmental perspective on prenatal diagnosis. She was the inaugural Allen C. Crocker Family Fellow with the Institute for Community Inclusion and the Massachusetts Developmental Disabilities Council. And she recently produced a series of short films for the National Down Syndrome Society's "My Great Story" public awareness campaign.

She is the co-chair of the Department of Elementary and Secondary Education Special Advisory Committee, a family faculty member of Boston Children's Hospital Institute for Professional Ethics and a family faculty member for The Arc of MA Operation House Call.

2. Keeping Children and Adolescents with Down Syndrome Healthy, All the Medical Updates

Parents Need to Know – Brian Skotko, MD, MPP & Allie Schwartz, MD, Co-Directors, Massachusetts General Hospital Down Syndrome Program

Related to Children ages 0-5	Related to Children ages 5-12	Related to Teenagers
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In this presentation, Dr. Brian Skotko and Dr. Allie Schwartz review all of the questions and concerns that parents most often have about their sons and daughters with Down syndrome. They provide the answers and action steps, stemming from the latest clinical research on people with Down syndrome. Based on their clinical experience in the Down Syndrome Program at Massachusetts General Hospital, Dr. Skotko and Dr. Schwartz make sure that every parent can anticipate medical conditions so that the potentials of all people with Down syndrome are maximized.

Brian Skotko, MD, MPP - A Board-certified medical geneticist and Co-Director of the Down Syndrome Program at Massachusetts General Hospital, Dr. Skotko has dedicated his professional energies toward children with cognitive and development disabilities. In 2001 he co-authored the national award-winning book, *Common Threads: Celebrating Life with Down Syndrome* and, most recently, *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters*. He is a graduate of Duke University, Harvard Medical School, and Harvard Kennedy School. Dr. Skotko recently authored major research on how physicians deliver a diagnosis of Down syndrome to new and expectant parents. He has been featured in *The Wall Street Journal*, *The New York Times*, *The Washington Post*, *The L.A. Times*, NPR's "On Point," and ABC's "Good Morning America." Dr. Skotko serves on the Honorary Board of Directors for the Massachusetts Down Syndrome Congress, the Board of Directors for the Band of Angels Foundation, and the Professional Advisory Committee for the National Center for Prenatal and Postnatal Down Syndrome Resources.

Allie Schwartz, MD - Dr. Schwartz is an internist and pediatrician who is passionate about improving the lives of individuals with special health care needs. She completed a combined residency in the Harvard Internal Medicine-Pediatrics Residency Program where she presided as an Ambulatory Chief Resident in the Department of Medicine. Dr. Schwartz obtained degrees in both child development and medicine from Tufts University and has served as a Residential Coordinator at a school for children and adolescents with autism and traumatic brain injury. Dr. Schwartz is very interested in working with individuals with special health care needs and serves as the Clinical co-director of the MGH Down Syndrome Program which is a multidisciplinary clinic that sees kids and

adults with Down syndrome. She is also a med/peds primary care physician at MGH Everett Family Care where she enjoys caring for families and precepting med/peds residents.

3. Behavior and Down Syndrome: The Respond but Don't React Method – David S. Stein, PsyD, Pediatric Psychologist, Founder New England Neurodevelopment

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Behavior problems impact 30% of children with Down syndrome. Left untreated, these same children often exhibit behavior problems as adults, limiting work and independent living opportunities. Many typical behavioral management tools are less effective for children with DS. In order to address behavior problems in DS effectively, one must understand the brain-based reasons for these challenges and direct treatment appropriately. This workshop will present the basic neuroscience of Down syndrome and how this informs effective behavior management, with practical strategies provided for use in the home and school settings.

David Stein, PsyD - Dr. David Stein is the founder of New England Neurodevelopment, a pediatric psychology practice in the greater Boston area of Massachusetts. He is the author of Supporting Positive Behavior in Children and Teens with Down Syndrome: The respond but don't react method, published by Woodbine House in 2016. Dr. Stein has served as Co-Director of the Down Syndrome Program at Boston Children's Hospital, a pediatric psychologist within the Division of Developmental Medicine at Boston Children's, and an instructor at Harvard Medical School through 2016. Dr. Stein's clinical work is focused on neuropsychological testing, behavior therapy, and parent training with children who have neurodevelopmental disorders. Dr. Stein's research is focused on accurate phenotyping of complex and comorbid neurodevelopmental conditions, factors affecting long-term outcomes, and quality improvement. Dr. Stein is a native of Boston who began working with children with Down syndrome during his own childhood, volunteering with a local advocacy group. He completed his bachelor's degree with high honors at Tufts University with high honors, his doctorate in psychology at William James College, his internship at Harvard Medical School & The Cambridge Hospital, and his post-doctoral fellowship at Harvard Medical School & Boston Children's Hospital.

4. What We Know About Teaching Reading to Children with Down Syndrome - Kathleen Whitbread, PhD, Associate Professor of Education, University of Saint Joseph

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This presentation will focus on current research, best practices, and practical strategies for improving the literacy outcomes of children with Down syndrome. The results of a national survey on the literacy experiences of children with Down syndrome will be shared, highlighting home- and school-based practices that contribute to a strong literacy foundation. Participants will have an opportunity to explore literacy concepts through hands-on activities.

Kathleen Whitbread, PhD - Kathleen Whitbread, Ph.D. is an Associate Professor of Education at the University of Saint Joseph in West Hartford, CT. For more than 30 years, Dr. Whitbread has provided training and technical assistance to school districts, families and community organizations on research-based practices in special education, with specific expertise in literacy instruction for children with Down syndrome. She maintains a blog, Open Books Open Doors (<http://openbooksopendoors.com>), which features current research and practice on reading instruction. Through her private practice, Dr. Whitbread mentors teachers who teach reading to

children with Down syndrome. She maintains an active Special Education teaching license as well as associate level certification in Orton Gillingham reading methodology. Dr. Whitbread has published articles about her research in Teaching Exceptional Children, Research in Middle Level Education, The Journal of the Connecticut Association for Reading Research, Topics in Early Childhood Special Education and Current Issues in Education.

5. Alternative and Augmentative Communication Tools – Bridging Access to the World Through Communication – *Kate Ahern, MS Ed, Assistive Technology Specialist/Special Educator, Easter Seals Massachusetts*

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Many students with Down syndrome, particularly those with additional complex needs, such as a dual diagnosis of Autism and Down syndrome have significant communication challenges that impact all aspects of daily functioning, both in school, at home and in the community. In this session, we will explore the use of Augmentative and Alternative Communication Strategies and the positive impact that their use can have on the lives of many of children and adults..

Kate Ahern, MS Ed - Ms. Kate Ahern completed combined undergraduate and Master of Science program in special education at Simmons College in Boston. She taught intensive special education for 15 years in private and public schools. In 2012, Kate moved to working full time as an assistive technology specialist. Her interests include augmentative communication in children with complex communication needs, and assistive technology implementation in schools. She is the recipient of the Federation for Children with Special Needs Inclusive Special Education Teacher Award in 2014 and the Fighting Angels Foundation Award for work in Angelman Syndrome in 2016.

BREAKOUT SESSION II
11:00 AM - 12:30 PM (Choose one)
PARENTS/GENERAL SESSIONS

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6. Promising Developments in Alzheimer's Research & Down Syndrome – *Bjoern Sperling, MD, Senior Director Neurodegeneration, Biogen; Brian Skotko, MD, MPP, Co-Director, Massachusetts General Hospital Down Syndrome Program; Hiruy Meharena, Postdoctoral Fellow at Massachusetts Institute of Technology*

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In this workshop, three speakers will discuss the latest and local research efforts to untangle the connections between Alzheimer's disease and Down syndrome. Dr. Brian Skotko of Massachusetts General Hospital will begin by discussing a Phase I clinical trial of ACI-24, a vaccine that might prevent the symptoms of Alzheimer's disease in adults with Down syndrome. This clinical trial is open to people with Down syndrome, ages 25-45, at Massachusetts General Hospital. Dr. Bjoern Sperling of Biogen will next discuss Aducanumab, a so-called monoclonal antibody, which demonstrated significant removal of the Amyloid Beta plaques and slowing of cognitive decline in neurotypically developing people with early Alzheimer's disease. He will discuss two large scale studies that are underway and the promise of this antibody for the Down syndrome population. Dr. Hiruy Meharena of MIT will discuss his lab's efforts in understanding the molecular mechanisms of how an extra copy of chromosome 21 leads to the challenges in memory and learning for people with Down syndrome. During his portion, you will learn all about the epigenetic and transcriptomic signatures that are unique to people with Down syndrome.

Bjoern Sperling, MD - Bjoern Sperling MD, Sr. Medical Director, Clinical Development Neurodegeneration, received his medical degree from and completed his training as Neurologist at University of Copenhagen, Denmark. Post-gradual research focused on brain imaging with SPECT and MRI and was later associate professor, Copenhagen University Medical Faculty. He (co)authored more than 40 peer reviewed papers in his 20+ years within the Danish Public Health System, latest as head of Hilleroed MS Clinic.

Bjoern has worked in Biotech since 2008. In 2011 he moved to a global role in Biogen, Cambridge, MA latest as Medical Affairs Lead of Biogen's MS portfolio. Presently Bjoern leads a clinical development team focused on Alzheimer's Disease (AD), including exploring treatment of AD in people with Down syndrome.

Bjoern also serves on the board of directors for Lumind Research Down Syndrome Foundation and the Down Syndrome Biobank.

Brian Skotko, MD, MPP - A Board-certified medical geneticist and Co-Director of the Down Syndrome Program at Massachusetts General Hospital, Dr. Skotko has dedicated his professional energies toward children with cognitive and development disabilities. In 2001 he co-authored the national award-winning book, *Common Threads: Celebrating Life with Down Syndrome* and, most recently, *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters*. He is a graduate of Duke University, Harvard Medical School, and Harvard Kennedy School. Dr. Skotko recently authored major research on how physicians deliver a diagnosis of Down syndrome to new and expectant parents. He has been featured in *The Wall Street Journal*, *The New York Times*, *The Washington Post*, *The L.A. Times*, NPR's "On Point," and ABC's "Good Morning America." Dr. Skotko serves on the Honorary Board of Directors for the Massachusetts Down Syndrome Congress, the Board of Directors for the Band of Angels Foundation, and the Professional Advisory Committee for the National Center for Prenatal and Postnatal Down Syndrome Resources.

Hiruy Meharena, PhD - Hiruy Meharena received his PhD in biomedical sciences from the University of California, San Diego in 2015. His research in graduate school focused on understanding the intramolecular regulation of Eukaryotic Protein Kinases under the mentorship of Dr. Susan Taylor. His research utilized biochemical, biophysical, structural and computational approaches to decipher the mechanics governing the inactive state as well as the highly dynamic active state. After completing graduate school, he transitioned into neuroscience research where he currently focuses on understanding the molecular mechanisms regulating memory and learning and specifically studying the alteration of these processes in Down's Syndrome under the mentorship of

Dr. Li-Huei Tsai. He currently utilizes induced pluripotent stem cell (iPSC) derived models as well as mouse models to understand the molecular aberrations induced by triplication of chromosome 21 and how these alterations play a role in the process of memory and learning.

7. Person-Centered Planning: Honoring Dreams & Gifts in Preparing for the Future – Cheryl Ryan Chan, Founder & Principle, Person-Centered Planning Partners

Related to Teenagers	Related to Young Adults	Related to Adults	Related to ASD	Related to Complex Needs
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Each one of us dreams of living independently and with dignity, to the best of our ability and with the supports we need to be safe and happy. We live in a system-centered world where a person's deficits are the focus, not their dreams or desires. Person-centered planning provides a structured plan that honors a person's own vision for their future first and foremost; then accounts for those things that are important to and important for them.

Cheryl Ryan Chan - Cheryl Ryan Chan is, first and foremost, Mom to Nicky – a 24-year-old man severely impacted by autism. Cheryl has spent over 18 years in Massachusetts, integrating her son and family into the disability community and becoming a well known leader in community organization, legislative activism, mentoring and public speaking. She has served on Boards for a number of nonprofit human service providers, mental health providers, and Support Centers. Her work as a Person-Centered Planning facilitator began in 2010 and has become her greatest passion. Cheryl has been trained in Person-Centered Planning in Toronto and New Hampshire. Learn more about Cheryl at about.me/cherylyryanchan.

8. Promoting Early Communication Development and Augmentative and Alternative Communication: Considerations for qualification, implementation, and debunking the myths – Mia Grossman, MS, CCC-SLP Speech Language Pathologist, Boston Children's Hospital

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Augmentative and Alternative Communication (AAC) is often viewed as a "last resort" for communication. If AAC is introduced to a student, a "one size fits all" solution is often presented to every child. It is difficult for parents, SLPs, team members, and caregivers to know how to proceed. This presentation will focus on the real-world role of AAC, taking the Who, What, When, Where, and How of aided language systems into consideration.

Mia Grossman, MS - Mia Grossman is a Speech-Language Pathologist at Boston Children's Hospital. Mia graduated with a master's of science degree in Communication Science Disorders from Emerson College, and completed her clinical fellowship at Boston Children's Hospital. She specializes in the diagnosis and treatment of pediatric feeding and swallowing disorders and works in the Down Syndrome Program and Growth and Nutrition Program specialty clinics. She also provides speech, language and feeding therapy services through the Martha Elliot Early Intervention Program.

9. Finally ABLÉ to Save: A New Savings Tool for People with Disabilities – Heather Sachs, JD, Vice President of Advocacy & Public Policy, National Down Syndrome Society; John Boroff, Director, Product Management, Fidelity; John W. Nadworny, CFP®, Special Needs Financial Planning, a specialty practice to Shepherd Financial Partners.

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Achieving a Better Life Experience (529A or “ABLE”) accounts are finally available and are a useful savings tool for individuals with disabilities to accumulate funds for college, job training, transportation, health care and many other expenses. This presentation provide answers to frequently asked questions about ABLE accounts, and will discuss how they can be used to enhance financial savings and independence without jeopardizing eligibility for public benefits. Individuals with disabilities and their families will also gain insight into current and future ABLE program offerings.

Heather B. Sachs, JD - Heather Sachs is the Vice President of Advocacy & Public Policy for the National Down Syndrome Society. She spearheads all federal, state and local policy initiatives on behalf of NDSS, which is the leading human rights organization advocating for all people with Down syndrome and their families. Heather has been one of the national leaders in coordinating the passage of state Achieving a Better Life Experience (ABLE) bills and is now working with legislators, financial industry leaders and ABLE administrators on ABLE program design, implementation and educating stakeholders about ABLE programs around the country.

Heather has nearly a decade of experience doing advocacy work in the disability community. Prior to joining the NDSS staff, she served on the NDSS Affiliate Advisory Board and was an NDSS DS-AMBASSAOR® for Maryland. Heather is a founding member of the statewide Maryland Down syndrome Advocacy Coalition. She also served on the board of the Down Syndrome Network of Montgomery County in Maryland for six years, during which time she chaired the acclaimed education conference Techniques for Success. Heather received a BA from the University of Pennsylvania and a JD from Columbia University School of Law, and she is a member of the District of Columbia Bar. She lives in Potomac, Maryland, with her husband and three children, one of whom happens to have Down syndrome

John Boroff - John Boroff joined Fidelity Investments in 2007 after more than a decade spent in various marketing, CRM and consulting roles in the pharmaceutical, education and retail industries. At Fidelity John has held several marketing and product management roles including product management of Fidelity’s Traditional and Roth IRA products from 2011 to 2016 and he had primary responsibility for the development of the Fidelity Roth IRA for Kids which launched in October of 2015. In the Spring of 2016 he took on the responsibility of overseeing the product development and management of the new MEFA/Fidelity Achieving a Better Life Experience (ABLE) program which will launch in the Spring of 2017.

John Nadworny - As a financial professional and father of James, a young man with Down syndrome, John Nadworny works with families of individuals with disabilities to create options and build solutions for their future.

John is co-author of the book *The Special Needs Planning Guide: How to Prepare for Every Stage of Your Child’s Life* and is author of the article, *Incorporating the ABLE Act into Special Needs Planning* published in the *Journal of Financial Planning*.

John along with his partner Cynthia Haddad and daughter, Alexandria Nadworny, are Certified Financial Planner™ professionals forming Special Needs Financial Planning, a specialty practice to Shepherd Financial Partners in

Winchester, MA. Their mission, as a multi-generational team, is to serve the parents and future caregivers of individuals with disabilities.

An advocate for individuals with disabilities for decades, John is currently a part of the executive advisory group strategically planning the implementation of the Real Lives Law.

10. Supporting Individuals and Families During Transition Planning – Victor Hernandez, Deputy Assistant Commissioner, Department of Developmental Services; Margaret Van Gelder, Employment & Family Support Director, Department of Developmental Services

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DDS will review the transition process and supports available to help youth and families develop a vision, understand service options, and plan for the future. DDS will discuss the role of the DDS Transition Coordinator, the support services available through the DDS Family Support system and the array of DDS services offered to the youth and their families

Victor Hernandez - Victor Hernandez currently holds the position of Deputy Assistant Commissioner for the Department of Developmental Services (DDS). His responsibilities include the statewide coordinator for MA Ch 688, the Legislative Liaison for DDS and the Commissioner’s liaison for special projects with the DDS 4 regions and 23 area offices. Victor has also served as the DDS Assistant Area Director for the Merrimack Valley Area Office and previously had administrative roles in schools and agencies for multi-handicapped individuals in California and Massachusetts.

Margaret Van Gelder - Margaret Van Gelder has worked professionally in the human services field in the area of disability services for over 37 years. For the past 19 years she has worked for the Massachusetts Department of Developmental Services in the Central Office as the Statewide Director of Employment and Family Supports. A major focus of her work is designed to foster meaningful social inclusion and community membership for individuals with disabilities and their families.

11. Grandparents: Sharing and Caring
– Facilitated by Sue Laing, MDSC Grandparent

Being an active and supportive grandparent is a way to help everyone thrive, grandparent included. Sometimes the road is rough, and being part of a team makes the journey easier. Sometimes the road is joyful, and it is wonderful to share that. Regardless of distance or difficulty, finding our own way to be an active and supportive grandparent is the key. Come and share with other grandparents!





AWARDS LUNCHEON 12:45 PM-2:15 PM

Keynote Presentation

Awards Luncheon Featuring:

Graham Campbell, Pianist

Sindrome Down Folklore Latino Dance Troop
and Collete Divitto, Owner, Colletty's Cookies,
Featured on CBS Nightly News and Good Morning
America

Exhibitors/Break 2:15 PM -2:45PM

BREAKOUT SESSION III 2:45 PM - 4:15 PM (Choose one) PARENTS/GENERAL SESSIONS

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12. Real Jobs for Real Pay - New Initiatives to Create Integrated Employment Opportunities--

Joshua Komyerov, MA, Director of Communications & Operations, MDSC; Margaret Van Gelder, Employment & Family Support Director, Department of Developmental Services; Kristianne Widman, Employer Liaison/ Project Coordinator, North Suburban Employment Collaborative

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Come learn about the range of work being done in Massachusetts to create meaningful integrated employment opportunities for our loved ones with Down syndrome. The MA Department of Developmental Services' (DDS) Employment First initiative has an ambitious goal to make integrated employment the first and preferred service option for all adults with ID/DD. The state's Regional Employment Collaboratives is working "in the trenches" connecting qualified employees and employers looking to hire. And the MDSC's Your Next Star employment campaign is connecting with employers online and at regional forums and opening their eyes to the power of people with Down syndrome in the workplace. Together, these collaborations are taking on this intractable problem and making a difference in the disability hiring landscape.

Joshua Komyerov, MA - Joshua Komyerov is the Communications & Operations Director for the Massachusetts Down Syndrome Congress, a nationally recognized non-profit advocating for people with Down syndrome. In 2015, Josh led the MDSC's effort to launch a new employment initiative called Your Next Star. A former reporter for the Charlotte Observer and Boston Globe, Komyerov once spearheaded an investigation that helped free a wrongfully convicted man from prison in North Carolina. He served as a Peace Corps Volunteer in Togo, West Africa from 1996-1998. He holds a master's degree in journalism from the University of North Carolina at Chapel Hill and a bachelor's degree from Tulane University.

Margaret Van Gelder - Margaret Van Gelder has worked professionally in the human services field in the area of disability services for over 37 years. For the past 19 years she has worked for the Massachusetts Department of Developmental Services in the Central Office as the Statewide Director of Employment and Family Supports. A major focus of her work is designed to foster meaningful social inclusion and community membership for individuals with disabilities and their families.

Kristianne Widman - Kristianne graduated from Brewster Academy and the University of Vermont. Her career in Corporate Human Resources covered over 25 years including specialties in Recruiting, Training, and Employee Relations. In 2011, Kristianne moved into the not-for-profit world as a Job Coach at Minute Man Arc in Concord, MA. She then moved into the Job Developers role. In mid 2014 she joined Riverside Community Care as the Project Coordinator/Employer Liaison for the North Suburban Employment Collaborative. She continues that work currently.

13. IEP Development - Tips for Effective Advocacy – *Maureen Blazejewski, M Ed, MDSC Educational Consultant, 3-21 Foundation, Cambridge, MA*

Related to Children ages 5-12	Related to Teenagers	Related to Education
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Coming together with your child's team each year can be both exciting and stressful as you reflect upon your child's progress and plan out for the new areas of focus over the next calendar year. This workshop will offer parents information, insight and tips that will lead to more effective communication and advocacy as you come together with your district team to plan for your child's educational needs.

Maureen Blazejewski, M Ed - Maureen Blazejewski is a special education teacher who works as an Educational Consultant to the Massachusetts Down Syndrome Congress (MDSC) and school districts across Massachusetts through the 3-21 Foundation. Within schools, she collaborates with school teams in a direct consultation/coaching role to support districts in the ever-evolving process of developing individualized educational programs for students with complex educational needs. Through the MDSC, she transitioned from the role of Education Director to Education Consultant where her primary goal is to support families and education professionals by providing information and resources around the best practices for educating students

with Down syndrome and other intellectual and developmental disabilities. In addition, she has been involved with the Learning Program Boston/3-21 Foundation since September 2009, engaging closely with students, staff and families to design and implement monthly social and educational monthly programs designed for students with Down syndrome. Prior to her work at the MDSC and 3-21 Foundation, Maureen worked for 17 years in public school settings in a variety of roles in general and special education including classroom teacher and Inclusion Specialist. She holds a Master’s Degree in Special Education from Wheelock College in Boston, MA and a Bachelor’s Degree in Communication and Elementary Education from Stonehill College in Easton, MA.

14. A Look at Down Syndrome and Autism through the Life Span – *Charlotte Gray, Executive Director, Syndrome- Autism Connection; Jeanne Doherty, Family Support Program Specialist, MDSC*

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ASD

Outline

Charlotte Gray - Charlotte Gray is the proud mother to her 14 year old son Jacob, who has Down syndrome and other complex needs including Autism. She is the co-founder of Morning Travelers, a playgroup for families who have a child with Down syndrome. When her son was diagnosed with Autism in 2008, she founded Morning Travelers 2, a support group for families who have a child with DS-ASD. Charlotte has worked for a child psychologist as a floor time therapy consultant for children with ASD. She has her MBA in Accounting and she serves as the Executive Director of the Down Syndrome-Autism Connection.

Jeanne Doherty - Jeanne Doherty lives in the Boston area with her husband and 3 daughters, including Jessica who was diagnosed with Ds-ASD at age 7. Jeanne has supported families with loved ones with Ds-ASD for over 10 years. She is currently the Family Support Specialist for the Massachusetts Down Syndrome Congress. She also serves as President of the Board for Alternative Services, Inc., a company that owns and operates group homes, as well as President of the Board for the Down Syndrome -Autism Connection. Jessica is a young adult now, so Jeanne brings with her a wealth of experience and knowledge about providing care to an individual with complex needs.

15. PT, OT, and SLP evaluations for infants and toddlers – *Joy Huebner, PT, DPT; Sharon Serinsky, MS, OTR/L; Michele Donlon, MS, CCC-SLP, Massachusetts General Hospital Down Syndrome Program; Sam Johnston, MDSC Parent*

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16. Keeping Adults with Down Syndrome Healthy, All the Medical Updates Families and Providers Need to Know – *Dr. Allie Schwartz, MD, Co-Director, Massachusetts General Hospital Down Syndrome Program*

Related to Young Adults	Related to Adults	Related to Complex Needs
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Adults with Down syndrome are now living longer and fuller lives. In the 1980's, the average lifespan for a person with Down syndrome was 25 and now people are living into their 60s. This is truly remarkable. We are now faced with a new and exciting challenge of helping these individuals to stay healthy and happy. This talk focuses on overall mental wellness by promoting healthy habits and self determination. We review several cases that highlight common medical and mental health issues that are often seen in individuals with Down syndrome. Each case offers a diagnostic question, evaluation and treatment plan. We will also review resources that are available to individuals with Down syndrome.

Allie Schwartz, MD - Dr. Schwartz is an internist and pediatrician who is passionate about improving the lives of individuals with special health care needs. She completed a combined residency in the Harvard Internal Medicine-Pediatrics Residency Program where she presided as an Ambulatory Chief Resident in the Department of Medicine. Dr. Schwartz obtained degrees in both child development and medicine from Tufts University and has served as a Residential Coordinator at a school for children and adolescents with autism and traumatic brain injury. Dr. Schwartz is very interested in working with individuals with special health care needs and serves as the Clinical co-director of the MGH Down Syndrome Program which is a multidisciplinary clinic that sees kids and adults with Down syndrome. She is also a med/peds primary care physician at MGH Everett Family Care where she enjoys caring for families and precepting med/peds residents.

BROTHER AND SISTER SESSIONS (Ages 11-18)

Come spend the day with others who have a brother or sister with Down syndrome in a confidential setting! We have a fun, interactive day of activities planned! We want you to share your experience, thoughts, and concerns, enhance your understanding of general disability issues, and ultimately develop your advocacy skills with other brothers and sisters.

Breakout Session I (9:00 AM - 10:30 AM)

Strengths & Challenges: How Being a Sibling Can Affect Us Over Our Lifetime

Breakout Session II (11:00 AM - 12:30 PM)

Q & A: A Panel of Experts Ready to Tackle Even Your Toughest Questions

Breakout Session III (2:45 PM - 4:15 PM)

Count Me In: Inclusion for Yourself and Your Sibling

SELF-ADVOCATE WORKSHOP SESSIONS (Ages 13 and up)

Breakout Session I (9:00 AM - 10:30 PM)

Saving Makes Sense!

Would you like to learn more about working with money? You're in luck! Our awesome friends from PricewaterhouseCoopers (PwC) will lead interactive and fun activities to talk about earning and saving money, needs v. wants, debit cards, and more! Everyone- from beginners to those with more experience- will benefit.

Breakout Session II (11:00 AM - 12:30 PM)

3, 2, 1... Action!

It's your time to shine- whether you like the spotlight or a role behind-the-scenes! Using creativity and teamwork, we'll work in groups to act out different scenarios and come up with ways you can tackle common challenges.

Breakout Session III (2:45 AM - 4:15 PM)

Let's Play: MDSC Friendly Feud!

We'll start our afternoon with some relaxing yoga, and then- your chance to be a game show contestant is here! Teams will face-off in a friendly competition to win prizes, meet new friends and share lots of laughs.