



NDSS Virtual Adult Summit Week Two

All scheduled times are Eastern Daylight Time

Monday, May 11, 2020

1:00 – 2:15 PM

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

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

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

Finding a provider who can appropriately assess mental wellness and behavioral health in adults with Down syndrome is a common concern for families and self-advocates. Whether you are visiting a Down syndrome clinic or a seeing a general practitioner, there are things you should be looking for before, during and after an appointment, to make sure a behavioral health consultation for an adult with Down syndrome is useful and informative. Bryn and Dr. McGuire will discuss common behavior characteristics of adults with Down syndrome and how they can be used to support overall wellness and be channeled into strengths. They will also discuss what to expect and how self-advocates, families and caregivers can prepare for behavioral health consultations with their local providers.

1:00 – 2:15 PM

Legal Issues 101

Michael Toobin, PC, Law Office of Michael D. Toobin

Families with a member who has special needs face a myriad of unique legal matters. These include estate planning issues and guardianship. Michael will discuss the need to plan and why the plan must be in writing, and the documents everyone needs for basic estate planning. He will also explain various types of special needs trusts, government benefit programs, as well as guardianship and alternatives to guardianship.



3:30 – 4:45 PM

The Improvaneer Method Workshop

Rob Snow, *Parent, Motivational Speaker, Founder, Stand Up of Downs, Creator, The Improvaneer Method*

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

You may have heard of this ground-breaking and game-changing program, and now it's time to experience it up close and without a net. Rob Snow, the creator of The Improvaneer Method, and Nick Doyle, original cast member and troupe leader, will introduce improvisation for all attendees of all abilities. Don't worry, no one will be embarrassed or asked to do something they don't want to do, and no one will be left out. This introduction to this amazing art form will help get the mind and body moving together in ways they haven't before. It will be fun, funny, and incredibly entertaining, and to make the parents happy, it might also be educational as well. We can't wait to see the imaginations of this group take off! Please note, this **session will cap with a maximum of 40 self-advocates**.

Parents/caregivers can sit near the self-advocate to **listen and observe**, but only the self-advocate is to be on screen. This **session will not be recorded**.

Tuesday, May 12, 2020

1:00 – 2:15 PM

Resume Building 101

Matteo Lieb, NDSS Employment Policy and Program Manager

For anyone looking to get a job, a resume is a fundamental part of that journey! Join us for a productive workshop on how to build an amazing resume! This workshop will help participants build a resume from scratch, and therefore a word processing system (such as Microsoft Word) is beneficial. Each participant will receive support for their specific resume throughout the workshop. This workshop is perfect for individuals who are looking to improve their current resume as well as for those who don't currently have one! Participants should come away from this session with both a resume they feel confident with as well as general tips for building one going forward.



1:00 – 2:15 PM

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

Thanks to recent advances in medical research in the past several decades, life expectancy and quality of life of people with Down syndrome have improved dramatically. However, major healthcare challenges remain and are the focus of new research. This presentation will review some of the areas of research that have the potential to bring new treatment options to families in the future. Topics such as digital medicine, gene therapy, autoimmune conditions, and issues related to independence will be discussed. In addition, LuMind IDSC will provide results of a recent family survey on independence. The session will also inform families and self-advocates on how they can support, participate and become educated on research.

3:00 – 4:15 PM

Empowering Athletes

**** Self-Advocate Friendly**

Ronny Jones, *Self-Advocate, Staff Member, Special Olympics Arizona*

Hannah Stewart, *Programs Assistant at SOAZ*

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.

3:00 – 4:15 PM

An Overview of NIH-Funded Research Related to Down Syndrome

Sujata Bardhan, *PhD, DS-Connect® Registry Coordinator, National Institutes of Health (NIH)*

DS-Connect® is a powerful resource where people with Down syndrome and their families can connect with researchers and health care providers. In this session, participants will learn how they can take part in clinical studies on Down syndrome, including studies of new medications and other treatments, and take confidential health-related surveys that are aimed at better understanding of the health of people with Down syndrome across their lifespans



Wednesday, May 13, 2020

11:00 AM – 12:15 PM

Life with Down Syndrome: A Sibling's Journey

Embry Burrus, Sibling

As the full-time caregiver for her older sister, Margaret, who is now 61 years-old, Embry will describe her heartfelt, uplifting and often humorous story of growing up as the younger sibling of a person with Down syndrome in the 1960s.

3:30 – 4:45 PM

Dementia Friends

Marty Williman, BSN, RN, Program Director, Ohio Council for Cognitive Health

Jennifer Wolfe, MSW, LISW-S, Provider Training Coordinator, Lucas County Board of Developmental Disabilities

Experience Dementia Friends and learn how this new program, being presented in communities across America, is changing the way we think, act, and talk about Alzheimer's disease and other dementias. This global movement, developed by the Alzheimer's Society in the United Kingdom and now underway in 56 countries, helps everyone in a community understand five key messages about dementia, how it affects individuals, and how we each can make a difference in the lives of people living with the disease. With funding from a grant by the Department of Health & Human Services, Administration for Community Living (#90ADPI0008-01-00) adaptation of the Dementia Friends workbook was developed for individuals with intellectual and developmental disabilities and dementia. An overview of the grant project will be included in the presentation.

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, Prudential Advisors

Join Andrew, the parent of a young child with Down syndrome and a..... as he shares important information to help families safely fund special needs trusts. Andrew will discuss the different types of special needs trusts, the easiest and most economical way to fund them, and share how to set up a trust that can avoid the Medicaid Pay Back Provision.



12:00 – 1:15 PM

My Doctor's Appointment is About Me!

****Limited Space Available***

****Self-Advocate Friendly***

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

In this interactive session, participants will explore basic healthcare issues, including why a doctor is important, when we need to see them, and how to share important information. Through role-playing, and problem-focused doctor visits, self-advocates will review parts of the body, as well as common symptoms and medical conditions that people with Down syndrome may have. We will also identify members of the health care team and learn to recognize why and when help from a parent, sibling or friend is needed to assure the very best health care.

There are limited spaces in this session. Dr. Siegel asks that a family member or support person participate with their self-advocate. This session will not be recorded.

12:30 – 1:45 PM

LuMind Focus Group – Limited Space Available

Marly Chevrette, Marketing Director, LuMind RDS

3:00 – 4:15 PM

Living a Healthy Life! Five Ways to Promote Your Health – Limited Space Available

***** Self-Advocate Friendly***

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

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

Living longer and healthier lives is an active process. Adults with Down syndrome are encouraged to participate in their own health promotion. But where do we start? Laura and Katie will share five areas to focus on when making healthy lifestyle choices. They will discuss why these five areas are important, facilitate activities to reinforce the information, and share strategies that can be incorporated at home and in the community.



We request that a family member or caregiver “attend” with the participant with Down syndrome so that they can hear the information and help reinforce it later.

We recommend that the participants join on a computer or tablet (rather than a phone) so that they can see the words and pictures on the slides. This will help them be able to participate in the interactive portions of the workshop. This session will not be recorded.

3:00 – 4:15 PM

How to Ace Your Next Interview

Matteo Lieb, *NDSS Employment Policy and Program Manager*

David Egan, *Self-Advocate, SourceAmerica, Sargent Shriver International Global Messenger, Joseph P. Kennedy Jr. Public Policy Fellow*

Have you ever felt nervous going into an interview? Did an interview ever get in the way between you and your dream job? If so, this workshop will be a great resource! This session will take an interactive approach to building interview skills. We will cover a selection of commonly asked interview questions as well discussing additional ones from the audience. Whether you have not yet been through an interview process or are looking to build on previous experience, this workshop will provide valuable insight on how to close the deal and land that next job!

Friday, May 15, 2020

11:00 AM – 12:15 PM

Becoming a Sexual Self-Advocate

Katherine McLaughlin, *M.Ed., Elevatus Training*

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

People with developmental disabilities are often left out of the conversation about sexuality, almost as if they are incapable of having thoughts, feelings, and needs. In reality, they, too, are sexual beings that need information and skills for making healthy decisions about sexuality. One of these skills is the ability to be a sexual self-advocate. As defined by Green Mountain Self-Advocates, Sexual Self-Advocacy (SSA) means: "Speaking up for yourself, sexually;" "Getting information;" "Taking a stand;" "Saying to whomever - this is my choice;" "Stating your sexual limits and desires with your partner, respecting others limits and desires;" and, "Starting to do what you want with relationships." During this workshop, self-advocates, parents, and professionals will learn what sexual self-advocacy is, explore ways a person can become a sexual self-advocate, practice speaking up for the right to be in a relationship and for your rights within a relationship, and learn ways to support people with disabilities to become sexual self-advocates.



1:00 – 2:15 PM

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2:30 – 3:45 PM

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*

Megan McCormick, *Self-Advocate, B.A. University of Kentucky, Para Educator*

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

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.*

Colleen Hatcher, *NDSS Community Outreach and Engagement Manager*

All of us have dreams for our lives. Join these self-advocates to learn how they create the life they want as they become strong women and even stronger self-advocates. The ladies will explore tools such as person-centered planning, social networking, shared interests, and keys to a happy life.

2:30 – 3:45 PM

Research Update: Sleep and Sleep Apnea & Down Syndrome

James Hendrix, *Chief Science Officer, LuMind IDSC Foundation*

Sleep has an important and underappreciated role in human health. Unfortunately, disrupted sleep is often untreated and very common in children and adults with Down syndrome. Obstructive Sleep Apnea



(OSA) is a common cause of disrupted sleep in Down syndrome. Untreated sleep apnea is associated with many health issues including daytime sleepiness, impaired cognitive function and is even with Alzheimer's disease later in life. This session will describe options for diagnosis and treatment of OSA. Results from a recent LuMind IDSC survey of families on sleep apnea will also be presented.