



## 2019 DSG Keys To Success Conference Schedule January 26<sup>th</sup>, 2019 at the Overland Park Convention Center

8:00 – 8:30AM Registration, Continental Breakfast and Meet the Vendors

8:30 – 9:30AM Keynote Speakers – Rachel Osterbach & Laurie Osterbach  
Megan Bomgaars & Kris Bomgaars

9:30 - 10:45 AM Breakout Session #1

**Basic of Behavior, Stacy Taylor** - In this session learn more about how behavior can be frustrating and confusing, but the good news is that there is a science of learning and behavior that can help you better address any behavioral concerns you have no matter what age or stage your child is in. It is important to understand the basics of behavior because once you do, you can apply them to a variety of situations in your child's life.

**National DS Clinical Research Updates, Weir, Hatcher, Randazzo, Sherman, Kaeser**

This session, led by NDSS President and CEO Sara Weir and Community Outreach and Engagement Manager Colleen Hatcher, will provide information to people with Down syndrome and their families about exciting developments in clinical studies and Down syndrome research. It will feature national speakers who will: (1) provide an overview of recent policy initiatives to improve and expand Down syndrome research; (2) highlight a nationwide research study, open to participation by individuals with Down syndrome, that is helping to understand what causes the extra chromosome 21 to be present, and why some children with Down syndrome are more likely than others to have certain medical problems; and (3) provide information about DS-Connect®, the Down syndrome patent registry hosted by the National Institutes of Health, which is a resource where people with Down syndrome and their families can connect with research, health care providers, and more.

**Multi-Sensory Math Strategies, Courtney Heigle** – This session will introduce educators and parents to strategies and tools that can be used with all learners to reinforce foundational math skills by providing tools and strategies for making abstract concepts concrete and experiential. Strategies and tools for number sense, early addition and subtraction, telling time, counting money, computation with regrouping and introductory multiplication and division will be presented. This session will also address ways to introduce these strategies into your child's classroom and incorporate supportive tools into their individualized educational program.

**Mediocre Mom's Guide to Parenting, Stephanie Meredith** - Parents of kids with Down syndrome don't need to be superheroes to be great. Parents can allow their kids to eat junk food sometimes, watch TV, and play video games, and their kids can still be amazing by being treated like any other kid. I'm a slacker who used to fudge therapy sometimes and didn't always finish the round of antibiotics, but the one thing I've been consistent about is advocating for inclusion at school, church, and extracurricular activities. We always assumed he belonged wherever he wanted to be (and provided support where needed), and most people rolled with it. So this session will discuss how you too can raise a child with Down syndrome as a mediocre parent, and sometimes your mediocrity can even help your kid be more independent. We'll also talk about how most people will also just roll with it if we assume our child belongs and provide support when they need it.

**What You Need to Know About ABLE, Matt Syverson, Tom Treacy** - Have you heard about the ABLE Account? It's a new opportunity for people with disabilities to supplement their SSI and Medicaid arrangements with tax free resources that they control for a wide array of living expenses throughout their lifetimes. People with disabilities from all ages and stages can benefit from this important presentation.

**11:00 – 12:15 PM**

**Breakout session #2**

**Toilet Training Tips and Tricks, Stacy Taylor** - Toilet training is a definite rite of passage for children and parents. Don't let this important skill become frustrating for your family. Come and learn some practical tips and tricks and set everyone up for success!

**Local DS Research Updates, Talib, Kitchen, Funk, Jones** - This session will focus on current and future opportunities in research conducted by local researchers at Children Mercy to ensure that children with Down syndrome have access to the best treatments with minimum side effects of the medications, early diagnosis of associated conditions to allow for early intervention and improve the quality of lives of children with Down syndrome.

**IEP's 101, Sarah Mai**- Are you new to the IEP process? DSG is here to assist you! Come to this session to learn the components of the IEP document and the steps of the IEP process. Attendees will also learn tips for communication with their IEP team and how to collaborate and establish individualized goals. Presenter has 15 years of experience serving families of children with DS and a decade of experience in the school setting.

**Q&A with Born This Way Cast Members**- Learn more about our keynote speakers and how they became successful adults who are achieving their dreams.

**Improving Feeding Skills in Children w/DS, Minnie Bray** -Children with Ds often have difficulty with early feeding skills and transitioning from a liquid diet to table foods. Learn more about how caregivers can support the development of appropriate feeding skills from infancy through childhood. Gain an understanding of common maladaptive feeding behaviors seen in children with Ds and how we can help adequate feeding skills develop. Learn more about how to make mealtimes successful for all family members.

**12:15 – 1:00 PM Lunch and Visiting with Vendors**

**1:15 – 2:30 PM Breakout Session #3**

**Developing Behavior Plans Like a Boss, Stacy Taylor**- What do you do when problem behaviors occur? Are these behaviors dysfunctional? Absolutely not! Participants will learn how to find the function in what many consider "dysfunctional" behavior. We will discuss prevention and effective consequences. These principles and strategies are best practices in the science of learning and behavior and they are exactly what you need to understand in order to help develop and implement an effective plan for your child.

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**HELP! My Child Isn't Talking, Betsy Sylvester**- Is your child with DS older than 5 and still not talking? Do they have a few words they use but are easily frustrated because others don't understand them? Attendees will learn how to enhance and facilitate communication, increase oral motor skills, build vocabulary and lengthen utterances. Verbal communication will be the goal but

along the way you may also consider sign language or communication devices to support communication.

**Fostering Independence in Children with DS, Amy Allison-** Is your student/child with DS prompt, praise and reward dependent? Do you spend a significant amount of your day trying to keep the student on task? Learn strategies for structuring your home life and classroom to promote independence and on task behavior.

**Medical Advances for Children/Adults with DS, Talib, Kitchin –** Children's Mercy Hospital physicians will provide an update on the Health supervision Guidelines for Adults and children with Down syndrome and discuss medical advances in care of children with condition such as regression, behavior problems, joint problems, respiratory illnesses, OSA and obesity.

**2:30 – 2:45 PM Afternoon Break with Vendors**

**2:45 – 4:00 PM Breakout Session #4**

**Q&A with Born This Way Cast Members -** Learn more about our keynote speakers and how they became successful adults who are achieving their dreams

**Transition Planning and Entitlement Programs, Scott Adams -** There are a number of issues to address between the ages of 16 and 25 for families who have a child with special needs. We will cover the transition from school to adulthood and outline why Social Security and Medicaid are critical components to enhancing the quality of life for our children. We will also review the regulations involved with retaining Social Security.

We will discuss the advantages and disadvantages of graduating at age 18 and the transition from the school system to adulthood. The eventual transition from living at home into an independent living or a residential setting will be worked through and work programs discussed. You will walk out with a better understanding of the resources available prior to age 18 and more importantly beyond age 18.

Guardianship will be defined and we'll consider what alternatives may be available. The workshop will cover why you need to develop a continuity of care plan for when you are no longer able to take care of your child or children. We'll also illustrate how Special Needs Trusts help to ensure the quality of life for your child when you are no longer able to provide support.

**Social Language Skills for People with DS, Betsy Sylvester-** We will discuss the individuals with Down syndrome are known for their openness and desire to be social with others. However, they often lack the pragmatic skills to appropriately engage in social situations. This presentation will discuss the basics of Pragmatic Language, how it is seen in our population, and strategies to address difficulties across the lifespan.

**Building Dreams and Skills for Employment, Stephanie Meredith-** Learn about how to start cultivating a child's dreams for the future and employment skills throughout the school years by taking real, meaningful steps all along the way. This presentation will share strategies and examples for raising expectations and building employment skills as a youth through volunteer work, household responsibilities, and extra-curricular activities. You will come away with a list of employment resources and an action plan for what you can do today as the parent of a child in school and ideas for future steps toward employment.

**DS and Autism, Natalie Hautain and Brian Belden -** Despite the reputation of children with Down Syndrome (DS) having a friendly and sociable temperament, there is growing consensus that a significant proportion of them also meet criteria for a diagnosis of Autism Spectrum Disorder (ASD)—a disorder characterized by marked impairment in social-communication skills. The unique developmental trajectory and intellectual disability associated with DS make the evaluation of co-occurring ASD particularly challenging for clinicians, yet the additional diagnosis of ASD carries important implications for the child's treatment and services, as well as for their family members' adjustment. This presentation will review the scientific literature on individuals with DS-ASD, describing what is known about the prevalence, risk factors, developmental trajectory, and characteristics. Strategies and recommendations for evaluating autism in children with DS will be discussed, and the literature on intervention will be summarized. Finally, important avenues for future research in this relatively new field of study will be identified.

**4:15 – 4:30 PM Closing Remarks and Prize Drawing**