



NDSS Virtual Adult Summit

All scheduled times are Eastern Daylight Time

Monday, April 26, 2021

12:00 -1:15 PM ET

COVID-19: The Impact for Employees with Down Syndrome

David Egan, Community Relations Coordinator at SourceAmerica

David Silverman

Jason Sypolt

Moderator: Matteo Lieb, Employment Policy and Program Manager, NDSS

The COVID-19 pandemic has caused significant disruption to many employees within the workforce. This is especially true for employees with disabilities who, according to the Department of Labor, had an unemployment rate of roughly 19% in April 2020 (DOL). This session features several perspectives on the discussion of how COVID-19 has impacted employment for people with Down syndrome. We will discuss the impact to self-advocates themselves, the availability of support services and how employers have adjusted. Additionally, we will discuss how the employment landscape may look for employees with Down syndrome in the years to come.

2:00 – 3:15 PM ET

The Return to Normal - But Not Just Yet? COVID-19 Part 2

Dr. Nicole Baumer, MD, Med

Dr. Katie Frank, PhD, OTR/L

Dr. Lina Patel, PsyD

The world shut down abruptly when COVID-19 hit, forcing so many people to change their schedules and adopt new behaviors. At some point in time, hopefully, we'll get to go back to the way things were. But this will also represent a change in behaviors and adopting new schedules. This webinar will provide insights and information on mental health, best practices for re-entering everyday life and how to best support our families with this shift to post-COVID-19 life.



Tuesday, April 27, 2021

12:00 – 1:15 PM ET

Mental Health Issues and Interventions

Dr. Jenny Kimes, Director of Children's Programming and Clinical Services at Down Syndrome of Louisville

Adults with Down syndrome can present with increased vulnerability to generalized anxiety, depression, social withdrawal, diminished self-care and regression associated with mental health issues. In this session we'll discuss mental health issues and interventions experienced in clinical practice at Down Syndrome of Louisville and a practical approach to addressing these issues. Attendees will leave with an overview of effective strategies to address anxiety, depression, relationship issues and behaviors related to autism and dementia.

2:00 – 3:15 PM ET

EmployMATE: A Virtual Approach to Job Coaching

Peter Leisen, Project Manager

Michael Smith, GRADSA Ambassador and Self-Advocate

Tiffany Thrash, Executive Director

Many employees with Down syndrome rely on accommodations, including job coaching, to maintain success in the workplace. However, oftentimes there are limitations to just how physically present a job coach can be to support an employee with Down syndrome. Join us for a session led by Peter Leisen of the Arc of Northern Virginia to discuss EmployMATE – a virtual option for support in the workplace. Peter will provide an overview of EmployMATE and we will also hear how it works in practice from an NDSS affiliate organization and self-advocate.

4:00 – 5:15 PM ET

Approaching Law Enforcement Agencies About Accepting Training On Disability Issues and Becoming Advocates for People With Disabilities

Steve Slack, NDSS DS-Ambassador

According to the Ruderman Family Foundation, 50% of people killed during encounters with police have a disability. Many of them are non-violent and do not have a prior criminal history. These tragedies are devastating for all involved. While first responder training regarding people with disabilities is often either not mandatory or limited, police departments are open to training. This session will guide you on approaching departments about disability training. We will discuss the methods that you will use to give the training to active-duty officers and cadets. Finally, you will learn ways to encourage officers to become disability rights activists. During the session you will also learn how politicians, universities and the press can assist you in promoting the training.



Wednesday, April 28, 2021

12:00 – 1:15 PM ET

Advocacy and Policy with the NDSS Team!

Nicole Patton, Manager of Grassroots Advocacy, NDSS

Kayla McKeon, Manager of Grassroots Advocacy, NDSS

Adrian Forsythe Korzeniewicz, Advocacy Program Specialist, NDSS

Ashley Helsing, Director of Government Relations, NDSS

Do you want to learn more about how to advocate for laws that will positively impact people with Down syndrome and their families? This session is for you! Our Advocacy and Public Policy team will work with attendees to guide them through the legislative process, share best practices for advocacy and teach attendees more about what policies impact people with Down syndrome and their families.

2:00 – 3:15 PM ET

Creating a Low-Cost Branded Experience

Elizabeth Hague, Co-founder, Brand Expert

In this session, Elizabeth Hague will walk you through how to engage with your customers in a world where in-person interactions have dramatically decreased. This workshop will give businesses a checklist of ways to best implement branded experiences that drive return customers while making the most of their budget. It will start with the basics of what branding is and how it influences marketing. It will break down complicated concepts into bite-size chunks and help you uncover new ways to excite and delight customers. Branding is part magic, part science. In this session Elizabeth will give you the recipe for successful branding and how to wow your customers and help them remember you and your business.

4:00 – 5:00 PM ET

I Want to Date! A Session for Self-Advocates on the Skills Needed for Successful Romantic Relationships

Katie Frank, PhD, OTR/L

Do you have an interest in dating? Do you have questions on how to meet someone to date or how to maintain a healthy relationship? This presentation will focus on what skills individuals with Down syndrome need in order to enter into and maintain dating relationships, as well as activities to help develop these skills.



Thursday, April 29, 2021

12:30 – 1:45 PM ET

ABLE Accounts for the Working Person

David Dominick, Marketing Manager - PA ABLE

Dave Amerine, Chief Executive Officer, UCO Industries

Diana Fishlock, Deputy Communications Director

Matthew Stagner, CFP®, ChSNC®, Sr. Special Needs Financial Consultant, Voya Cares®

Doug Jackson, Deputy Director of STABLE Accounts

Eric Ochmanek, Director of Special Projects at Ohio Treasurer of State

ABLE accounts are not just for “extra” money, but a place to save earned wages too. Even more, some employers are making contributions into an employee’s ABLE account. In this session, listen to two ABLE programs, an employer and a financial wellness company discuss earned wages being contributed into ABLE accounts, and learn about advocacy and collaboration opportunities that people with disabilities can facilitate regarding ABLE accounts with their own employer.

3:00 – 4:15 PM ET

Benefits Counseling: How to Navigate Working and Social Security

Marquita Siler-Tyler, Certified Benefits Specialist

Matteo Lieb, Employment Policy and Program Manager, NDSS

Becoming approved for Social Security benefits when you become disabled can sometimes be a daunting and perceivably insurmountable task; and for this reason, beneficiaries are leery of doing anything to jeopardize those benefits. This fear can paralyze them into accepting that they will never be able to enter the workforce again or even try to work without losing everything and having to start over from the beginning. This is not true. Social Security has a plethora of work incentives and safeguards in place to provide opportunities for those who want to return to work, to do so without automatically losing their benefits. In this session, we will discuss work incentives that are available to assist beneficiaries with their goal of returning to work, while providing them information about how this will impact their benefits.



Friday, April 30, 2021

12:00 – 1:15 PM ET

Connecting Families To Research That INCLUDEs Them: DS-Connect®: The Down Syndrome Registry

Dr. Sujata Bardhan, Health Scientist Administrator

Participants will learn about progress in studies being supported by the National Institutes of Health (NIH) through the New NIH initiative called INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome (INCLUDE) (<https://www.nih.gov/include-project>). NIH staff will also discuss DS-Connect®: The Down Syndrome Registry (<https://DSConnect.nih.gov>) and what it can offer to families. The presenter will describe how families can participate in research through the registry. Participants will learn about progress in studies being supported by DS-Connect® and can also inform NIH and researchers about the issues that matter to them and share their research interests and priorities.

2:00 – 3:15 PM ET

End Of Life Preparation: Conceptualizing Transitions and Commemorating Life

Leone Murphy, R.N., Parent

Kathy Service, RN, MS, FNP-BC, CDDN

Moderator: Dr. Lucille Esralew, PhD

How can we prepare for end of life? How do we commemorate a life well lived? This session will cover these questions and more as our panelists navigate the topic of end-of-life preparation. This session will cover topics such as: what it means to conceptualize transition periods in every aging adult's life, understanding the foundational aspect of end-of-life planning and understanding how your loved one wants to be remembered. The goal of this session is to continue the conversation of end-of-life preparation by understanding how family connection, trust in your healthcare workers and an understanding of "comfort care" all intertwine.