



NDSS Virtual Adult Summit

All scheduled times are Eastern Daylight Time

Monday, April 12, 2021

12:00 -1:15 PM

Do You See What I See? Advocating for Your Loved One's Functional Vision

Kellye Knueppel, OD, FCOVD

Functional vision is how your entire visual system -- the eyes, the brain, the visual pathways -- work together to help you interact with your environment. Functional vision includes the following visual skill areas: eye teaming, eye focusing, eye movements and visual perception. People with Down syndrome are much more likely to have functional vision problems. This session will discuss how functional vision matters for work, school and fun activities with special consideration for people with Down syndrome. What can be done to make sure that vision is helping rather than getting in the way? What information should be mentioned to the eye doctor? What questions should be asked at the eye exam? How do I find a doctor who will evaluate functional vision skills?

2:00 – 3:15 PM

Supporting Your Loved One with Down Syndrome to Learn Skills Necessary for Developing Healthy Relationships

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

Does your loved one with Down syndrome have an interest in dating? Do you feel like you need more information in order to better support them on this journey? This presentation will focus on what skills individuals need in order to enter into and maintain dating relationships, as well as how to help them develop these skills.

4:30 – 5:45 PM

Publication of the 1st Evidence-Based Medical Care Guidelines for Adults with Down Syndrome

George Capone, Director, Down Syndrome Clinic and Research Center

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

The much-anticipated GLOBAL Medical Care Guidelines for Adults with Down Syndrome are now published and available! Learn about the first set of evidence-based, updated recommendations for families and self-advocates to share with their medical providers across the US. This first version of the Global Guidelines covers nine topic areas deemed critically important for the health and well-being of adults with Down syndrome, resulting in 14 recommendation statements and four statements of good practice. This presentation will cover the guideline creation process, how family focus groups informed the guidelines and the patient toolkits created to accompany the guidelines. We will discuss how families and self-advocates can access the guidelines and how/why they may differ from previous guidelines. We will also outline the future research needed to build up the existing evidence base and map out a plan for the second version of the guidelines, expected over the next 5-6 years.



Tuesday, April 13, 2021

12:00 – 1:00 PM

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

Limited Space Available

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

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

Do you have 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 help develop these skills.

4:30 - 5:45 PM

Panel on Grief, Behavior and Aging

Dr. Kathleen Bishop, National Task Group on ID and Dementia Practices VP, Co-chair of the Education and Training Committee

Risley Linder, MA, M. Ed., BCBA

Patti Wade, Director of Center on aging, dementia and longevity

Kathy Service, Nurse Practitioner at DMR

Are you the caregiver of a loved one struggling with grief or sudden behavior changes? All behavior has a meaning, but sometimes it may be difficult to identify the root cause. This session will address behavior, grief and the emotional support a caregiver can provide to their loved ones going through difficult times. Caregivers will hear from panelists about the medical and emotional support that can help support their loved ones, and how we all can create space for grief to support quality of life.



Wednesday, April 14, 2021

12:00 – 1:15 PM

MapHabit: Automated Visual Mapping for Independence and Employment Support

Limited Space Available

Jill Reffett, Parent and MapHabit Advocate

Visual supports, schedules and maps are the gold standard, but how do they take us beyond the printer, beyond the paper taped to the bathroom wall and into the real world to create opportunity for independence and employment? Take your job coach, skills support and task reminder right along with you, wherever you go. Join us to look at visual mapping in a new way that you may not have previously considered.

2:00 – 3:15 PM

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4:00 – 5:30 PM ET

What You Need to Know about COVID-19 and Down Syndrome

Stephanie L. Sherman, PhD, Professor Emerita, Emory University

Bryn Gelaro, Senior Director of Adult Initiatives and Special Projects, Global Down Syndrome Foundation

Stephanie L. Santoro, M.D., Director of Quality Improvement Research, MassGeneral Hospital Down Syndrome Program Down Syndrome Research Program

Moderator: James Hendrix, Chief Scientific Officer, LuMind IDSC

The risk for serious health issues due to COVID-19 is higher for people with Down syndrome than in the general population. In this session, the current research findings on COVID-19 in Down syndrome will be discussed, along with useful resources for families. The session will also include time for questions and discussion.



Thursday, April 15, 2021

2:30 PM – 3:45 PM

"Can You Help Me Do Nothing?": How We Can Support Leisure Skills

Risley Linder, MA, M. Ed., BCBA

What has the pandemic world shown us regarding activity and social engagement with individuals with ID/DD? Can we take these lessons with us to our new, post-pandemic, world? This session will explore how robust, preferred activity schedules can serve as a foundation for promoting quality of life for those with ID/DD, while assisting caregivers and direct support professionals in day-to-day service provision. The aim of this presentation is to provide attendees with methods and suggestions for developing daily schedules for individuals who need support in engaging in leisure and social activities, not just activities of daily living and skill acquisition. It is not uncommon for individuals with ID/DD to need assistance with engaging in leisure activities, particularly independent leisure activities, which can require similar levels of support as when teaching new skills.

4:30 PM – 5:45 PM

Transition from School to Work

Erin Riehle

Patricia Morrison, Director, Division of Registered Apprenticeship

Chanda Hermanson

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

As a student with Down syndrome approaches the end of their high school experience, they are faced with many choices. Should I pursue post-secondary education? Should I enter the workforce? Should I pursue vocational training? This session features experts from vocational rehabilitation and other workforce development organizations who will discuss these options and more.



Friday, April 16, 2021

2:00 – 3:15 PM

Action You Can Take on Medical Care and Research

Hampus Hillerstrom, President & CEO, LuMind IDSC

James Hendrix, Chief Scientific Officer, LuMind IDSC

Led by LuMind IDSC, this session will provide information on two medical care tools, the Down syndrome Clinic to You (DSC2U, now available commercially) and the Q&A with Dr. Brian Chicoine. The session will also provide information on the new myDSC platform with 400+ diverse resources for families. The session will also share examples of research from home opportunities (GoalNav, MapHabit, survey caregivers of adults) and highlight the critical need for research participation by people with Down syndrome.