



**Massachusetts Down Syndrome Congress (MDSC)  
28th Annual Conference**

*Style Down Syndrome*



DCU Center Worcester, MA  
March 17, 2012

**Detailed Workshop Description  
and  
Speaker Bios**

## Annual Meeting

8:00 AM – 8:45 AM

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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) PARENTS/GENERAL SESSIONS

#### 1. **Communication Styles: Augmentative Communication and E.I. as a Foundation to Success** -

*John M. Costello, M.A., Speech-Language Pathologist, Director, Augmentative Communication Program @ Children's Hospital Boston*

*Children with Down syndrome have a unique profile of receptive and expressive language development that for some may be supported and enhanced through the use of augmentative communication strategies. This seminar will focus both on what is known about communication development and Down syndrome as well as the use of speech, sign language and visual supports using both electronic and non-electronic communication tools to enhance speech and language development and communication success. Early intervention with Augmentative Communication to promote success will be highlighted throughout the discussion. Engineering the environment to support total communication and early literacy will be highlighted through discussion and clinical video*

**John Costello** has been a speech-language pathologist for nearly 27 years and is Director of the Augmentative Communication Program at Children's Hospital Boston. He has provided augmentative communication assessment and treatment for children with Down syndrome for years and has been a speaker at the MDSC conference several times in the past.

#### 2. **Down Syndrome Medical Updates that Parents Need to Know** – *Brian Skotko, MD, MPP, Clinical Geneticist, Down Syndrome Program, Children's Hospital Boston*

*In this presentation, Dr. Brian Skotko reviews all of the questions and concerns that parents most often have about their sons and daughters with Down syndrome. He provides the answers and action steps, stemming from the latest clinical research on people with Down syndrome. Based on his clinical experience in the Down Syndrome Program at Children's Hospital Boston, Dr. Skotko makes sure that every parent can anticipate medical conditions so that the potentials of all people with Down syndrome are maximized.*

A Board-certified clinical geneticist at Children's Hospital Boston, Massachusetts General Hospital, Brigham & Women's Hospital, and Dana Farber Cancer Institute, **Dr. Skotko** has dedicated his professional energies toward children with cognitive and development disabilities. He is one of the specialists in the Down Syndrome Program at Children's Hospital Boston. 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 Board of Directors for the Massachusetts Down Syndrome Congress, the National Down Syndrome Society, and Band of Angels Foundation. He further serves on the Professional Advisory Council to the National Down Syndrome Congress

**3. Children with Autism and Down Syndrome; Making sense of autism treatments** – Karen Levine, Ph.D., Psychologist, *Helping Children with Challenges*, Instructor, Harvard Medical School

*Children with Autism and Down syndrome have unique needs. Through video clips and lecture this workshop provides an overview of current treatment approaches including ABA and Floortime, focusing on commonalities, differences and key components across treatment models. Individualizing intervention based on children's and families' specific needs will be the theme throughout.*

**Karen Levine, Ph.D.**, is an Instructor at Harvard Medical School and a practicing Psychologist in Lexington MA. She was the co-founder and co-director of the Autism program at Boston Children's Hospital in the 1990s, and of the Autism Center at Cambridge Health Alliance. Her focus is on developmental relationship based approaches to treating social and emotional challenges in children with autism or other developmental disabilities, with Naomi Chedd, she authored *Replays: Using Play to Enhance Emotional and Behavioral Development for Children with Autism Spectrum Disorders*. Their second book, *Treatment Planning for Children with Autism Spectrum Disorders: An Individualized, Problem-Solving Approach* is in press (Wiley). She has also authored numerous articles and book chapters. She is on the Scientific Advisory Board of the Williams Syndrome Association and served as a Commissioner on the Massachusetts Governor's Autism Commission 2010-2011. She is the recipient of the 2010 Federation for Children with Special Needs Founders Award, and the 2000 BIDIP (Boston Institute for the Development of Infants and Parents) Award for Excellence. She is a frequent regional and national presenter.

**4. Grandparents: Sharing and Caring** – Regina Kando, Beverly Beckham and Betsy Pelz

*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!*

**Beverly Beckham** began her writing career in 1979. Her articles and essays have appeared in newspapers and magazines around the world. Beckham wrote columns and editorials for the Boston Herald for 19 years and currently writes a weekly Sunday column for the Boston Globe plus a bi-monthly column for the website [www.grandparents.com](http://www.grandparents.com). Beverly is an active MDSC Board member and has been honored by MSDC for her writing. Beverly lives in Canton with her husband, Bruce and has three children and five grandchildren. Her inspiration for many articles is her granddaughter Lucy

**Regina Kando** retired in 2008 and soon after became the Chair of the Lunch and Learn Program at Tufts and a member of the Executive Board. In late 2011, she resigned her positions at Tufts to start the Grandparent Support Group for MDSC. Regina's advocacy efforts were sparked by the birth of her granddaughter, Sophia Pineda, who has Down syndrome. Sophia, who is eight years old, is a first grader and lives with her parents and brother in Fredericksburg, Virginia.

**Betsy Pelz** is a proud grandmother of Milo, aged 3. She lives in New Salem, which is 70 miles from Milo's home and feels lucky to be close enough to participate in Milo's life. Betsy is a retired high school English teacher and department Coordinator. She is using those skills as the Co-chair of the MDSC Education Task Force. Betsy is a member of the writing and editing team for the *MDSC Resource Guide for Elementary Educators*, a booklet which will hopefully be available in the fall of 2012. She is a happy walker in the annual MDSC October Buddywalk in Wakefield as a member of what the family calls Milo's Marching Band. Betsy has found the MDSC community to be a wonderful source for inspiration, ideas and energy for the whole family.

5. **Moving Out - My Way** – *Dafna Krouk-Gordon, M.Ed. Founder and President - Toward Independent Living and Learning Inc. (TILL)*

*The presentation is designed to help navigate the participant through the complicated emotional, financial and practical aspects of planning and implementing residential services. Everyone's situation is unique. There is no "one size fits all" when it comes to residential planning. The options are as diverse as the people needing them. Still, individuals and their families have much in common as they embark upon adult residential services. This presentation is intended to guide you through the process of getting yourself and other family members ready and then identifying the best residential arrangement for your situation. If the situation does not already exist, the presentation will assist by showing you models to stimulate your thinking and provide information on how to create them and perhaps run it yourself by deciding if that is an option suitable for your situation.*

**Dafna Krouk-Gordon** is the founder and President of Toward Independent Living and Learning, Inc. a not for profit human service company based in Dedham, MA, established in 1980 in response to the need for community based services for people who were mandated to leave the large public institutions as a result of class action law suits. TILL has been a leader in developing innovative residential and vocational services and currently operates an extensive range of residential settings, day centers, vocational training sites, a mental health clinic and support services for individuals on the autism spectrum and their families. TILL also provides professional training to individuals with disabilities through a very successful catering, gift shop and food service business and manages school breakfast and lunch programs throughout MA and southern NH.

Ms. Krouk-Gordon has served on the Governor's Commission on Mental Retardation and is active on a statewide level in fiscal planning, policy, advocacy and legislative issues affecting community services. She has worked with hundreds of families over her years at TILL and prior to that, in other states on policy planning, funding and program development.

She has presented extensively to family and professional groups and has consulted in creating individualized residential and vocational models of service which fit the needs of the person rather than expecting the person to fit the service model. TILL works with hundreds of families and individuals and operates programs which service over 2000 people per year with an employee base of 800.

- **Exhibitors/Break 10:30 AM - 11:00 AM**

## BREAKOUT SESSION II

11:00A M - 12:30 PM (Choose one)

PARENTS/GENERAL SESSIONS

**6. New Parents: Sharing Our Journey** – Sarah Cullen, Family Support Director, MDSC, Angela Lombardo, Program Coordinator, Down Syndrome Program at Children's Hospital, Emily Jean Davidson, MD, MPH, Director of the Down Syndrome Program at Children's Hospital Boston, Melanie Perkins McLaughlin, Down Syndrome Family Support Group and MDSC First Call parent and Jeff Roback, President DADS.

*Four mentor parents will share the highlights of our journeys with our children with Down syndrome. We invite new parents to come and share their 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. Sarah is the parent of three children, including Matthew, who is 15 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 the Leadership Education in Neurodevelopmental and Related Disabilities Program at Children's. In addition to those two 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 16 year old son, Isaiah, who has Down syndrome.

**Melanie Perkins** is an award-winning documentary filmmaker and the mother of three children, the youngest of whom has Down syndrome. In 2007, at the height of her career, Perkins received a prenatal diagnosis. Her unborn child had Trisomy 21 and a heart defect. She had no experience with Down syndrome and struggled with the decision of whether to continue the pregnancy. After meeting other families through the MDSC First Call program she and her husband agreed to continue the pregnancy. Their daughter, Gracie, had her heart repaired at two months old. Today Gracie is an active, inquisitive 4 year old who attends a full-time fully inclusive preschool at Tufts University.

With over 20 years in documentary film production Perkins has worked on films for HBO, PBS, ABC, A&E, The Discovery Channel and The History Channel. She is currently producing a documentary about life with Down syndrome, "Accepting Grace".

**Jeff Roback**, Jeff and his wife Jennifer are the proud parents of two children, including Paul who was born in 2007 and has Down syndrome. Through the MDSC First Call program, they met another family, and began the journey of connecting with others to build a positive future for their child. In the summer of 2008, Jeff attended the NDSC national conference held in Boston. He felt an immediate bond with a father who was the founder of a national group called Dads Appreciating Down Syndrome (DADS). It was then that Jeff realized the value of Dads connecting with one another. Jeff reached out to a few other dads here in MA and together they organized the Dads Appreciating Down Syndrome group here in Massachusetts. Jeff's DADS group has grown to 250 DADs who are working together to support each other and to enrich the lives of families. DADs of Massachusetts is now a formal affiliate of the MDSC.

**Emily Jean Davidson, MD, MPH** is the Director of the Down Syndrome Program at Children's Hospital Boston. She holds a bachelor's degree from Harvard-Radcliffe College, an MD from Yale School of Medicine and an MPH from Harvard's School of Public Health. She completed her internship and residency in pediatrics at Children's Hospital Boston and stayed at Children's to complete fellowship in Developmental Behavioral Pediatrics. She is an instructor at Harvard Medical School and is board certified in General Pediatrics & Neurodevelopmental Pediatrics. Dr. Davidson's clinical work focuses on children with special health care needs and developmental disabilities and she has worked in a wide range of clinical settings including the cerebral palsy clinic, the Cotting school, Perkins school for the Blind, the Children's Extended Care Center (now Seven Hills) and the Complex Care Service inpatient and outpatient settings as well as the Developmental Medicine Center. She is an attending physician in the Complex Care Service and also serves as Medical Director for the Pediatric Community Medical Alliance's Special Kids, Special Care program for children with complex needs in foster care. Her research interests focus on coordination of care for children with complex needs, respite for families and increasing physical activity for children with special health care needs and disabilities, particularly those from underserved populations.

### **7. Helping Children Develop Effective Communication: Birth to Five Years** – *Libby Kumin, Ph.D., CCC-SLP, Professor Speech-Language Pathology, Loyola University Maryland*

*Focus is on early communication skills in children with DS from birth-5. What comes before the first spoken word? How does your child progress from the first word to multiple word conversations and language readiness for school? Dr. Kumin will demonstrate techniques, activities, and resources you can use at home*

**Libby Kumin** is a Professor of Speech-Language Pathology/Audiology at Loyola University Maryland. Since 1968, she has been active in teaching and research, and has been working extensively with families of children with communication disorders. She specializes in communication, speech, and language skills of infants, toddlers, children, adolescents, and adults with Down syndrome. Her book, *Early Communication Skills in Children with Down Syndrome* is a newly revised (2012) version of her classic guide used by thousands of families since 1994. *What Did You Say? (2006 DVD)* focuses on how to help children develop intelligible speech. *Helping Children with Down Syndrome Improve Speech (2008)* focuses on communication skills in older children from ages 6-14. Her current research focuses on speech intelligibility in people with Down syndrome, computer usage in children with Down syndrome, and communication skills in adults with Down syndrome related to employment and activities of daily living. Dr. Kumin has written extensively and spoken around the country. She is listed in *Who's Who in America*, *Who's Who in Medicine and Healthcare*, and *Foremost Women of the Twentieth Century*. She is an active clinician, teacher, researcher and scholar whose heart shines through her work.

### **8. Special Education Law** – *Daniel T.S. Heffernan, Esq., Kotin, Crabtree & Strong, LLP*

*This workshop will provide an overview of special education law, focusing on issues that impact students with Down syndrome. Specific areas that will be covered include inclusion, placement in specialized programs, participation in extracurricular activities and transition from school.*

**Daniel T.S. Heffernan** is a partner with Kotin, Crabtree & Strong and concentrates his practice in special education, civil rights and personal injury. He graduated *magna cum laude* from Boston College in 1981 where he was a member of Phi Beta Kappa, and *cum laude* from Harvard Law School in 1987. He has served on the faculty of Harvard Law School's Trial Advocacy Program, instructing law students in trial preparation and trial techniques. From 1995 to 2007 he served as the president of the board of directors of the Federation for Children with Special Needs, and in 2002 he and his wife, Julie, received the Dr. Allen C. Crocker Award of

Excellence by the Massachusetts Down Syndrome Congress. He writes and lectures frequently on special education law and advocacy. He has been named a *Super Lawyer* in special education every year since 2005. From 1995 to 2000, he served as the president of the board of directors of Community Legal Services and Counseling Center. He also serves on the MDSC Education Task Force. He has two daughters, Maggie and Evie, and a twenty-one year old son, Brian, with Down syndrome.

**9. Promoting Mental Health for Teens and Adults with Down syndrome** – Dennis McGuire, PhD  
Director of Psychosocial Services and Brian Chicoine, MD Medical Director Adult Down Syndrome Center of Advocate Lutheran General Hospital

*Teens and adults with Down syndrome are participating in a wider variety of activities than ever before. This presentation will focus on promotion of mental health including preparing for opportunities, how to prevent problems associated with new challenges as well as how to manage them if they occur.*

**Dennis McGuire Ph.D.**, Director of Psychosocial Services for the Adult Down Syndrome Center of Advocate Lutheran General Hospital, in suburban Chicago. Dr. McGuire helped to establish the Adult Down Syndrome Center which has served the health and psychosocial needs of over 5000 adolescents and adults with Down syndrome since its inception in 1992. Dr. McGuire received his Master's degree from the University of Chicago and his doctorate from the University of Illinois at Chicago. His work experience includes over 30 years in mental health and developmental disabilities fields. He presents regularly at national and regional conferences, published numerous articles and co-authored two books "Mental Wellness of Adults with Down Syndrome," and "The Guide to Good Health for Teens and Adults with Down Syndrome" published by Woodbine House Press.

**Brian Chicoine M.D.**, is the Medical Director of the Adult Down Syndrome Center of Advocate Lutheran General Hospital and on the faculty of Family Medicine at Lutheran General Hospital of Advocate Health Care in Park Ridge, Illinois. Dr. Chicoine is co-founder of the Adult Down Syndrome Center. This Center has served and documented the health and psychosocial needs of over 5000 adolescents and adults with Down syndrome since its inception in 1992. Dr. Chicoine graduated from Loyola University Stritch School of Medicine and completed his Family Medicine residency at Lutheran General Hospital. He presents regularly at national and regional conferences, published numerous articles and co-authored two books "Mental Wellness of Adults with Down Syndrome," and "The Guide to Good Health for Teens and Adults with Down Syndrome" published by Woodbine House Press.

**10. Explore Prepare Act - Work without Limits Training Team** – Kim Plaut, EPA Metro Trainer, Massachusetts Advocates Standing Strong, Andre Williams EPA Metro Trainer, MASS, Joan Low, EPA Metro Mentor, MASS

*Come to this workshop to learn more about "Explore Prepare Act", a training for self-advocates on strengthening your skills and finding the job you want. It's about getting real jobs!!*

**\*Note:**

Session #10 is for adults with Down syndrome (18 and over)

## AWARDS LUNCHEON 12:30 PM-2:00 PM

Keynote Speaker:

**Ned Reichenbach, Self Advocate**

- **Exhibitors/Break 2:00 PM -2:30PM**

## BREAKOUT SESSION III

2:30 PM - 4:00 PM (Choose one)

PARENTS/GENERAL SESSIONS

11. **What your other children without Down syndrome are thinking: Sibling Issues.** - *Brian Skotko, MD, MPP, Clinical Geneticist, Down Syndrome Program, Children's Hospital Boston and Susan Levine, MA, CSW, Co-founder and Social Workers at Family Resource Associates, Inc.*

*Through discussion and a series of interactive exercises, parents will explore what questions, needs, and concerns are often raised by children who have a brother or sister with Down syndrome. Parents and/or professionals will come away with practical answers to commonly raised questions. This presentation draws upon Brian Skotko and Sue Levine's publication in American Journal of Medical Genetics and their new book, *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters**

**Susan Levine, MA, CSW**, is a co-founder and social worker at Family Resource Associates, Inc., a private, non-profit agency serving individuals with disabilities and their families in central New Jersey. She earned a B.A. degree in psychology from Bucknell University and a M.A. degree in Child Development and Family Relations from the University of Connecticut. Susan has spent her entire professional career working with children with disabilities and their families. She has conducted support programs for parents and siblings of children with differing abilities for the past 30 years. Among those programs, Susan has coordinated support groups specifically for parents of children with Down syndrome. She has presented on the needs of siblings at national and regional conferences on Down syndrome, spina bifida, and Rett syndrome, as well as for New Jersey school system parent groups. Additionally, she has written quarterly newsletters for brothers and sisters (*For Siblings Only*, for children aged 4-9, and *Sibling Forum*, for children aged 10 through teen) which are available on the web at the agency website [www.frainc.org](http://www.frainc.org). She also co-authored the book, *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters*.

A Board-certified clinical geneticist at Children's Hospital Boston, Massachusetts General Hospital, Brigham & Women's Hospital, and Dana Farber Cancer Institute, **Dr. Skotko** has dedicated his professional energies toward children with cognitive and development disabilities. He is one of the specialists in the Down Syndrome Program at Children's Hospital Boston. 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 Board of Directors for the Massachusetts Down Syndrome Congress, the National Down Syndrome

Society, and Band of Angels Foundation. He further serves on the Professional Advisory Council to the National Down Syndrome Congress

**12. Understanding and Applying Sensory Integration Principles to Individuals with Down Syndrome** – Janet Wright, M.S., OTR/L

**13. Behavior and Down Syndrome: A Workshop for Parents and Professionals** – David Stein, Psy.D. attending Psychologist, Children’s Hospital Boston and Instructor, Harvard Medical School

*This workshop aims to orient parents and professionals to the causes of behavioral difficulties in children with Down syndrome and to provide specific tools for improving behavior. A comprehensive and practical system of supporting positive behaviors will be presented. Domains for intervention that will be reviewed include maintaining a positive relationship between child and caregiver, adjusting language, building skills in areas of difficulty, effective implementation of token economies, and using effective discipline strategies geared specifically toward children with Down syndrome.*

**Dr. Stein** is attending Psychologist at Children’s Hospital Boston in the Developmental Medicine Center and an Instructor at Harvard Medical School. Dr. Stein works as part of the Down syndrome Program (DSP) at Children’s Hospital completing behavioral consultations and treatment as well as neurodevelopmental evaluations of children with Down syndrome. He has designed a parent-training program for behavioral management of children with Down syndrome based on positive behavioral supports and skills-oriented interventions. A native of Boston, Dr. Stein completed his undergraduate degree at Tufts University and his doctoral degree at the Massachusetts School of Professional Psychology. His clinical training was completed through Harvard Medical School/The Cambridge Hospital (internship) and Children’s Hospital, Boston (fellowship).

**14. Speech, Language and Communication Skills: Preparing for Adult Life** - Libby Kumin, Ph.D., CCC-SLP, Professor Speech-Language Pathology, Loyola University Maryland

*Communication strengths and challenges of adolescents and adults with DS. Focus on social communication and conversational skills, as well as communication skills and transition planning for employment and adult life. Strategies, techniques and resources that families can use at home and in the community to promote effective communication.*

**Libby Kumin** is a Professor of Speech-Language Pathology/Audiology at Loyola University Maryland. Since 1968, she has been active in teaching and research, and has been working extensively with families of children with communication disorders. She specializes in communication, speech, and language skills of infants, toddlers, children, adolescents, and adults with Down syndrome. Her book, *Early Communication Skills in Children with Down Syndrome* is a newly revised (2012) version of her classic guide used by thousands of families since 1994. *What Did You Say? (2006 DVD)* focuses on how to help children develop intelligible speech. *Helping Children with Down Syndrome Improve Speech (2008)* focuses on communication skills in older children from ages 6-14. Her current research focuses on speech intelligibility in people with Down syndrome, computer usage in children with Down syndrome, and communication skills in adults with Down syndrome related to employment and activities of daily living. Dr. Kumin has written extensively and spoken around the country. She is listed in Who’s Who in America, Who’s Who in Medicine and Healthcare, and Foremost Women of the Twentieth Century. She is an active clinician, teacher, researcher and scholar whose heart shines through her work.

**15. Improve Your Advocacy and Speak Up for Individuals with Down Syndrome** – Madeleine C. Will, M.A., Vice President of Public Policy, Director, National Down Syndrome Policy Center, Sara Hart Weir, M.S., Vice

*President, Advocacy & Affiliate Relations, National Down Syndrome Society and Laura Noble, Chair MDSC Legislative Task Force*

*Meet the experts and learn how to join forces with the NDSS National Policy Center and the MDSC Legislative Advocacy Task Force to achieve positive systems change for individuals with Down syndrome and other intellectual disabilities at the federal, state and local levels of government. Policies and advocacy efforts focus on four major areas: Improving Health Outcomes and Quality of Life for People with Down syndrome; Improving Education Opportunities; Increasing Opportunities for Adults with Down syndrome; and Creating an Economic Future for Individuals with Down syndrome. We need to act as one strong voice to send a message to elected officials.*

**Madeleine C. Will** is a long-time leader in the disability movement and nationally recognized expert in special education and disability policy. She has led efforts in the United States to: establish services nationally for infants and toddlers with disabilities and their families; to promote the concept of inclusion in general education classrooms for students with disabilities; and to create transition and supported employment programs. As an international disability consultant, she helped develop community-based services and supports for people with disabilities in Czech Republic, Slovakia, Hungary, Russia and Bulgaria. A former Assistant Secretary of the U. S. Department of Education, she is currently the NDSS Vice President for Public Policy and Director of the NDSS National Policy Center. Ms. Will was also the chairperson of the US President's Committee for Persons with Intellectual Disabilities from 2002-2006. She has won numerous professional honors and awards including the ARC "IDEA Hero Award" and is frequently interviewed by publications such as *Newsweek* and *The Wall Street Journal*.

**Sara Hart Weir** has been an advocate for people with Down syndrome for over a decade. Sara currently serves as the National Down Syndrome Society's (NDSS) Vice President of Advocacy & Affiliate Relations. Sara advocates before Congress and a wide variety of federal departments and agencies for people with Down syndrome. Sara leads the work of NDSS advocacy and affiliate program, which includes several initiatives like the Ds e-advocate program, the Ds-Ambassador program, and the NDSS Government Affairs Committee (GAC) program. Sara's passion of advocating for all people with Down syndrome and their families stems from her friendship with a young woman from Lenexa, Kansas, Kasey Kittell, who happens to have Down syndrome. Sara first served as a mentor to Kasey while in college and graduate school. Kasey is a lifetime friend to Sara and her family. Prior to joining NDSS, Sara was a Manager on GlaxoSmithKline's Federal Government Relations team and a Vice President at B&D Consulting in Washington, DC. Sara worked for Congressman Dennis Moore (D-Kansas) in 2004. Sara earned a Bachelor of Arts in Psychology and Political Leadership from Westminster College (Fulton, Missouri) and a Master's of Science in Public Policy and Management from Carnegie Mellon University's Heinz College.

**Laura Noble** of Winchester, MA is the parent of 21 year-old Jeffrey Noble who was born with Down syndrome. For nearly two decades, Laura has been a dedicated advocate for people with intellectual and developmental disabilities. She is a self-taught special education parent consultant and an expert navigator of the systems of care for Children with Special Health Care Needs (CSHCN). In 2009, Laura completed the prestigious LEND Fellowship (Leadership & Education in Neurological Disorders) Certificate Program and earned a Masters of Public Administration Degree with a concentration in Health Policy from Suffolk University. Professionally, she serves as the Health Educator and Wellness Advisor at Neighborhood Health Plan (NHP) in Boston. Prior to this role, she served on the Social Care Management team at NHP as the Parent Advisor for CSHCN. She has applied her academic studies and front line advocacy experience to a very active volunteer membership in the MA Down Syndrome Congress (MDSC) where she has most recently chairs the MDSC Legislative Task Force. Additionally, Laura currently chairs a Legislative Committee of the Central Middlesex Area Citizens Advisory Board for the Massachusetts Department of Developmental Services.

**16. Informal Networking Sessions: New Parents, Dads, Grandparents, Preschool, Elementary, Middle/ High School, Transition, Dual Diagnosis, Complex Medical Needs and Self-Advocate Advisory Council** – Sarah Cullen and other experienced facilitators

*An opportunity to meet others, network, and share ideas!*

**\*Note:**

Educators are welcome to attend parent/general sessions.  
Please contact Elaine Crowley at [ecrowley@mdsc.org](mailto:ecrowley@mdsc.org) if you wish to do so.

## EDUCATOR SESSIONS

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

**Comprehensive SLP Services for Children with DS and their Families: K-12** - Libby Kumin, Ph.D., CCC-SLP, Professor Speech-Language Pathology, Loyola University Maryland

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*SLPs provide direct treatment services, serve as a language resource to teachers for curriculum and testing, and support and share information with families. This workshop will focus on EBP techniques and resources to help us identify, assess and match the communication strengths, challenges and needs of children with DS from K-12. Dr. Kumin will present a model to identify and focus on educational language skills*

**Libby Kumin** is a Professor of Speech-Language Pathology/Audiology at Loyola University Maryland. Since 1968, she has been active in teaching and research, and has been working extensively with families of children with communication disorders. She specializes in communication, speech, and language skills of infants, toddlers, children, adolescents, and adults with Down syndrome. Her book, *Early Communication Skills in Children with Down Syndrome* is a newly revised (2012) version of her classic guide used by thousands of families since 1994. *What Did You Say? (2006 DVD)* focuses on how to help children develop intelligible speech. *Helping Children with Down Syndrome Improve Speech (2008)* focuses on communication skills in older children from ages 6-14. Her current research focuses on speech intelligibility in people with Down syndrome, computer usage in children with Down syndrome, and communication skills in adults with Down syndrome related to employment and activities of daily living. Dr. Kumin has written extensively and spoken around the country. She is listed in *Who's Who in America*, *Who's Who in Medicine and Healthcare*, and *Foremost Women of the Twentieth Century*. She is an active clinician, teacher, researcher and scholar whose heart shines through her work.

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

**Presuming Competence Every Day in the Classroom** - Cheryl M. Jorgensen, Ph.D., Inclusive Education Consultant; Affiliate Faculty, Institute on Disability and Department of Education, University of New Hampshire

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*This session will provide a rationale for presuming that all children with Down syndrome are competent. Parents, general and special education teachers, and related service providers will come away with a variety of strategies for translating the presumption of competence into children's educational experiences in the classroom.*

**Cheryl M. Jorgensen, Ph.D.**, is an internationally known speaker, researcher, and educator. From 1985 until her retirement in 2011 from the Institute on Disability at the University of New Hampshire, she was the director of state and federal inclusive education projects totaling more than \$14,000,000. She is the author of many research articles and four books, including *The Inclusion Facilitator's Guide* and *The Beyond Access Model*. In her "semi-retirement" she is working as an independent inclusive education consultant, providing student-specific technical assistance, IEP team-building, professional development workshops, and consultation supporting systematic educational reform. She participates in the Universal Design for Learning Community of Practice, and the Collaboration to Promote Self-Determination. Dr. Jorgensen also serves in an advisory capacity to the I am Norm (<http://www.iamnorm.com>) youth inclusion campaign and recently participated in an invited symposium on Ethics in Autism Research at Harvard University. She is a long-time member of TASH and currently a member of its Inclusive Education Committee. In 2008, Dr. Jorgensen received an award from the National Down Syndrome Congress for her contributions to inclusive education research.

### 19. **Breakout Session III (2:30 PM - 4:00 PM)**

**Make the APPsolute Fit! Select the Right Mobile Device Apps** - Madalaine Pugliese, Ed. S, Assistive Technology Graduate Program Director Simmons

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*Availability of free and low-cost apps for mobile devices grows exponentially. Many practitioners and families have turned to these lesser expensive tools and content hoping for a simple and affordable way to accommodate learners with special needs. However, we must keep already known decision-making processes in mind when designing and recommending interventions. Practitioners need to be careful of "magic wand syndrome". Take care to make the fit for the user just as you would for any other assistive technology. One decision-making process is the Stages Framework. The focus on learners with cognitive and language delay helps to narrow the scope of the apps being considered. Recommended apps that purposely align with the Stages Framework are demonstrated and accompanied by a thorough handout.*

**Madalaine Pugliese** is the Graduate Program Director in Assistive Special Education Technology for the Education Department in the College of Arts and Sciences at Simmons College. She coordinates the Program Faculty, serves as liaison to the rehabilitation and supported learning publishing community, and advises students who major in assistive technology in graduate programs both on and off campus. Madalaine has over 20 years of experience in K-12 public education, plus 18 years in higher education, and is a nationally recognized speaker and authority in assistive technology. Her achievements outside of Simmons College include:

- Former developer and Director of the Assistive Technology Project for the Massachusetts Department of Education,
- Former Co-director of Camp Apple, summer program for educators on new instructional technology,
- Founder of Adaptive Rehabilitation Technology, a nonprofit organization offering information and resources for families and individuals with needs for adaptive technologies.

**\*Note:**

Parents are welcome to attend educator sessions.

Please contact Elaine Crowley at [ecrowley@mdsc.org](mailto:ecrowley@mdsc.org) if you wish to do so.

## 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)

#### Getting the Facts

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Get to know other brothers and sisters by playing a variety of fun games. We'll talk about Down syndrome and the reasons why everyone is here. Let's find out what other brothers and sister are experiencing.

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

#### Down Syndrome Awareness: Informing Others and Ourselves

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You'll have the opportunity to become teachers and decide how to help others learn about Down syndrome. We will analyze how the media informs others about people with disabilities and we'll discuss what *Style Down Syndrome* really means.

### Breakout Session III (2:30 PM - 4:00 PM)

#### Becoming an Advocate

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Brothers and Sisters will practice advocacy skills and brainstorm ways they can make a difference in their life, their sibling's life and in the community.

## YOUNG ADULT SESSIONS (Ages 13 and up)

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

#### What's Your Style? Explore New Talents Choose from a Variety of Mini-Workshops!

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*We'll jumpstart the morning by getting our hearts pumping with Zumba, a Latin-inspired dance and aerobics activity. Then pick 2 mini-workshops that you want to attend to learn something new and express your unique style through art, nutrition, writing, and more!*

**Logan Reckert** started doing Zumba 2 years ago and soon decided that she wanted to teach Zumba classes for people with special needs. She now teaches at the Needham YMCA on the 2<sup>nd</sup> and 4<sup>th</sup> Sunday of each month and has also done classes for AIM (Advocates in Motion) and the J.C.C. (Jewish Community Center) of Newton. Logan takes 8 Zumba classes per week to keep up her skill. Though she has Down syndrome and Juvenile Diabetes, that doesn't stop her!! Logan is 24 years old and has her own apartment with a wonderful roommate. She works at Babson College and at the Women's Lunch Place in Boston, plus is part of the Jewish Family and Children Services of Waltham.

**The Self-Advocate Advisory Council (SAAC)** is comprised of 6 adults with Down syndrome living in Massachusetts. SAAC members serve on the Council for 2 years and develop leadership and self-advocacy skills.

The SAAC advises the MDSC on issues of importance to adults with Down syndrome and looks for ways to increase the role of self-advocates within the organization.

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

### **How to Have Fun and Be Safe Online** - Barbara Oliver

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*This interactive workshop addresses the Opportunities and Threats of participating in online Social Media platforms, particularly Facebook. Barbara presents easy "common sense" solutions on how you can enjoy the online world while maintaining as much security as possible. The session discussion addresses information sharing ("how much is too much"), work/life boundaries on Facebook, the issue of bullying, and basic net etiquette - "netiquette". Helpful handouts are provided, and your questions are welcome throughout the workshop!*

**Barbara Oliver** is Director of Communications at LIFE, Inc., a non-profit organization, serving adults with Intellectual Disabilities on Cape Cod. She also consults on integrated online communications and social media for a variety of non-profits and businesses. She is a recommended presenter of Facebook Safety classes for the Commonwealth of Massachusetts' Department of Developmental Services. She did her BFA studies at Massachusetts College of Art and Design and has 15+ years' experience working with individuals with special needs in the area of arts advocacy and communications.

## **Breakout Session III (2:30 AM - 4:00 PM)**

### **Talent Show Spectacular!**

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It's your time to shine! Sing, dance, tell a joke, display a piece of artwork, or show photos from a travel experience or sports accomplishment- we want to see what YOUR style is all about!

Participation is optional. Those participants who may be too shy to perform/present in front of the group can bring a piece (photo, drawing, poem, etc.) to be displayed throughout the room. Participation Forms must be submitted to Colleen Endres by March 5<sup>th</sup>, 2012.