### Making the Most of a Behavioral Health Consultation for Adults with Down Syndrome

**Bryn Gelaro, MSW, LSW, Director of Adult Initiatives and Special Projects, Global Down Syndrome Foundation**

Bryn Gelaro, LSW, is a social worker with a passion for behavioral health of adults with Down syndrome. She was a consultant for the Global Down Syndrome Foundation for 2 years before becoming the Director of Adult Initiatives and Special Projects in 2017. Her work includes furthering Global’s adult care initiatives, including serving as a co-author of the Adult Medical Health Care Guideline update and supporting Global’s efforts to open a World Class Medical Clinic for adults with Down syndrome. In addition to her work with Global, she previously served as a Behavioral Health provider at the Adult Down Syndrome Clinic at Denver Health in Denver, Colorado. Bryn earned her Bachelors of Science in Psychology from the Pennsylvania State University in 2012 and a Masters (AM) in social work from the University of Chicago’s School of Social Service and Administration in 2015.

**Dennis McGuire, PhD, LCSW, Senior Consultant Adult Initiatives, Global Down Syndrome Foundation**

Dr. Dennis McGuire has over 30 years of experience in the field of mental health and developmental disabilities and is the former Director of Psychosocial Services for the Adult Down Syndrome Center of Lutheran General Hospital in suburban Chicago, the largest, most prestigious clinic for adults with Down syndrome in the United States. He helped establish the center, which serves over 4,000 unique adult patients with Down syndrome each year. Dr. McGuire keynotes at events around the world and is the co-author of two prominent books about promoting wellbeing in adults with Down syndrome: *Mental Wellness of Adults with Down Syndrome* (2006), and *The Guide to Good Health for Teens and Adults with Down Syndrome* (2011), both by Woodbine House. He received the National Down Syndrome Congress Theodore D. Tjossem Research Award in 2003 and the World Down Syndrome Day Scientific Award in 2010. As a consultant for the Global Down Syndrome Foundation, Dr. McGuire has played an integral role in the development of a future world class multidisciplinary clinic serving adults and serves as a lead author on the updated Medical Care Guidelines for Adults with Down Syndrome. McGuire continues to see couples, families, and individuals in a private practice in the Chicago area.
MICHAEL D. TOOBIN has been in the private practice of law in Northern Virginia since 1974. He graduated from The American University in Washington, D.C. in 1971 and received his law degree from the University of Connecticut in 1974. His practice is general in nature, with emphasis on estate planning, special needs estate planning, administration of estates, and real estate law. He is a member of the Academy of Special Needs Planners, the board of directors of the disability Law Center of Virginia (formerly the Virginia Office for Protection and Advocacy), and a member of the Fairfax County Long Term Care Coordinating Council. He is a former member of the board of directors of the Arc of Northern Virginia and a former adjunct professor of The American University. He is an extensive lecturer on estate planning matters, and has presented at many different venues including the Arc of Virginia annual convention, the National Down Syndrome Society annual conference, the Accessibility Summit, the Circle of Support conference, FutureQuest, and the Williams Syndrome annual meeting. He is a contributing author of the books, Virginia Elder Care Planning: How to Protect Assets and Provide for Services (National Business Institute, 2005), The Probate Process From Start to Finish (National Business Institute, 2006), and Estate Planning Basics (National Business Institute, 2007). Michael and his wife, Merle, live in Burke, Virginia.
<table>
<thead>
<tr>
<th>The Improvaneer Method Workshop</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Rob Snow</strong>, Parent, Motivational Speaker, Founder, Stand Up of Downs, Creator, The Improvaneer Method</td>
</tr>
</tbody>
</table>

Rob Snow is the founder of Stand Up For Downs and creator of The Improvaneer Method. He is also a nationally recognized public speaker, author of two books, husband, father of two boys, and for some reason, hasn't been able to quit the day job! In 2009 two major events happened to Rob, he reignited a decade long hiatus from his comedy past and his son Henry was born with Down syndrome. The rest of his life has been a merger of those two things. Rob's passion for comedy and the disability community have culminated in the creation of The Improvaneer Method. This program sets out to prove that improvisation can build and develop key skills that will greatly increase social and workplace opportunities in those with developmental disabilities. His Improvaneers became the world's first all Down syndrome improv troupe, and the world took notice. Rob's keynote will show how this group started, and show the "proof in the comedy pudding" that promises to bring this program to all corners of the globe. The Improvaneer Method has received numerous national media attention and is already being booked all over the country. Rob can't wait to share this ground-breaking and game-changing journey with the NDSS audience, and maybe find a few new cast members in the process!

| Nick Doyle, Director, The Improvaneer Method, Original Cast Member, The Improvaneers, Board Member, Stand Up for Downs, and Gigi's Playhouse, Gabi's Boyfriend. |

Nick Doyle is the natural leader of The Improvaneers. Once he joined the troupe he almost immediately took on the role of the "older brother." Other cast members look up to him and are eager to hear his compliments, as well as criticisms. He is always very kind and respectful and wants everyone to feel like an equal part of the team.
| Resume Building 101 | Matteo Lieb, Employment Policy and Program Manager at the National Down Syndrome Society (NDSS)  

In this role, Matteo develops training resources, works with NDSS’ CEO Commission for Disability Employment and other corporate partnerships, manages data collection and works on employment policy issues for the Down syndrome community. Since joining the NDSS team in 2019, Matteo has built partnerships with Fortune 500 companies, non-profit service providers and state agencies. Prior to joining NDSS, Matteo worked in Supported Employment at a mental-health non-profit in Washington, DC. Matteo is originally from the Bay Area in California and is currently completing his Master of Public Policy degree from Georgetown University. |
|---|---|
| Advances in Down Syndrome Research | Hampus Hillerstrom, MBA, Masters in Economics and Finance, MSc in Health Sciences and Technology, President and CEO of LuMind IDSC Foundation  

President and CEO of LuMind IDSC Foundation since September 2017, after serving on the board of directors for three years, including one year as Vice-Chair. Previously, he co-founded Proclara Biosciences in 2007, a company developing a novel approach for treating Alzheimer’s, Parkinson’s and other protein misfolding diseases, and, he served as Executive Vice President and Chief Financial Officer prior to joining LuMind IDSC as CEO. Previously, he spent three years as an associate at leading European biotech venture capital firm HealthCap where he participated in a large number of investment transactions including several IPOs. Hampus also spearheaded a project at AstraZeneca to evaluate decision-making leading to Phase III clinical trials and worked on the pharmaceutical industry at investment bank Lazard.  

Hampus holds a Masters in Economics and Finance from the University of St. Gallen (Switzerland), an MBA from Harvard Business School, and an MSc in Health Sciences and Technology from MIT/Harvard Medical School (HST). Hampus and his wife, Lianor are raising sons Oskar, the oldest who has Down Syndrome, and his partner in mischief Sebastian. In addition to his focus on research, Hampus and Lianor are big proponents in their community for early intervention therapies and meaningful inclusion in school. Having grown up in the Swiss Alps, Hampus is an avid skier and also a golfer. Hampus and his wife are cooking and hosting aficionados. |
### Empowering Athletes

**Self-Advocate Friendly**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ronny Jones, Self-Advocate, Staff Member, Special Olympics Arizona</strong></td>
<td>Ronny is a Special Olympic Athlete who is currently staff for Special Olympics Arizona. He will share his life story and describe how the Special Olympics program has played a positive role in his personal achievements and growth. Ronny and Hannah will discuss the Health and Athlete Leadership program. Learn how you can get involved in Special Olympics Arizona’s programs as an athlete, parent, professional, or volunteer.</td>
</tr>
<tr>
<td><strong>Hannah Stewart, Programs Assistant at SOAZ</strong></td>
<td>Hannah Rae Stewart, I moved over to the State of Arizona a couple of months ago to pursue my passion working with Intellectual Disabilities. I grew up in Washington State my entire life and have always had the biggest heart and overall best work ethic for supporting and being an advocate for Down syndrome. I am now assisting SOAZ with Health Programs and Athlete Leadership. I am excited to not only be able to work with this incredible population, but grow and be apart of the success and implementation of Athlete Leadership/Health Messenger Programs. I look forward to seeing where this program goes from this point forward. I am here to not only be a voice for ID, but to support and fight for their voices to be heard.</td>
</tr>
<tr>
<td><strong>Sujata Bardhan, PhD, DS-Connect® Registry Coordinator, National Institutes of Health (NIH)</strong></td>
<td>Dr. Sujata Bardhan is a Health Scientist Administrator in the Intellectual and Developmental Disabilities Branch at the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), at the National Institutes of Health (NIH). Dr. Bardhan received her doctoral degree in Chemistry from Boston University. Prior to joining NICHD in April 2013, she worked in Wyeth Pharmaceuticals and was also an Adjunct Assistant Professor in the Department of Chemistry at the College of Staten Island, New York. She has been involved in the development of &quot;DS-Connect®: The Down Syndrome Registry,&quot; and currently serves as the registry coordinator. The Registry is an online, confidential database with demographic and health information from individuals with Down syndrome designed to provide resources to the Down syndrome community and connect them with research opportunities. Currently she is also involved in the new NIH initiative called INCLUDE.</td>
</tr>
<tr>
<td>Time</td>
<td>Session</td>
</tr>
<tr>
<td>--------------</td>
<td>-----------------------------------------------------</td>
</tr>
<tr>
<td>11:00 AM-12:15 PM</td>
<td><strong>Life with Down Syndrome: A Sibling’s Journey</strong></td>
</tr>
<tr>
<td>3:30-4:45 PM</td>
<td><strong>Dementia Friends</strong></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Thursday, May 14, 2020
11:00 AM - 12:15 PM

Understanding How to Fund a Special Needs Trust: Avoid the Medicaid Payback Provision

Andrew Morris, MBA, CSA

A trusted sales executive with a history of proven results over 20 years of experience as an external wholesaler of financial services products. My expertise covers mutual funds, variable annuities, insurance products, investments and retirement. Currently focused on expanding the FIA distribution for DMI marketing a 30 year trusted IMO for advisors. I work with independent advisors & agents with utilizing FIA’s as an alternative to fixed income with principle protection as a retirement solution. Formerly I worked at Navian Capital at the VP level as the Regional Relationship Manager for their East Coast operations as their external wholesaler for MLCDs, Structured Notes & FIA’s (Fixed Index Annuities). my time with my previous employers, I grew their market share significantly and consistently delivered excellent results providing sales strategies & relationship building.

12:00-1:15 PM

My Doctor’s Appointment is About Me!

*Limited Space Available

*Alyssa Siegel, MD, Medical Director, The Children’s Hospital of Philadelphia’s New Jersey Transition to Adulthood Comprehensive Care Program

Dr. Alyssa Siegel, MD is a pediatrics specialist in Philadelphia, PA and has been practicing for 23 years. She graduated from Stony Brook Univ Health Sciences Center School of Medicine in 1994 and specializes in pediatrics.
Living a Healthy Life!
Five Ways to Promote Your Health

*KSelf-Advocate Friendly
Limited Space Available

3:00 – 4:15 PM

Katie Frank, PhD, OTR/L, Occupational Therapist III, Advocate Medical Group Adult Down Syndrome Center, Park Ridge, IL

Katie Frank, PhD, OTR/L is an Occupational therapist at the Adult Down Syndrome Center in Park Ridge, IL. The majority of her work has been with individuals with Down syndrome (DS) of all ages. Dr. Frank has experience with treatment and evaluation as well as facilitating groups for people with Down syndrome, conducting trainings for families and caregivers, and offering a variety of other educational opportunities both locally and nationally. She earned her PhD in Disability Studies from the University of Illinois at Chicago, where her dissertation was “Parents as the Primary Sexuality Educators for their Adolescents with Down Syndrome.” Dr. Frank has been the primary investigator on multiple research studies including individuals with DS and/or their families and has had her work published in peer-reviewed journals.

Laura Chicoine, Project Manager, Research and Education, Advocate Medical Group Adult Down Syndrome Center, Park Ridge, IL

Laura Chicoine is project manager for research and education at the Advocate Medical Group Adult Down Syndrome Center in Park Ridge, IL. She manages the planning, implementation, and evaluation of projects related to research and education. Her responsibilities include overseeing the development and growth of an online database of resources, creating a library of health education videos featuring adults with Down syndrome, contributing to the planning and implementation of research studies, assisting with health and wellness groups for individuals with Down syndrome, and planning events such as presentations, workshops, and an annual run/walk. As part of her role, she collaborates with a variety of groups in the wider Down syndrome and intellectual disability community.

How to Ace Your Next Interview

Limited Space Available

** Self-Advocate Friendly

Matteo Lieb, Employment Policy and Program Manager at the National Down Syndrome Society (NDSS)

In this role, Matteo develops training resources, works with NDSS’ CEO Commission for Disability Employment and other corporate partnerships, manages data collection and works on employment policy issues for the Down syndrome community. Since joining the NDSS team in 2019, Matteo has built partnerships with Fortune 500 companies, non-profit service providers and state agencies. Prior to joining NDSS, Matteo worked in Supported Employment at a mental-health non-profit in Washington, DC. Matteo is originally from the Bay Area in California and is currently completing his Master of Public Policy degree from Georgetown University.
### How to Ace Your Next Interview

**Limited Space Available**

**Self-Advocate Friendly**

David DeSanctis, Self-Advocate, NDSS Public Relations & Outreach Associate

David is the Public Relations Outreach Associate for The National Down Syndrome Society (NDSS). In his role, he serves as a face for NDSS at various functions and events. David is an inspirational speaker and an actor, and he is thrilled to be able to use his talents to raise awareness for NDSS and Down syndrome!

---

### Friday, May 15, 2020

11:00 AM - 12:15 PM

### Becoming a Sexual Self-Advocate

Katherine McLaughlin, M.Ed., Elevatus Training

Katherine McLaughlin, M.Ed. CSE, is a national expert and trains individuals, staff, and parents on sexuality and developmental disabilities. She teaches sexuality education to people with DD/ID as well as trains them to be peer sexuality educators themselves. Katherine is the author of an agency and school curriculum: Sexuality Education for People with Developmental Disabilities, and has developed two online courses; one to train professionals, Developmental Disability and Sexuality 101, and one for parents: Talking to Your Kids: Developmental Disabilities and Sexuality. Katherine has spent her career trying to elevate the status of all people, which is why the new name for her growing company is Elevatus Training. Contact Katherine www.elevatustraining.com

Jennifer Katz, NDSS Job Coach and Office Assistant, Partners in Policymaking Graduate

Jennifer Stern Katz grew up in Maryland, as the youngest of three girls. She was diagnosed with Mosaic Down syndrome at age 9 and had the support of her family to help her achieve her educational and life goals. After graduating American University in Washington D.C, she married and had two daughters; they've lived in four different states since they were born! Jennifer has worked for Parent to Parent of Georgia and completed Partners in Policymaking training, where she developed her skills in advocacy and self-advocacy. She now lives in New York and works for the National Down Syndrome Society as the Senior Office Assistant and has been employed with them for over two years. Jennifer enjoys cooking, reading, jigsaw puzzles, spending time with her partner and her dog, and talking with her friends and family.
| 1:00-2:15 PM | Matteo Lieb, Employment Policy and Program Manager at the National Down Syndrome Society (NDSS)  
In this role, Matteo develops training resources, works with NDSS’ CEO Commission for Disability Employment and other corporate partnerships, manages data collection and works on employment policy issues for the Down syndrome community. Since joining the NDSS team in 2019, Matteo has built partnerships with Fortune 500 companies, non-profit service providers and state agencies. Prior to joining NDSS, Matteo worked in Supported Employment at a mental-health non-profit in Washington, DC. Matteo is originally from the Bay Area in California and is currently completing his Master of Public Policy degree from Georgetown University. |
| --- | --- |
| Resume Building 101  
Limited Space Available  
** Self-Advocate Friendly | Matteo Lieb, Employment Policy and Program Manager at the National Down Syndrome Society (NDSS)  
In this role, Matteo develops training resources, works with NDSS’ CEO Commission for Disability Employment and other corporate partnerships, manages data collection and works on employment policy issues for the Down syndrome community. Since joining the NDSS team in 2019, Matteo has built partnerships with Fortune 500 companies, non-profit service providers and state agencies. Prior to joining NDSS, Matteo worked in Supported Employment at a mental-health non-profit in Washington, DC. Matteo is originally from the Bay Area in California and is currently completing his Master of Public Policy degree from Georgetown University. |
| 2:30 – 3:45 PM | Mary Borman, Self-Advocate, Special Olympics Athlete, Health, Nutrition and Fitness Speaker, NDSS Ambassador, NDSS 2018 Self-Advocate of the Year  
Mary Borman is a 21-year-old woman with Down syndrome. The first person with Down syndrome to attend the University of Arkansas in Fayetteville, she is also the first person with Down syndrome to model in NWA Fashion Week. She is an ambassador for Down syndrome for the National Down Syndrome Society (NDSS) and in 2018 was named their Self-Advocate of the Year. She has been to Washington, D.C. on a number of occasions to lobby for disability rights and was instrumental in helping pass the national ABLE Act that allowed people with disabilities to save money for education. Mary swims competitively, both nationally and internationally, with Special Olympics and the Down Syndrome International Swimming Organization. She speaks to organizations all over the country concerning health, fitness, and nutrition for individuals with Down syndrome as well as helping others understand what it is like to have Down syndrome. |
| Build Your Life…Live Your Dream | Mary Borman, Self-Advocate, Special Olympics Athlete, Health, Nutrition and Fitness Speaker, NDSS Ambassador, NDSS 2018 Self-Advocate of the Year  
Mary Borman is a 21-year-old woman with Down syndrome. The first person with Down syndrome to attend the University of Arkansas in Fayetteville, she is also the first person with Down syndrome to model in NWA Fashion Week. She is an ambassador for Down syndrome for the National Down Syndrome Society (NDSS) and in 2018 was named their Self-Advocate of the Year. She has been to Washington, D.C. on a number of occasions to lobby for disability rights and was instrumental in helping pass the national ABLE Act that allowed people with disabilities to save money for education. Mary swims competitively, both nationally and internationally, with Special Olympics and the Down Syndrome International Swimming Organization. She speaks to organizations all over the country concerning health, fitness, and nutrition for individuals with Down syndrome as well as helping others understand what it is like to have Down syndrome. |
**Megan McCormick, Self-Advocate, B.A. University of Kentucky, Para Educator**

Graduated Cum Laude from the University of KY with a BA degree in Liberal Studies in May 2019. Her college experience was challenging but it was rewarding and a very exciting achievement. Megan has been working part-time in an Elementary School, which was her Alma Mater, as a Para Educator since 2017. Her goal is to be a full-time Para Educator in an Elementary school, working and helping children with different abilities to achieve academic success and to improve their opportunities to get a post-secondary education just as she did. Megan incidentally was born with Down syndrome. However, she is quick to state that Down syndrome is not what defines her. She believes that with support and raised expectations everyone is capable of achieving their individual highest potential. Megan’s family, friends and her educators were all instrumental in building her self-confidence in her abilities and she continues to be a strong advocate for inclusive education, post-secondary education and for supported employment in a field of their choice for each person with different abilities. Megan is very involved with her church, Special Olympic swimming, and is a global messenger for supporting Special Olympics in Kentucky. She loves music, movies, cooking, playing the piano and hanging out with friends. This year, she joined the Bell Choir in her church and enrolled in a studio to learn ballroom dancing! She takes social and private dance lessons and loves this new challenge. Megan hopes to share her primary, secondary and post-secondary educational experiences with us as well as the start of her journey into employment in the field she has chosen, and gratefully acknowledges the many educators who have helped her get to where she is today.

**Eden Rapp, Self-Advocate; Employee, MOD Pizza; Competent Communicator, Toastmasters; Board Member, Disability Voices United; Founder/Co-Facilitator, UpVoice; Ambassador, Best Buddies**

I am 23 years old and have many abilities. Music is my passion, and I love to write; I attended community college for two years, use public buses, and cook dinner for my family on the weekends. My goals are to become a stronger self-advocate and a woman of faith; and to grow in my job and independent living skills. One of the things I enjoy doing is becoming a better self-advocate. I have lobbied in Washington, D.C. with the National Down Syndrome Society, and I also serve on the board of Disability Voices United. We lobby in Sacramento and host statewide conferences and webinars. It is fun being able to encourage lawmakers with my story. I also started UpVoice, a club for young adults with disabilities to become stronger self-advocates and better readers. We read books chapter by chapter, and the walk to different restaurants in our community for hangouts. I also teach them about person-centered planning, independent living like money skills, safety, conversation, I see a lot of growth in them in social skills, independence and reading. It is fun seeing them grow like that. I have spoken at local and regional workshops, and at several National Down Syndrome Congress conventions. To help me become a better speaker, I am in Toastmasters, and I earned my Competent Communicator award in 2019. Other Awards: Voice Award, Down Syndrome Association, Los Angeles,
Build Your Life…Live Your Dream

Candace Whiting, Self-Advocate, CEO, Great Life Unlimited, lifestyle consultant, motivational speaker, Global Messenger for Special Olympics, certified peer mentor, and decorated Special Olympic athlete.

Candace is a woman with Down syndrome who does not want people to see through her label. She has not let her “different-ability” stop her from reaching her dreams. Using her 10 Key Points she can motivate people of “different-abilities” to realize their dreams and live their best life. Her session will encourage others to find their place in the world by describing her business model and demonstrating how that model inspires people to optimize their own abilities, talents and gifts to be extraordinary people who live extraordinary lives. She founded her public speaking business, “Candace Whiting Unlimited” in 2011. Candace is now the CEO of a rebranded “Candace Whiting Unlimited” now called “Great Life Unlimited”. She is a lifestyle consultant, motivational speaker, Global Messenger for Special Olympics, certified peer mentor, and decorated Special Olympic athlete. Candace wants to use her voice for those who do not have a strong voice themselves. She hopes to expand her business to lifestyle consulting by connecting with people who are not limited by different abilities. She is in the process of writing a book highlighting her 10 Key Points to an extraordinary life.

Colleen Hatcher, NDSS Community Outreach and Engagement Manager

Colleen Hatcher is the Manager of Community Relations at the National Down Syndrome Society. She works with self-advocates, families and affiliates across the country to ensure they are provided with the most up-to-date resources on Down syndrome. Colleen was inspired to advocate for individuals with Down syndrome by her best friend, Gina, who has Down syndrome. Colleen has known Gina for over 20 years and credits Gina for her love for the disability community. Colleen has a bachelor’s degree in Elementary Special Education and a Master’s degrees in Elementary Special Education, Severe Disabilities.
### Research Update: Sleep and Sleep Apnea & Down Syndrome

<table>
<thead>
<tr>
<th>James Hendrix, Chief Science Officer, LuMind IDSC Foundation</th>
</tr>
</thead>
<tbody>
<tr>
<td>As the Chief Scientific Officer, Dr. Hendrix directs scientific initiatives for LuMind IDSC. A critical element of his role is to establish the nationwide Down Syndrome – Clinical Trial Network (DS-CTN) and to oversee the first clinical trial in the DS-CTN, the Longitudinal Investigation for Enhancing Down Syndrome Research (LIFE-DSR) Study. The LIFE-DSR study is a natural history study focused on adults 25 years of age and older at high risk for Alzheimer’s disease. Dr. Hendrix is also focused on building potential collaborations with industry, academic and government scientists focused on Down syndrome research to maximize LuMind IDSC’s scientific impact.</td>
</tr>
<tr>
<td>Prior to joining LuMind, Dr. Hendrix was Director of Global Science Initiatives, at the Alzheimer’s Association. A critical element of his role was the management of industry consortia such as the Alzheimer’s Association Research Roundtable (AARR); lead the Global Biomarker Standardization Consortium; and assist with the coordination of the $100 million dollar Imaging Dementia—Evidence for Amyloid Scanning (IDEAS) Study on the clinical usefulness of amyloid PET imaging.</td>
</tr>
<tr>
<td>Before joining the Alzheimer’s Association, Dr. Hendrix was a pharmaceutical scientist with a focus on drug discovery for CNS diseases. Dr. Hendrix spent 18 years working at Sanofi-Aventis and predecessor companies, where he rose to level of senior director, U.S. site head for CNS research. He also spent two years working in the biotech industry with various companies, including companies focused on the treatment of Alzheimer’s disease. Dr. Hendrix received his Ph.D. and a postdoctoral fellowship from Colorado State University.</td>
</tr>
</tbody>
</table>