



North Carolina
**Down Syndrome
Conference**

**2021 North Carolina
Down Syndrome
Conference**

SATURDAY
NOVEMBER

13

Presented Virtually by
The North Carolina Down Syndrome Alliance

November 13, 2021 North Carolina Down Syndrome Conference

Plenary Presentation 8:30 AM

The Groove in Individuals with Down Syndrome

Session One 10:45

Social Security Disability Insurance and Supplemental Security Income benefits: What you need to know

Sleepless Children and Exhausted Parents – Understanding Sleep Problems and Exploring Options

Is it Sensory or is it Behavior?

Lunch with Friends 12:30 PM

Birth - 3

Pre-K to Elementary School Age

Middle School/Teen

Teen to Transition to Adulthood

Session 2 1:15 PM

Ditching the Diapers: How to Move Forward with Toileting

Let's Talk: Sexual Health Education

Ds & Autism: Recognizing the signs, understanding the process, and behavioral supports

Session 3 3:00 PM

The Down Syndrome Diet

What Happens When I'm Gone? Special Needs Planning for North Carolina Parents

Down Syndrome: The Early Years

Alzheimer's and Dementia in Down Syndrome



2021 North Carolina Down Syndrome Conference Learning creative ways to help people with Down syndrome and developmental disabilities reach their potential

Welcome and thank you for joining us for the 2021 North Carolina Down Syndrome Conference. The North Carolina Down Syndrome Alliance (NCDSA) mission is to empower, connect, and support the lifespan of individuals with Down syndrome, their families, and the community through outreach, advocacy, and education in North Carolina. The Staff and Board of Directors of the NCDSA believe we have met that goal by organizing a full day of information and resources to help you create the future you want for the individual with Down syndrome in your life. We have brought together professionals from multiple disciplines to share their knowledge and experience to help you envision a world of possibilities and help you navigate your way there. Whether you are new to this journey and prefer your plans are organized years in advance or you have been traveling this road for years and you need new resources and ideas, the North Carolina Down Syndrome Conference will provide you with the materials you need to take the next step or finalize existing plans.

The Staff and Board of Directors of the NCDSA would like to thank everyone who worked diligently to make the 2021 North Carolina Down Syndrome Conference a success. NCDSA sincerely appreciates our generous sponsors, presenters, and volunteer committee members.

North Carolina Down Syndrome Alliance

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The Groove in Individuals with Down Syndrome

Presenters: Brian Chicoine MD & Katie Frank, Ph.D., OTR/L

The groove is a common characteristic seen in individuals with Down syndrome of all ages. The groove is a preference for sameness, repetition, or routine. Drs. Chicoine and Frank will describe advantages and disadvantages of the groove, strategies to address problematic grooves, and methods to establish new grooves.

Katie Frank, PhD, OTR/L

Dr. Frank has worked as an occupational therapist at the Adult Down Syndrome Center since 2016 and in the field of occupational therapy since 2001. She earned her undergraduate degree in occupational therapy from Saint Louis University and her master's degree from University of Indianapolis. She earned her PhD in Disability Studies from the University of Illinois at Chicago. Dr. Frank's experience includes treatment and evaluation as well as conducting trainings and leading groups. In addition, she presents locally and nationally, does research, and shares her work in peer-reviewed journals.

Brian Chicoine, MD

Dr. Chicoine is the Medical Director and Co-Founder of the Adult Down Syndrome Center, which has served and documented the health and psychosocial needs of over 6000 adolescents and adults with Down syndrome since its inception in 1992. He is on the faculty of Family Medicine at Advocate Lutheran General Hospital. Dr. Chicoine graduated from Loyola University Stritch School of Medicine and completed his Family Medicine residency at Lutheran General Hospital. Dr. Chicoine has provided medical care for adults with intellectual disabilities for over 30 years and has presented and written extensively on caring for adults with Down syndrome.

Breakout Session One

Is it Sensory or is it Behavior?

Presenter: Katie Frank, Ph.D., OTR/L

Has anyone ever suggested your loved one with Down syndrome has sensory processing deficits? Can transitioning between activities or places be challenging? Are certain medical procedures difficult to complete? Do you find that your loved one seeks out sensory input or maybe even tries to avoid it all together? Sensory processing impacts all of us, but for many individuals with Down syndrome, the inability to control their sensory needs can impact their independence and community participation. This workshop will describe sensory processing and the different ways sensory processing can impact individuals with DS as they age. Tips for deciding if it is truly a sensory need or actually a behavior will be shared. Practical sensory activities that can be incorporated daily as well as affordable equipment suggestions will be provided.

Dr. Frank has worked as an occupational therapist at the Adult Down Syndrome Center since 2016 and in the field of occupational therapy since 2001. She earned her undergraduate degree in occupational therapy from Saint Louis University and her master's degree from University of Indianapolis. She earned her PhD in Disability Studies from the University of Illinois at Chicago. Dr. Frank's experience includes treatment and evaluation as well as conducting trainings and leading groups. In addition, she presents locally and nationally, does research, and shares her work in peer-reviewed journals.

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Sleepless Children and Exhausted Parents – Understanding Sleep Problems and Exploring Options

Presenter: Terry Katz Ph. D.

Abstract: This talk is designed for parents and providers who want to learn more about sleep, why children with special needs may have difficulty sleeping, and what they can do to help everyone in the family sleep better. The session will be informative and practical, providing families with ideas that they can use at home.

Objectives:

1. Review information about the basics of sleep
2. Discuss reasons why children with special needs have difficulty with sleep
3. Identify treatment strategies that will help children (and their families!) sleep better

Outline:

- I. Sleep basics
- II. Common sleep difficulties
- III. How poor sleep impacts day-to-day functioning
- IV. Review of medical conditions that impact sleep
- V. Discussion of common challenges
- VI. Behavioral strategies that help with sleep
- VII. How to handle sleep resistance and anxiety
- VIII. Ways to address nighttime waking
- IX. Resources

*Terry Katz is a licensed psychologist and Senior Instructor with Distinction who has been privileged to work with children with developmental disabilities and their families for over 30 years. She co-founded a sleep behavior clinic in 2009 and a toileting clinic in 2011 for children with special needs at Children's Hospital Colorado. She has worked in both clinics since they were first established. Dr. Katz has helped develop a number of educational materials for caregivers. These include sleep and toileting toolkits for Autism Speaks and a book on sleep, *Solving Sleep Problems in Children with Autism Spectrum Disorders: A Guide for Frazzled Families*. She also wrote a chapter on sleep in the book *When Down Syndrome and Autism Intersect: A Guide for Parents and Professionals* (edited by M Froehlke and R.S. Zaborek.) She just recently published a book on toileting: *Potty Time for Kids with Down Syndrome: Lose the Diapers, Not Your Patience*.*

Social Security Disability Insurance and Supplemental Security Income benefits: What you need to know

Presenter: David J. Melton

The Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs both pay benefits to people with a disability. The two programs differ in fundamental ways and this session will discuss the distinctions, how both children and adults may qualify, how to file an application for benefits, and what you can do now or in the future to access these benefits.

Mr. Melton is magna cum laude graduate of Northwestern State University located in Natchitoches, LA. While attending college he was a member of the Sociology and Anthropology Clubs, Kappa Sigma fraternity, and President of the Association of Men Students.

Mr. Melton began his career with the Social Security Administration in September 1976 as a Claims Representative in the New Iberia, LA field office. During August 1979 he transferred to the Lake Charles, LA District Office and worked there as a Claims Representative, Operations Analyst, and Operations Supervisor. In June 1989, he transferred to the Winchester VA District Office. In June 1990, he was selected as the Field Representative for a 14-county district in Virginia and West Virginia that is serviced by the Winchester, Manassas, Culpeper and Martinsburg SSA field offices. He was responsible for the coordination of public information & education activities throughout the district. On March 6, 2005, Mr. Melton was selected as a Public Affairs Specialist for the Washington, D.C. Metropolitan Area. As a member of a 3-person public information team working in cooperation with 14 offices serving the District of Columbia, Maryland, Virginia and West Virginia, he is involved in a variety of public affairs activities. Through the establishment and maintenance of networks of

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working relationships, he consults with a wide variety of media outlets, governmental entities, special interest groups and key employers. He ensures the public is properly informed as to the solvency, direction and purpose of Social Security Administration programs. Mr. Melton also served as the Acting District Manager of the Martinsburg WV District Office on two occasions.

Breakout Session Two

Ditching the Diapers: How to Move Forward with Toileting

Presenter: Terry Katz Ph. D.

Abstract: This presentation will cover issues related to toileting including the challenges involved in toilet training children with special needs and useful and practical strategies to teach this important skill.

Objectives:

1. Understand the challenges involved in toilet training individuals with special needs
2. Discuss key components of a successful toileting program
3. Review materials and resources for families

Outline:

- I. Determining toilet readiness
- II. Review of medical considerations
- III. Discussion of common challenges
- IV. Presentation of strategies, tools, and techniques
- V. How to handle toilet refusal and anxiety
- VI. Using the toilet away from home
- VII. Ways to address bedwetting
- VIII. Resources

*Terry Katz is a licensed psychologist and Senior Instructor with Distinction who has been privileged to work with children with developmental disabilities and their families for over 30 years. She co-founded a sleep behavior clinic in 2009 and a toileting clinic in 2011 for children with special needs at Children's Hospital Colorado. She has worked in both clinics since they were first established. Dr. Katz has helped develop a number of educational materials for caregivers. These include sleep and toileting toolkits for Autism Speaks and a book on sleep, *Solving Sleep Problems in Children with Autism Spectrum Disorders: A Guide for Frazzled Families*. She also wrote a chapter on sleep in the book *When Down Syndrome and Autism Intersect: A Guide for Parents and Professionals* (edited by M Froehlke and R.S. Zaborek.) She just recently published a book on toileting: *Potty Time for Kids with Down Syndrome: Lose the Diapers, Not Your Patience*.*

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Down syndrome with comorbid autism spectrum disorder: Recognizing the signs, understanding the diagnostic process, and exploring options for behavioral supports

Presenters: Nancy Raitano Lee, Ph.D. and Taralee Hamner, PhD

About 20% of children with Down syndrome meet criteria for a co-occurring diagnosis of autism spectrum disorder (ASD). However, less is known about this group than children with either condition in isolation. This session will describe the signs and symptoms of ASD in children with Down syndrome as well as the diagnostic process. During the session, research on the learning and behavior challenges that may be experienced by children Down syndrome and co-occurring ASD will be discussed. Suggestions for the types of behavioral supports that may benefit children with Down syndrome and co-occurring ASD will be provided. Additionally, information about empirically supported interventions for ASD will be described in order to introduce attendees to the types of approaches that may be helpful for children with Down syndrome and co-occurring ASD.

Nancy Raitano Lee, PhD, is a licensed psychologist and associate professor in the Department of Psychological and Brain Sciences at Drexel University. She received her Bachelor of Science Degree in Human Development and Family Studies from Cornell University and her doctorate in Child Clinical Psychology from the University of Denver. Her clinical training includes the completion of a pre-doctoral internship at the Children's Hospital of Colorado and a post-doctoral fellowship at the University of Colorado School of Medicine's Center for Excellence in Developmental Disabilities. As a postdoctoral fellow, she received specialized clinical training in the diagnosis and treatment of neurodevelopmental disorders, with a particular emphasis on diagnosing autism spectrum disorder (ASD) in young children with genetic disorders associated with intellectual disability, such as Down syndrome. Following her training in psychology, Dr. Lee completed a fellowship at the National Institute of Mental Health focused on the use of structural neuroimaging to study the developing brain in youth with Down syndrome and other genetic disorders as well as children with typical development. Dr. Lee currently leads the LADDER (Learning and Developmental Disabilities Educational Neuropsychology Research) Lab at Drexel where she conducts both clinical and translational research on neurodevelopmental disorders, with a particular emphasis on neurogenetic syndromes. She has published on executive function, language, and ASD symptoms in youth with Down syndrome and those with sex chromosome disorders. She has also published research on the developing brain in these groups. Dr. Lee's research has been funded by the Lejeune Foundation and the National Institutes of Health. The long-term goal of her research is to identify novel targets of treatment to ameliorate the cognitive weaknesses that characterize different neurodevelopmental disorders in order to optimize outcomes and quality of life for these groups.

Taralee Hamner, PhD, is a postdoctoral fellow in pediatric neuropsychology at Nationwide Children's Hospital. She received her bachelor's in Psychology at Georgia State University. After working at the Marcus Autism Center in Atlanta, Georgia, she obtained her masters and doctorate degrees in Clinical Psychology at Drexel University in Philadelphia, Pennsylvania, under mentorship of Dr. Nancy Raitano Lee. She completed a doctoral internship at the Kennedy Krieger Institute / Johns Hopkins Hospital in Baltimore, Maryland. Taralee has expertise in neurodevelopmental disorders with a particular passion for working with those who have special healthcare needs or co-occurring conditions. She has published on brain development as well as cognitive and autism profiles for children with Down syndrome. Clinically, she has provided early intervention to children with co-occurring Down syndrome and ASD. Her research focuses on early social learning across conditions in order to inform interventions and promote quality of life for children and their families.

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Let's Talk: Sexual Health Education

Presenter: Margaret DeRamus, MS, CCC-SLP

Sexuality and relationship education is *more* than teaching about sexual activity. It should be an ongoing process starting early and encompassing basic body awareness, health information, communication skills, decision making, and social skills. However, discussing sexuality with children (and adult children!) is challenging for many parents and caregivers. To overcome this barrier and gain comfort and confidence in addressing uncomfortable topics, this session will provide parents and caregivers support and resources to help them begin to talk to their tweens and teens about sexual development and health. Specific topics addressed in this session will include how bodies change during puberty, how hormones affect one both physically and emotionally, and the importance of hygiene.

Margaret DeRamus (duh-RAY-muhs) is a licensed speech-language pathologist at the Carolina Institute for Developmental Disabilities (CIDD) at the University of North Carolina at Chapel Hill. She has over two decades of experience working with individuals with intellectual and developmental disabilities (IDD). In addition to providing direct clinical services, she has been involved with research focusing on individuals with a range of developmental disabilities. Ms. DeRamus co-facilitates a modified/accessible sexual health education (SHE) group for youth and adults with IDD and their families/caregivers. In addition, she co-leads a community partners workgroup to address the sexual violence epidemic in the IDD community. Ms. DeRamus is a member of the Association of University Centers on Disabilities (AUCD) Sexual Health special interest group.

Breakout Session Three

What Happens When I'm Gone? Special Needs Planning for North Carolina Parents

Presenter: Paul Yokabitus

Paul Yokabitus will be answering one of the most frequently asked questions and concerns of parents of children with Down syndrome and other disabilities: "What Happens When I'm Gone? This session will introduce and explain important legal planning tools and strategies to help give parents some peace of mind and a secure future for their loved one. Paul will cover information that every parent should know to help them protect their children in a life without them.

Paul Yokabitus is a Special Needs Planning Lawyer and owner of Cary Estate Planning in Cary, North Carolina. Originally from Grand Rapids, Michigan, Paul found his way to the Triangle where he attended Campbell University School of Law and later planted his roots in the Cary community. Paul helps families across the State of North Carolina with proactive legal planning like Special Needs Trusts and Adult Guardianship, as well as traditional estate planning. He makes the planning process easier to understand and navigate by taking an advisory and educational approach.

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The Down Syndrome Diet

Presenter: Jennifer Kimes Psy. D

Discover how to eliminate or reduce the symptomatology of many of the health and developmental issues impacting children and adults with Down syndrome including autism, attention deficit disorder, diabetes, hypothyroidism and even Alzheimer's Dementia. A literature review implicating the high sugar and carbohydrate diet with many of the gastrointestinal, neurological, endocrine and immune system dysfunctions associated with Down syndrome will be presented. A synthesis of recent research regarding dietary interventions will be discussed and recommendations from health care providers will be reviewed to see how we clinicians and caregivers can impact the course of some of the healthcare epidemics affecting individuals with Down syndrome.

Dr. Kimes is the Executive Director of Educational and Clinical Services at Down Syndrome of Louisville where she has served in a variety of roles for over 14 years. She provides direct early intervention services, as well as behavioral supports and family support services. Dr. Kimes also provides diagnostic clarification for co-occurring issues in her role as a licensed psychologist. She holds Bachelor's Degrees in Early Childhood and Elementary Education and a Doctoral Degree in Clinical Psychology. However, her favorite role is as mother of four children, one of whom happens to have Down syndrome and Autism.

Alzheimer's and Dementia in Down Syndrome

Presenter: James Hendrix, Ph.D.

This presentation will cover the current understanding of Down syndrome associated Alzheimer's disease and will explore the common dementia symptoms. The presentation will also cover the current state of research including the development of potential new treatments. General advice for caregivers will also be included.

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.

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. Before joining the Alzheimer's Association, Dr. Hendrix worked as a medicinal chemist 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 in organic chemistry from Colorado State University.

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Down Syndrome the Early Years

Presenter: Mahala Turner M. ED

Are you new to the journey of parenting a child with Down syndrome? It can often feel overwhelming and confusing to know where to begin or gain a clear understanding of certain needs. This session is ideal for expectant parents, new parents, and caregivers with children up to the age of 3 years old. We will cover some basic Down syndrome facts, but attendees will learn more about:

- Specific healthcare needs of children with Down syndrome
- What therapies to focus on as part of early intervention
- Benefits your child may qualify to receive
- How to become your child's best advocate
- Family life and how to support yourself and your loved ones
- The process of transitioning from early intervention to Pre-k services

We will also look ahead to the future. Attendees will be able to prioritize next steps for the overall care of their loved one with Down syndrome. Time will be allotted for Q&A so bring your questions and concerns.

Mahala Turner holds a bachelor's and master's degree in Special Education. Additionally, she received a certification in School Psychometry that allows her to administer and interpret educational assessments. Mahala has twelve years of experience as an educator in a variety of settings, grade levels, and educational environments. Currently, Mahala is the Family Support Specialist for the North Carolina Down Syndrome Alliance (NCDSA) providing assistance to families of children with Down syndrome across the lifespan. Through her work at the NCDSA, she is the facilitator of the North Carolina First Call Program. The First Call Program provides support to families when they receive a diagnosis of Down syndrome and welcomes new families with resources and information, connects new families with trained parent mentors, and nurtures an online space and social events for families to connect and communicate with one another. She is the teacher and facilitator of The Learning Program, a program that uses effective teaching strategies and customized materials to support families in the educational process of teaching their child reading and math. Mahala also plans medical outreach efforts by providing accurate and up to date information to medical providers ensuring they are prepared to deliver a diagnosis of Down syndrome and the best care possible for patients with Down syndrome. Mahala is also the parent to ten-year-old twins and four-year-old Beau. Beau just happens to have Down syndrome.

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The Groove in People with Down Syndrome

Adult Down Syndrome Center

November 13, 2021 | Brian Chicoine, MD and Katie Frank, PhD, OTR/L



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Adult Down Syndrome Center

Park Ridge, IL



Our mission is to enhance the well-being of people with Down syndrome who are 12 and older by using a team approach to provide comprehensive, holistic, community-based health care services.



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Disclaimer

This information is provided for educational purposes only and is not intended to serve as a substitute for a medical, psychiatric, mental health, or behavioral evaluation, diagnosis, or treatment plan by a qualified professional.



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Objectives

- Define the groove
- Outline advantages and disadvantages of the groove
- Describe problematic grooves, including the diagnosis and treatment of OCD
- Share strategies to address problematic grooves and establish new grooves



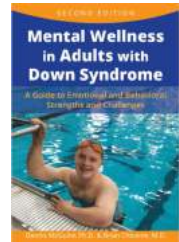
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What is the groove?

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Definition

- “Set pattern or routine in one’s actions or thoughts” ([McGuire & Chicoine, 2021, pg. 146](#))
- Preference for sameness, repetition, or routine



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Advantages

- Gives order and structure in daily life
- Can increase independence
- Can enhance performance and function
- Can help people manage stress

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Examples of grooves

- Using a precise and unchanging routine to complete tasks
- Meticulous care of room and personal items
 - “Everything has its place”
- Closing doors and blinds, turning lights off
- Repeating familiar phrases
- Listening to the same music, watching the same TV shows or movies

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Possible disadvantages

- Inflexibility
- Difficulty with transitions
- Difficulty with disruptions
- Difficulty generalizing skills and knowledge

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Problematic grooves

- Groove becomes less functional
- Grooves becomes more (or less) rigid
- Potential causes
 - Stress
 - Pain or physical ailment
 - Mental illness
 - Dementia
 - Communication
 - Sensory
 - Environment

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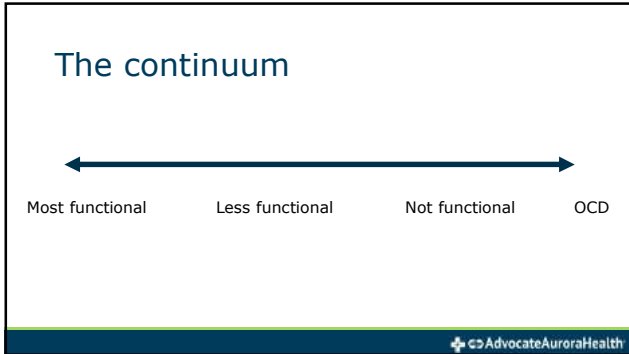
Managing the groove

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When should the groove be challenged?

- When it impacts safety
- When it impacts function
- When it impacts the family
- Periodically to promote flexibility
- In certain environments

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Strategies to address problematic grooves and/or establish new grooves

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Educate others

- Not about changing the person, but changing the environment
- Educate those who interact with the person with DS

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Encourage flexibility

- Pick a behavior that is possible to change
- Pick a time to encourage flexibility
- Provide alternative behaviors that are more appropriate
- To teach a new behavior, break the task down into manageable steps
- Use visual supports
- Make sure all participants are open to change and not stressed during new teaching
- Build the term "flexible" into exchanges and point out when others are being "flexible"

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Set expectations

- Give choices
- Set guidelines with the individual
- Use visuals
- Set time limits

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Practice social skills

- Compromise
- Handling being told no
- Flexible thinking
- Asking for help
- Managing emotions
- Socially appropriate behavior/manners

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Implementation

- Prepare the body
- Pair the problematic groove with another desired activity
- Pair changes together

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Common groove scenarios

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Lengthy routines

- Morning routine/Bedtime routine
 - Give choices
 - Set guidelines
 - Set time limits
 - Use visual supports
- Overall slowness
 - Sensory input
 - Use of visual supports

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Difficulty generalizing skills across different environments

- Location 1 vs Location 2
 - Encourage flexibility
 - Set guidelines
 - Use visual supports
 - Pair changes together

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Difficulty completing job tasks

- Needing to complete tasks in a certain order
 - Educate others about the groove
 - Build in flexibility
 - Set guidelines
 - Practice social skills
- Being interrupted
 - Educate others about the groove
 - Use visuals
 - Practice social skills

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Sitting in the same spot

- Educate others about the groove
- Build in flexibility
- Use visuals/social stories
- Pair the problematic groove with another desired activity
- Practice social skills

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Wearing the same outfit

- Encourage/build in flexibility
- Give choices
- Set guidelines
- Use visuals

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Getting unstuck

- Set guidelines
- Use visuals
- Work with the individual to set time limits
- Sensory/calming strategies
- Pair the problematic groove with another desired activity

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Establishing a new groove

- Set guidelines
- Use visuals
- Pair with another change or preferred activity
- Build in flexibility

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In summary...

- Educate others about the groove
- Encourage/build in flexibility
- Set expectations
- Practice social skills
- Implementation/execution

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Obsessive-compulsive disorder (OCD)

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Presenting concerns

- Repetitive behaviors
- Persistent thoughts
- Impairs function
- Limits opportunities
- Individual often is not upset by the behaviors/thoughts, but family may be
- Individual may get upset if the behaviors/thoughts are blocked or prevented.

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Causes

- Any of the previously mentioned causes for changes in the groove
- Imbalance of neurotransmitters in the brain

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Treatment

- Non-medicinal strategies
- Medicinal strategies
 - Start low, go slow
 - May need more than one medication
 - Medications

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Medications

- Antidepressants
 - Selective serotonin reuptake inhibitors (SSRIs)
 - Serotonin-norepinephrine reuptake inhibitors (SNRIs)
- Benzodiazepines
- Mood stabilizers
 - Anti-epileptic medications (seizure medications)
 - Anti-psychotic medications

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Take away points

- The groove is a preference for sameness or routine.
- There is a continuum from when a groove is the most functional to when it becomes OCD.
- When functional, it can help increase independence with a variety of tasks.
- When less functional, it can lead to lack of flexibility and difficulty with transitions or unexpected changes.
- There are a variety of non-medical strategies that can be used to help a less functional groove get unstuck or establish a new, more functional groove.
- If OCD is diagnosed, it is possible the non-medical strategies will be most effective if also paired with medication.

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Resources

- [Article on the Groove](#)
- [Mental Health Resources](#)
- [Sensory Resources](#)
- [Social Skills Resources](#)

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Resources Library:
adscresources.advocatehealth.com

Facebook:
facebook.com/adultdownsyndromecenter

Email Newsletter:
eepurl.com/c7uV1v

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Q & A

 AdvocateAuroraHealth

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Is it Sensory or is it Behavior?

Katie Frank, PhD, OTR/L
Adult Down Syndrome Center
Park Ridge, Illinois




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Our mission is to enhance the well-being of people with Down syndrome who are 12 and older by using a team approach to provide comprehensive, holistic, community-based health care services.



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Today's agenda

- Discuss sensory processing and how it impacts individuals with Down syndrome.
- How to determine whether it is a sensory need or a behavioral issue.
- Share practical sensory activities and suggestions for affordable equipment.

Is it Sensory or is it Behavior?

What is behavior?

- Anything that an organism does involving action and response to stimuli.
- That way in which an organism functions or operates.
- Everything we do is behavior!

Challenging/Problematic behaviors

- Aggression toward self or others.
- Destruction of property.
- Defiance, disobedience, or non-compliance.
- Tantrums or meltdowns.
- Manipulation of situation for own benefit.
- Disregarding the needs of others.
- Disrespecting authority.
- Non-conformity with social norms or expectations.

Rule out medical first

- Sleep
- GI issues
- Pain
- Celiac disease
- Food or environmental allergies
- Language delays
- Anxiety/OCD/other mental health issues
- Seizures/neurological conditions

Sensory or behavior?

- It can be both.
- Sometimes the only way to tell depends on which interventions are working...either sensory or behavior management.
- Sensory input should NEVER be removed as part of a behavior plan. Input is not a reward either.
- An approach that utilizes both sensory input and behavior management techniques typically work best.

Is it sensory?

Questions to ask yourself...

- Does the person's action disrupt your life? For example, do you avoid certain places because of noises, crowds or smells?
- Does the action occur with *everyone*?
- Does the person stop the action when given a reward?

“The hallmark of individuals with SPD is that their sensory difficulties are *chronic* and *disrupt* their everyday life. Children with SPD get “stuck.” And no matter what strategies a determined parent uses—stickers on a chart, praise, discipline, or some technique another parent said worked magic for them—kids with SPD stay stuck.”

(Miller, 2006)



Common reactions

Behavior

- Person can turn reaction on and off like a switch.
- Cry or tantrum, but usually without tears.
- Responds well to structure and boundaries.

Sensory

- Unable to calm self down immediately, even after they get what they want.
- Response is the same with everyone.

Tricks to help

Behavior

- Clearly defined rules and expectations.
- Consistent rewards and reasonable consequences.
- **CONSISTENCY.**

Sensory

- Provide sensory input at regular intervals. About once every 2 hours or so.
- Positive time out in a calm space.
- Determine sensory triggers and find ways to avoid/modify/adapt to them.

What is Sensory Processing Disorder?

Sensory processing disorder (SPD)

- Umbrella term to cover a variety of neurological disabilities
- Problems with the ability to process information received through the senses which **impact the ability for a person to function in their daily life.**
- SPD happens in the CNS which starts with the brain. When processing is disorderly, the brain cannot do its most important job of organizing sensory messages.

What SPD is NOT

- An eating disorder
- Anxiety
- ADHD
- Bipolar disorder
- Obsessive-compulsive disorder
- Autism Spectrum disorder

There are 8 senses!

Far Sensory Systems

- Touch
- Sight
- Smell
- Sound
- Taste

Near Sensory Systems

- Vestibular
- Proprioception
- Interoception

Types of SPD

- Sensory Modulation Problems
 - how a person regulates responses to sensations.
- Sensory Discrimination Disorders
 - how a person may have difficulty in distinguishing one sensation from another (vision, hearing, touch, taste/smell, position/movement).
- Sensory-Based Motor Problems
 - how a person may position the body in unusual ways and have difficulty in conceiving of an action to do, planning how to organize and move the body, and carrying out a plan.

Sensory modulation problems

- Over-responsive (aka sensory avoider or sensory defensive)
- Under-responsive (aka sensory disregarder)
- Sensory Craver (aka sensory seeker)

Red flags of sensory over-responsivity (SOR)

frequently triggered by:

- Textures.
- Noise or sounds, especially loud or unexpected.
- Movement (swings, slides, being upside down).
- Bright lights.
- Background noise.
- Smells or fragrances.
- Having hair or nails cut.
- Being dirty.



Behaviors associated with SOR

- Aggressive or impulsive.
- Irritable, fussy, or moody.
- Avoids group activities and has difficulty forming relationships.
- Excessively cautious and afraid to try new things.
- Upset by transitions and unexpected changes.

Red flags of sensory under-responsivity (SUR)

especially when seriously hurt.

- Doesn't notice if someone else touches them.
- Doesn't like trying new physical activities.
- Prefers sedentary activities.
- Slow or unmotivated to learn new skills-even skills like dressing or self-feeding.
- Often unaware of what is going on around them.
- Doesn't notice when they are dirty.



Behaviors associated with SUR

- Passive, quiet, withdrawn.
- Difficult to engage in conversation.
- Easily lost in own fantasy world.
- Easily exhausted.
- Excessively slow to respond to directions.
- Uninterested in exploring games or objects.

Red flags of sensory craving



- Constantly on the move. Difficulty sitting still.
- Often play is rough or risky. No regard for safety.
- Strong preference for spinning, swinging, rolling.
- Constantly touching others. No regard for personal space.
- Poor turn taking and often interrupts others.
- Listens to TV or music very loud.
- Licks, sucks, or chews on non-edibles.

Behaviors associated with sensory craving

- Becomes angry or even explosive when required to sit still or stop a physical activity.
- Intense, demanding, and hard to calm.
- Prone to create situations others perceive as bad or dangerous.
- Excessively affectionate physically.

Sensory modulation scenario

- Touch
 - Over-responsive
 - Avoids touching or being touched. Reacts with fight or flight response
 - Under-responsive
 - Is unaware of a messy face or hands. Doesn't recognize they have been touched. Does not notice how things feel or often drop objects.
 - Sensory craver
 - Wallows in mud, dumps toys, chews on inedible objects, bumps into people.

Sensory discrimination disorder (SDD)

- Touch
- Movement and balance
- Body position and muscle control
- Sights
- Sounds
- Smells and tastes

Red flags of SDD



- Unable to determine where someone touches them; poor body awareness.
- Cannot feel self falling.
- Klutzy, difficulty grading movements.
- Difficulty judging where things are in space; difficulty finding things that match.
- Recognizing differences between sounds, sings out of tune, poor auditory discrimination-easily distracted by other sounds.
- Cannot distinguish smells from one another or tastes like spicy or sweet-may refuse to eat food based on how it looks.

Behaviors associated with SDD

- Difficulty following directions.
- Gets lost easily.
- Aversion to playing with puzzles or other visual games.
- Difficulty completing worksheets in an organized manner.
- Easily frustrated when unable to discriminate information.
- Need for instructions to be repeated.
- Need to more time than other children when getting ready, transitioning, or completing tasks.

Sensory-based motor problems (SBMD)

- Postural Disorder
 - Difficulty maintaining control over body.
 - Impaired perception of body position in space.
 - Often seen with SUR.
- Praxis or dyspraxia
 - Difficulty translating sensory information into physical movement.
 - Difficulty thinking of, planning and/or executing skilled movements.

Red flags of SBMD



Postural Disorder

- Poor muscle tone.
- Holds head at desk when working.
- Difficulty playing tug of war.
- Doesn't shift body to catch a ball.
- Difficulty using both hands together like when using scissors.

Dyspraxia

- Slow to meet milestones.
- Difficulty with multi-step tasks.
- Difficulty learning new motor skills.
- Clumsy, awkward, or accident prone.
- Frequently breaks toys or other objects unintentionally.
- Struggles with handwriting.
- Difficulty keeping personal spaces organized.

Behaviors associated with SBMD

Postural Disorder

- Appearing lazy or unmotivated.
- Appearing weak or limp.
- Tiring easily.
- Avoids physical activity.
- Difficulty keeping up with peers in a game.

Dyspraxia

- Messy eater.
- Prefer to fantasize about what to do instead of doing it.
- Disheveled.
- Difficulty interacting with others while playing.
- Inability to organize belongings.
- May appear to ignore instructions.

Common sensory deficits in DS

- **Tactile**- not tolerating certain clothing types; not tolerating lotion on skin or brushing teeth; not tolerating water on face
- **Auditory**- likes their music loud, but may not tolerate other loud sounds
- **Visual**- poor depth perception making stairs an uneven surfaces challenging
- **Proprioception**- stuff food in mouth; difficulty regulating force
- **Interoception**- difficulty feeling thirst or satiation; difficulty with toilet training

Who can help?

What is occupational therapy (OT)?

- Health profession concerned with how people function in their respective roles and how they perform meaningful activities.
- “Occupation” is any activity in which one engages throughout the day.
- An OT will assess what is interfering with a person’s ability to engage in activities and often times it can be an impaired sensory system.

Role of an OT in sensory processing

- An OT will assess what is interfering with a person's ability to engage in activities and often times it can be an impaired sensory system.
- Not all OTs are as comfortable working with individuals who have sensory dysfunction.
- While there are formal assessments to "diagnose" Sensory Processing deficits, individuals with DS may not tolerate them. They are hours long.

Testing for sensory processing differences

- Sensory Processing Measure
- Sensory Profile 2
- SIPT

- The Sensory Symptoms Checklist

<https://sensationalbrain.com/pdf/SB-sensory-checklist.pdf>

(version in English and Spanish)

The image shows two pages of the Sensory Symptoms Checklist (SSC) form. The left page is the front side, titled "Sensory Symptoms Checklist". It includes instructions for use and a list of symptoms organized into sections: "Sensory Processing Checklist", "Sensory Processing Checklist", "Sensory Processing Checklist", and "Sensory Processing Checklist". The right page is the back side, titled "Sensory Symptoms Checklist". It includes a list of symptoms and a section for notes.

Role of OT in treating sensory

- Often times direct therapy in an outpatient setting.
- Sensory diet is provided.
 - Can include a combination of alerting, calming, and organizing activities.
- Often times it is trial and error to determine the "best" sensory activities for each person.
- Modifications can be made in a classroom/work/day program setting as well.

Reasons to seek treatment

- The person will NOT outgrow some of the sensory processing deficits. Treatment helps a person function smoothly.
- Helps to develop social skills.
- Helps with learning.
- Helps improve emotional well-being.
- Helps improve family relationships.

Sensory Diet

Sensory diet

- Designed to provide the right combination of sensory input to keep an optimal level of arousal or performance.
- Should be more like choosing from a menu rather than following a recipe.
- Needs to be individualized and may not necessarily be convenient.
- Sensory input should NEVER be given as a reward or removed as a punishment.

Types of activities in a sensory diet


Alerting

- Benefits the under-responsive person; someone who needs a boost.
- Organizing
 - Activities that help regulate the person's responses so they can be more attentive.
- Calming
 - Activities that help decrease the sensory over-responsiveness.



Mental wellness

- Fear /anxiety with medical procedures
 - Blood draws, injections, sleep studies, trips to the dentist
- Self-talk
- Haircuts and other activities that cause anxiety



<https://adscresources.advocatehealth.com>

Home > General Hospital > Health Services > Adult Down Syndrome Center > Resources

Adult Down Syndrome Center

Resources

We offer a variety of resources for people with Down Syndrome, their families and caregivers and the professionals who care for and work with them. Choose a section for a list of helpful resources, videos, educational materials and more. Click to learn about a variety of health topics that can be found in our video gallery.

<p>People with Down Syndrome</p> <p>This section contains resources created and written for adolescents and adults with Down Syndrome. Resources include informational handouts and articles on topics like exercise and nutrition, sleep and mental and social health.</p>	<p>Families & Caregivers</p> <p>This section contains resources created and written for families and caregivers of people with Down Syndrome. Resources include informational handouts and articles and must be read in conjunction with physical, mental and social health.</p>	<p>Professionals</p> <p>This section contains resources for health professionals, researchers and others who care for and work with people with Down Syndrome. Resources include scholarly articles, information on best practices, guides and more.</p>
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Key points to remember

- Rule out medical reasons for changes in behavior.
- Sensory processing differences does not mean the person is on the Autism Spectrum.
- If behavior strategies are not helping solve the problem, consider sensory.
- Proprioceptive input will help everyone so encourage physical activities throughout the day.
- Consider proprioceptive input when an activity or procedure may cause anxiety.
- When in doubt, talk to an Occupational therapist.

Resources



Follow us on Facebook and Join our Email Distribution List!

resources.advocatehealth.com/contact



www.facebook.com/adultdownsyndromecenter

Books

- Kranowitz, C.S. (2005). *The Out-of-Sync Child*. New York, NY: Penguin Group.
- Kranowitz, C.S. (2016). *The Out-of-Sync Child Grows Up*. New York, NY: Penguin Group.
- Miller, L.J. (2006). *Sensational Kids: Hope and Help for Children with Sensory Processing Disorder*. New York, NY: Penguin Group.
- Slutsky, C.M. & Paris, B. (2004). *Is it Sensory or is It Behavior?* New York, NY: PsychCorp.
- Voss, A. (2015). *Understanding Your Child's Sensory Signals, 3rd ed.* San Bernardino, CA: CreateSpace Independent Publishing Platform.
- Yack, E., Aquilla, P., & Sutton, S. (2002). *Building Bridges through Sensory Integration, 2nd ed.* Arlington, TX: Future Horizons.

Websites-General

- <https://www.spdstar.org/>
- <http://sensoryfun.com/home>
- <http://www.asensorylife.com>
- <https://sensationalbrain.com/>
- <https://www.advocatehealth.com/health-services/adult-down-syndrome-center/resources/>
- <https://www.amctheatres.com/programs/sensory-friendly-films>

Websites-Sensory Diet

- http://sensorysmarts.com/sensory_diet_activities.html
- http://www.superduperinc.com/handouts/pdf/132_sensory_diet_090212.pdf
- <http://www.developmental-delay.com/page.cfm/286>
- <http://sensorysmarts.com/sensory-diet.pdf>
- <http://www.alertprogram.com/index.php>

Websites-Equipment

- <http://www.specialneedstoys.com/>
- <http://www.southpawenterprises.com/>
- <http://www.therapro.com/>
- <http://www.flaghouse.com/>
- <http://www.therapyshoppe.com/>
- <http://store.schoolspecialty.com>

Personal contact information

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847-318-2303

Adult Down Syndrome Center,
1610 Luther Lane, Park Ridge, IL 60068

Sleepless Children and Exhausted Parents—Understanding Sleep Problems and Exploring Options

TERRY KATZ, PH.D.
DEVELOPMENTAL PEDIATRICS
UNIVERSITY OF COLORADO
SCHOOL OF MEDICINE



1

Sleep 101

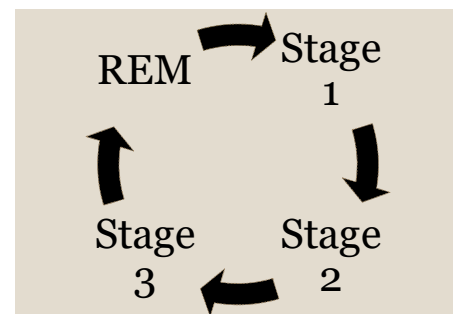
- Why do we sleep?
 - Alertness/performance
 - Memory, concentration, creativity
 - Better health
 - Mood

2

Sleep Is Needed To:

- Remember what we learned
- Organize our thoughts
- React quickly
- Work accurately
- Think abstractly
- Be creative

3



4

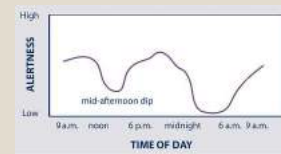
Circadian Rhythms

- Occur about every 24 hours
- Include Patterns of
 - Sleeping and waking
 - Activity and rest
 - Hunger and Eating
 - Fluctuations in Body Temperature
 - Hormone Release

5

Sleep and Wakefulness

- Bimodal
- Circadian Trough—maximum sleepiness
- Circadian Nadir—maximum alertness



6

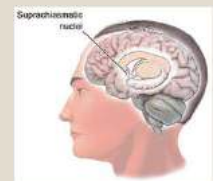
Zeitgebers

- Social Demands
- Time Cues
- Light

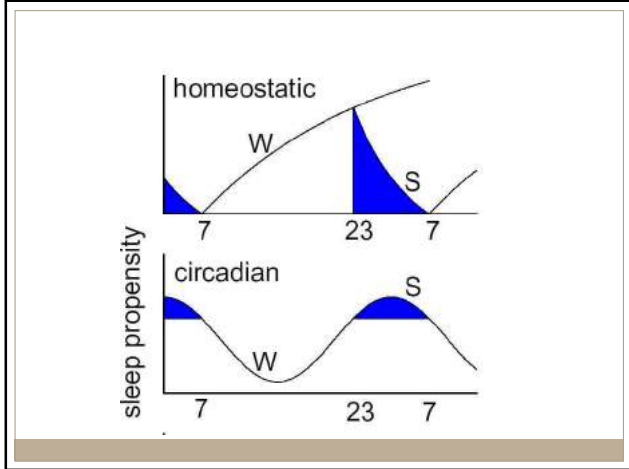
7

Melatonin

- Suprachiasmatic nucleus (SCN)
 - ✦ Pineal Gland
 - ✦ Produced when it is dark



8



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Descriptive Category	Age Range	Recommended	May be Appropriate	Not Recommended
Preschool	3-5	10-13	(8-9) or (14)	Less than 8 hours; More than 14 hours
School Age	6-13	9-11	(7-8) or (12)	Less than 7 hours; More than 12 hours
Teenager	14-17	8-10	(7) or (11)	Less than 7 hours; More than 11 hours
Young Adult	18-25	7-9	(6) or (10-11)	Less than 6 hours; More than 11 hours

From the National Sleep Foundation

10

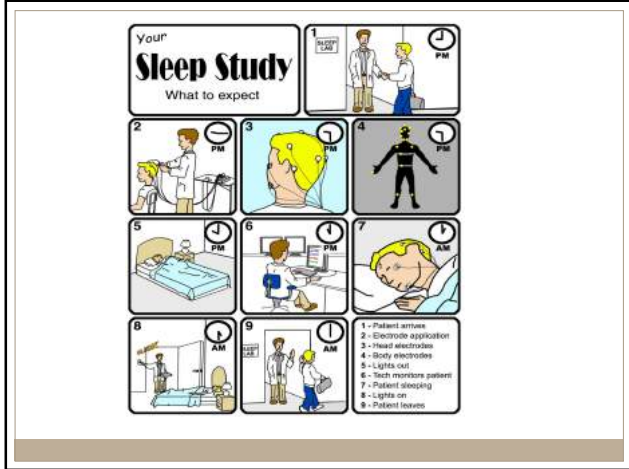
Key Sleep Screening Questions

- Regular sleep schedule?
- Problems falling asleep?
- Wake up during the night?
- Snore or problems breathing during the night?
- Unusual behaviors during the night?
- Sleepy or overtired during the day?

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Sleep Studies and EEGs

12



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Sleep Disordered Breathing

- Loud, continuous nightly snoring
- Apneic pauses
- Restless sleep
- Sweating during sleep
- Abnormal sleeping position
- Mouth breathing

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Obstructive Sleep Apnea

Normal Breathing
 - Airway is open
 - Air flows freely to lungs

Obstructive Sleep Apnea
 - Airway collapses
 - Blocked air flow to lungs

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Restless Leg Syndrome

- Genetic Link
- Sleep deprivation
- Iron deficiency
- Neurological Disorders
- Medications
- Caffeine

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Restless Leg Syndrome

- Does anything bother you at bedtime?
- Sleep
- Motor
- Discomfort
- Behavioral

19

Delayed Sleep Phase Disorder

- Sleep onset at a consistently late time
- Minimal difficulty with sleep maintenance
- Significant difficulty waking at the required time
- Persistent difficulty going to sleep at an earlier time
- Complaints of insomnia
- Daytime sleepiness

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Nightmares

- Recurrent episodes of awakening from sleep with **recall** of dream
- Full alertness upon awakening with little confusion or disorientation
- Delayed return to sleep after the episode
- Occurrence of episodes in the latter half of the typical sleep period

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Parasomnias

- Confusional Arousals
- Sleepwalking
- Sleep terrors

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Common Characteristics

- Occur early in the night
- Agitation, confusion, disorientation
- Increased agitation with comfort
- Amnesia for the event
- Positive family history
- Exacerbation by insufficient sleep or sleep fragmentation

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Most Common Difficulties

- Irregular sleep-wake cycles
- Difficulty settling
- Delayed sleep onset
- Night wakings
- Short sleep duration
- Early morning wake times

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Treatment

1. Rule out medical causes
2. Education
3. Pharmacology

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Medical Considerations

- Gastrointestinal Issues
- Seizures
- Pain/Discomfort
- Sleep Disorders (sleep disordered breathing, restless legs)
- Consideration of psychiatric/behavioral conditions
- Medications

26

Behavioral Treatment Works!

- Behavioral treatment produces reliable and durable changes (80% of children improve)
- 94% of studies report intervention was efficacious

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Behavioral Strategies

- Daytime Habits
- Evening Habits
- Sleep Environment
- Sleep Needs and Timing of Bedtime
- Bedtime Routines
- Use of Visual Supports

28

Daytime Factors

- Exercise
- Light
- Caffeine
- Naps
- Bedroom use



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Evening Habits

- Limit stimulating activities
- Less light
- Routines



30

Sleep Environment

- Temperature
- Texture
- Sound
- Minimal Light



31

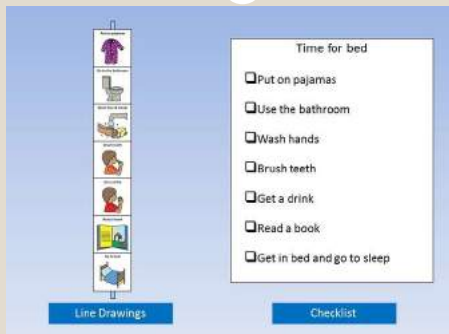
Bedtime Routines

- Consistent bedtime
- Calming activities
- Use of a visual schedule
- Limit electronic sleep aids



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Visual Supports



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Other visual strategies

- Schedules with photos
- Object schedules
- Cues in the environment



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Sensory Strategies

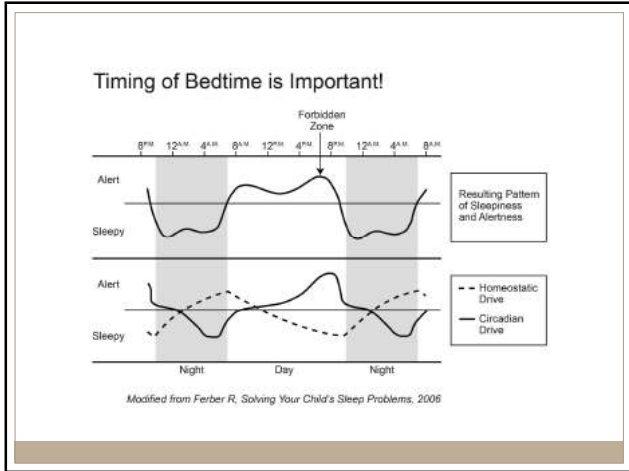
- Rocking and Swinging
- Snuggling
- Massage
- Lotion
- Listening to music
- Noise machine

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Timing

- Sleep needs for children with ASD
- When is bedtime?
- The forbidden zone

36



37

Sleep Resistance?

- Why?
 - Not sleepy
 - Anxious

38

Nighttime Fears

Common Characteristics:

- Fearful Behaviors
- Bedtime Resistance
- "Curtain Calls"
- Need to be with a parent or family member at bedtime

39

Strategies for Sleep Resistance

- Timing
- Unmodified extinction (cry it out)
- Graduated extinction (checking)
- Fading parental presence (rocking chair)
- Rewards

40

Understanding Night Wakings

Begin at bedtime (Durand, 1998)

- Learning how to fall asleep
- Falling asleep while drowsy



41

What to do?

- Respond quickly to distress
- Brief and boring
- Use of visual aids and social stories
- May get worse before getting better
- Rewards

42

The Bedtime Pass

Bedtime pass



Friman, Arch Pediatr Adolesc Med, 1999; 153(10): 1027-9

43



44

Bedtime Pass Social Story

My parents have made a bedtime pass to help me. The bedtime pass is like a ticket. The bedtime pass can be traded for a drink of water or get out of bed. If I ask for a drink of water or get out of bed, I have to give them the bedtime pass. When I am able to stay in bed all night, I get to keep the bedtime pass. This is a good thing! In the morning I can trade the bedtime pass for a treat.

45

Early Morning Awakening

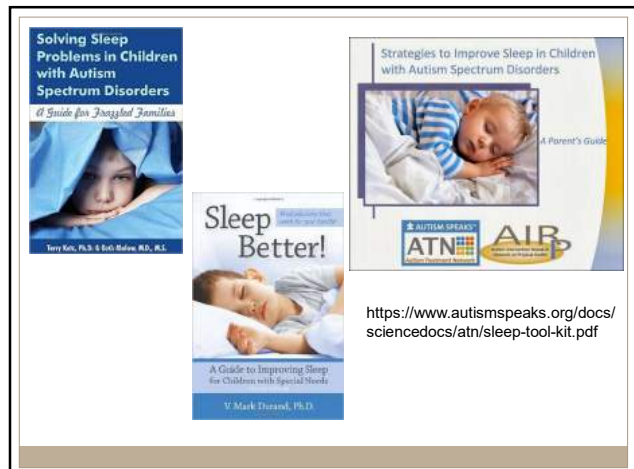
- Different from night wakings
- Consider possibility of depression
- Delay bedtime
- Learning to stay in bed or play quietly
- Rewards

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Safety Issues

- Child-proof doors and cabinets
- Baby monitor
- Alarm or bell on child's door

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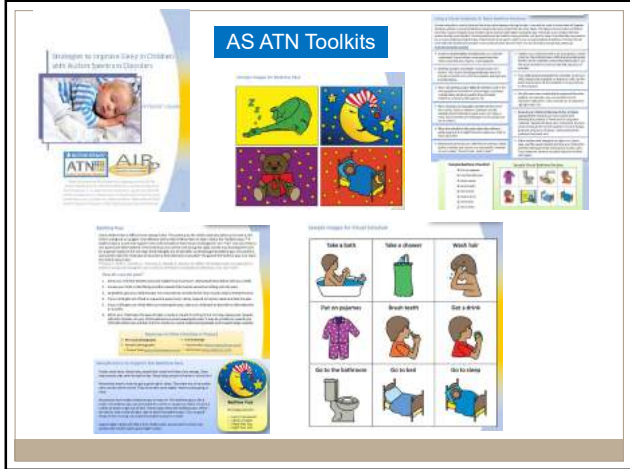
Solving Sleep Problems in Children with Autism Spectrum Disorders
A Guide for Frustrated Families
Terry Kotz, Ph.D., S. Ed. Bolon, M.D., M.S.

Sleep Better!
A Guide to Improving Sleep for Children with Special Needs
V. Mark Durand, Ph.D.

Strategies to Improve Sleep in Children with Autism Spectrum Disorders
A Parent's Guide
ATN AIR

<https://www.autismspeaks.org/docs/sciencedocs/atn/sleep-tool-kit.pdf>

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**Social Security:
With You Through Life's Journey...**



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and tomorrow



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**SSDI and SSI
Benefits**



3



Definition of Disability - Adult

The Social Security Act defines disability as:

- a person who cannot work due to a severe medical condition that has lasted, or is expected to last, at least one year or result in death; or
- the person's medical condition must prevent him or her from doing substantial gainful employment – work that he or she did in the past, and it must prevent the person from adjusting to other work.



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Requirements for Getting Disability Benefits

To be eligible for disability benefits, you must meet two different earnings tests:

- a recent work test, and
- a duration of work test.


Note: Certain blind workers have to meet only the duration of work test.

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Rules for Recent Work Test

If you become disabled	You generally need
In or before the quarter you turn age 24	1.5 years of work during the three-year period ending with the quarter you become disabled.
In the quarter after you turn age 24 but before the quarter you turn age 31	Work during half the time for the period beginning with the quarter after you turned 21 and ending with the quarter you become disabled.
In the quarter you turn age 31 or later	Work during five years out of the 10-year period ending with the quarter your disability began.

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Supplemental Security Income (SSI)

Social Security administers the Supplemental Security Income program, which pays benefits to disabled adults and children who have limited income and resources.

SSI benefits also are payable to adults age 65 and older who do not have disabilities, if these individuals meet the financial limits.

People who have worked long enough, recently enough, may be able to receive Social Security benefits – such as disability or retirement – as well as SSI.

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SSDI vs. SSI

Social Security Disability Insurance	Supplemental Security Income
Payments come from the Social Security trust funds and are based on a person's earnings.	Payments come from the general treasury fund, NOT the Social Security trust funds. SSI payments are not based on a person's earnings.
An insurance that workers earn by paying Social Security taxes on their wages.	A needs-based public assistance program that does not require a person to have work history.
Pays benefits to disabled individuals who are unable to work, regardless of their income and resources.	Pays disabled individuals who are unable to work AND have limited income and resources.
Benefits for workers and for adults disabled since childhood. Must meet insured status requirements.	Benefits for children and adults in financial need. Must have limited income and limited resources.

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When should I apply for disability benefits?

- Apply as soon as you become disabled.
- Processing an application for disability benefits can take three to five months.
- We may be able to process your application faster if you help us by getting any other information we need.

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How do I apply for disability benefits?

Online at www.socialsecurity.gov/disability

Call **1-800-772-1213** to make a telephone appointment with your local office (in-office interviews are limited due to COVID-19)

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SSDI: What Happens Next?

- Your application will be reviewed to make sure you meet some basic requirements for disability benefits.
- We'll check whether you worked enough years to qualify and evaluate any current work activities.
- If you meet these requirements, we'll forward your case to the Disability Determination Services office in your state.

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Disability Determination Services Office - State

- This state agency completes the initial disability determination decision for us.
- Doctors and disability specialists in the state agency ask your doctors for information about your condition(s). They'll consider all the facts in your case.
- They'll use the medical evidence from your doctors, hospitals, clinics, or institutions where you've been treated.

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How is a Disability Determination Made?

Five-step process:

1. Are you working?
2. Is your medical condition "severe" ?
3. Does your impairment(s) meet or medically equal a listing?
4. Can you do the work you did before?
5. Can you do any other type of work?

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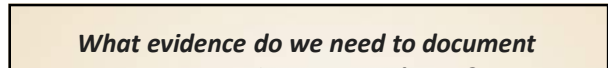
Disability Evaluation Under Social Security

- Provides physicians and other health professionals with an understanding of the disability programs administered by the Social Security Administration
- Explains how each program works, and provides information to help health professionals make sound and prompt determinations and decisions on disability claims

socialsecurity.gov/disability/professionals/bluebook

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What evidence do we need to document non-mosaic Down syndrome?


We need a copy of the laboratory report of karyotype analysis, which is the definitive test to establish non-mosaic Down syndrome. We will not purchase karyotype analysis. We will not accept a fluorescence in situ hybridization (FISH) test because it does not distinguish between the mosaic and non-mosaic forms of Down syndrome.

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Evaluating the effects of mosaic Down syndrome

When the effects of mosaic Down syndrome or another congenital disorder that affects multiple body systems are sufficiently severe we evaluate the disorder under the appropriate affected body system(s), such as musculoskeletal, special senses and speech, neurological, or mental disorders. Otherwise, we evaluate the specific functional limitations that result from the disorder.



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Compassionate Allowances (CAL)

- A way of quickly identifying diseases and other medical conditions that invariably qualify under the Listing of Impairments based on minimal objective medical information
- Allows Social Security to target the most obviously disabled individuals for allowances based on objective medical information that we can obtain quickly
- Is not a separate program from the Social Security Disability Insurance or Supplemental Security Income programs

socialsecurity.gov/compassionateallowances



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We'll tell you our decision...

- When the state agency makes a determination on your case, we'll send a letter to you.
- If approved, the letter will show the amount of your benefit, when your payments start, and your reporting responsibilities.
- If not approved, the letter will explain why and tell you how to appeal the determination if you don't agree with it.



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SSI



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Requirements for Getting SSI

To be eligible for SSI, you must:

- have limited income and few resources;
- be age 65 or older;
- be totally or partially blind; or
- have a medical condition that keeps you from working and is expected to last at least one year or result in death.


Note: There are different rules for children.



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Definition of Disability - Adult

The Social Security Act defines disability as:

- a person who cannot work due to a severe medical condition that has lasted, or is expected to last, at least one year or result in death; or
- the person's medical condition must prevent him or her from doing substantial gainful employment – work that he or she did in the past, and it must prevent the person from adjusting to other work.



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Requirements for Getting SSI

- Your income – money you receive such as wages, Social Security benefits, and pensions. Income also includes such things as food and shelter.
- Your resources – things you own such as real estate, bank accounts, cash, stocks, and bonds.
- Where you live – must live in the U.S., or Northern Mariana Islands. If you're not a U.S. citizen, but you are lawfully residing in the United States, you still may be able to get SSI.



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Special SSI Qualification Requirements for Non-Citizens

Effective August 22, 1996, most non-citizens must meet two requirements to be potentially eligible for SSI:

- be in a **qualified alien** category; and
- meet all of the other rules for SSI eligibility, including the limits on income and resources, etc.



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Income

Earned	Unearned
Wages	SSA benefits
Net earnings from self-employment	Veterans benefits
Payment for services in sheltered workshop	Unemployment benefits
	Interests
	Pensions
	Cash from family/friends

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Resources

Included Resources	Excluded Resources
Bank Accounts (CDs, IRAs)	Home in which you live
Stocks, Bonds, 401Ks (Liquid Assets)	First car
Second Car	Burial plots for self & family
Life Insurance	Some resources set aside for burial
Property other than where you live	

Individual Limit: \$2,000 / Couples Limit: \$3,000

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Living Arrangements

Living arrangements are another factor to determine how much SSI a person can get. Benefits may vary depending on where you live:

- In someone else's household
- In an institution – generally \$30/month maximum
- In a group care or board and care facility

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SSI for Children

Who is considered a "child" for SSI?

A disabled person who is neither married nor head of a household and:

- is under age 18; or
- is under age 22 and is a student regularly attending school.

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SSI Requirements for Children

- If under 18, the child has a physical or mental impairment (or combination) that results in marked or severe limitation in functioning.
- The child must be either blind or disabled. If the child is blind, he or she must meet the same definition of “blind” as applies for adults.
- Condition must be expected to last at least 12 months or result in death.

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SSI Requirements for Children (continued)


- Disabled children living in households with limited income and resources may be eligible to receive SSI benefits.
- For eligibility, the income and assets of the disabled child and parent(s) living in the household are assessed.

Children’s income examples:

- Child support
- Social Security auxiliary benefits
- Gifts

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Deeming

What is it?
The process of determining how much of a parent(s) income and resources will count is called deeming.

When does it apply?
If the parent(s) has income and/or resources that we must consider and:

- the child is under 18; and
- lives at home with his or her natural, or adoptive parents(s); or
- lives away at school, but comes home on some weekends, holidays, or school vacations and is subject to parental control.

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SSI Determination for Children Turning 18

- We make a new disability determination using the adult rules.
- We no longer count the income and resources of parent(s) for eligibility.
- If the child continues to live with parent(s) but does not pay for food or shelter, a lower SSI payment may apply.
- An SSI application can be made as early as the day of the 18th birthday.

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How to Apply for SSI (Adult)

You can begin the process and complete a large part of your application online!

You may be eligible to complete your application online if you:

- are between the ages of 18 and 65;
- have never been married;
- are a U.S. citizen;
- haven't applied for or received SSI benefits in the past; and
- are applying for Social Security Disability Insurance at the same time as your SSI claim.



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How to Apply for SSI (Under Age 18)

- Schedule an appointment with Social Security. Call 1-800-722-1213 (TTY 1-800-325-0778) from 7 a.m. to 7 p.m., Monday through Friday or contact your local Social Security office;

and

- Complete the online Child Disability Report at www.socialsecurity.gov/childdisabilityreport.



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SSI: What Happens Next?

- Your application will be forwarded to the state Disability Determination Services (DDS) agency.
- The DDS will contact medical providers to obtain medical records.
- The DDS may ask for additional information about how your condition(s) affect daily activities.



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We'll tell you our decision...

- When the state agency makes a determination on your case, we'll send a letter to you.
- If approved, the letter will show the amount of your benefit, when your payments start, and your reporting responsibilities.
- If not approved, the letter will explain why and tell you how to appeal the determination if you don't agree with it.



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TOILET TRAINING FOR INDIVIDUALS WITH DOWN SYNDROME

Terry Katz, PhD
Developmental Pediatrics
University of Colorado School of Medicine



1

Objectives

- Understand the challenges involved in toilet training individuals with Down syndrome
- Discuss key components of a successful toileting program
- Review materials and resources

2

Medical Considerations

- Always check with your healthcare provider
 - Constipation
 - Urinary tract infections
 - Voiding dysfunction

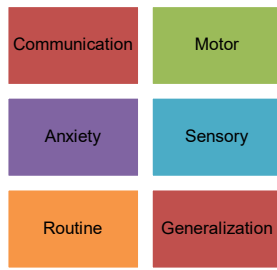
3

BRISTOL STOOL CHART

	Type 1 Separate hard lumps	Very constipated
	Type 2 Lumpy and sausage like	Slightly constipated
	Type 3 A sausage shape with cracks in the surface	Normal
	Type 4 Like a smooth, soft sausage or snake	Normal
	Type 5 Soft blobs with clear-cut edges	Lacking fibre
	Type 6 Mushy consistency with ragged edges	Inflammation
	Type 7 Liquid consistency with no solid pieces	Inflammation

4

Strengths and challenges?



9

Diet and Exercise

- Fluids
- Fiber
- Physical activity

10

Daily Fluid Requirements

Age Range	Gender	Total Fluid (Cups/Day)
4 to 8 years	Girls and Boys	5
9 to 13 years	Girls	7
	Boys	8
14 to 18 years	Girls	8
	Boys	11

Kids Total Daily Beverage and Drinking Water Requirements
Data are from Institute of Medicine of the National Academies.
Dietary Reference Intakes (DRIs) Tables. Recommended Daily Allowance and Adequate Intake Values:
Total Water and Macronutrients.

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Fiber

- Apples
- Pears
- Prunes
- Carrots
- Whole grain bread
- High fiber cereal
- Beans
- Peas
- Baked potato
- Berries with seeds



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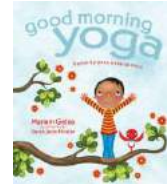
What Does Fiber Do?

- Increases feces bulk
- Softens stool
- Shortens transit time

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Exercise

- Yoga
- Walks
- Mini-trampoline
- Balance beam
- Sneaky Fitness



by Missy Chase Lapine and Larysa Didio

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Environmental Considerations

- ✓ Secure and stable seat
- ✓ Feet should touch the floor or a stable surface
- ✓ Knees should be above the hips
- ✓ Clothes are easy to take on and off
- ✓ Address anything in the bathroom that might make an individual anxious
- ✓ Decorate the bathroom
- ✓ Put a reward chart in the bathroom
- ✓ Keep special toys and books just for the bathroom

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Books and Videos Can Help

- ✓ Toileting books that capitalize on an individual's interests
 - Trains, pirates, princesses, Elmo, Dora
- ✓ Toileting videos
- ✓ Dolls and stuffed animals
- ✓ Social stories

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Social Stories

Using the Toilet

Sometimes I have to pee-pee. I go to the bathroom when I have to pee-pee. Sometimes I have to poop. I go to the bathroom when I have to poop. When I go in the bathroom, I pull my pants down. I sit on the toilet. Sometimes I pee-pee in the toilet. Sometimes I poop in the toilet. When I am finished going pee-pee and poop, I wipe my bottom with toilet paper. Sometimes I have to wipe again. I wipe to make my bottom clean and dry. After I wipe, I drop the dirty toilet paper in the toilet. I pull up my underwear. I pull up my pants. I flush the toilet. I go to the sink and wash my hands with soap and water. I dry my hands.

Adapted from Toilet Training for Individuals with Autism or Other Developmental Issues by Maria Wheeler

17

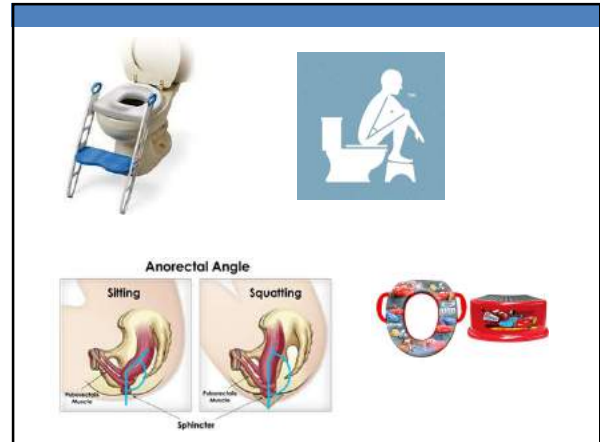
Toileting Aids

- ❖ Red or Blue food coloring™
- ❖ Tinkle Targets™
- ❖ Theme-oriented toilet seats
- ❖ WobL watch™
- ❖ Potty Time Potty watch™
- ❖ Wet alarms
- ❖ Squatty Potty™
- ❖ Mommy's Helper Contoured Cushie Step Up™

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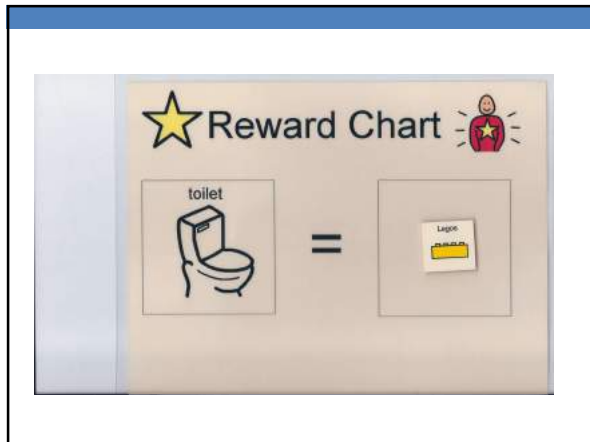
Visual Supports

- Visual Schedules
 - When to go
 - What to do when you are there
- Help with transitions
 - Timers
 - Objects

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Routines

- Start by establishing a routine
- Consistent toilet time
- Use the same words or signs
- Start with short sitting times and work up to 5-10 minutes
- Keep the routine consistent among caregivers

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Using a Visual Schedule

- Start with short schedules
- Use consistent cues
- Put completed items in an "all done" container
- Use physical prompts
- Physical prompts should be delivered from behind
- Use hand over hand prompting if needed so that only the individual touches the schedule
- Place the schedule in a convenient and central spot at home
- Include toileting on the schedule as well as snack and drink activities

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Best times to go

- Aim for a total of six times per day
- Mornings
- Natural transitions
- In between activities
- 15-20 minutes after a meal
- When fun activities can occur after a trip to the toilet

Try to avoid:

- Times that are hectic and busy
- Interrupting a favorite or preferred activity

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When to start?

- Good time for all key players
- Consider the needs of everyone in the family
- Remember that first steps can be very small and may make it easier to start

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Refusing to sit?

- Anxiety vs. refusal?
 - Start where the individual is
 - Develop a hierarchy
 - Reward all positive actions

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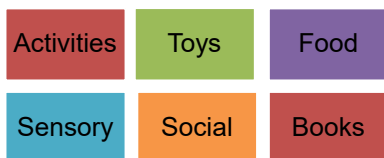
Sample hierarchy

- Stand next to the toilet
- Touch the toilet
- Sit on the toilet with the seat closed
- Sit on the toilet with the seat opened for 5 seconds
- Sit on the toilet for 10 seconds
- Sit on the toilet for 30 seconds
- Sit on the toilet for 1 minute
- Sit on the toilet for 2 minutes
- Sit on the toilet for 5 minutes
- Sit on the toilet for 7 minutes
- Sit on the toilet for 10 minutes

30

Reinforcement

- Rewards for big and small steps
- Bathroom specific
- Consider a variety of rewards:



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Problem Solving

- ✓ Fears
 - Noises
 - Positioning
 - Odors
 - Pain
- ✓ Separation
- ✓ Issues about food and fluids
- ✓ Need for privacy
- ✓ Social issues
- ✓ Flexibility

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Teaching skills

- Motor development
- Sensory issues
- Hierarchy of prompts
- Forward and backward chaining
- Generalization

33

Common challenges:

- Refusing to sit
- Flushing fears
- Too focused on flushing
- Playing in water
- Playing with toilet paper
- Poor aim
- Wiping problems
- Needs to use a diaper

34

The Hidden Curriculum

- Rules for boys
- Rules for girls
- Behavior in community toilets
- Safety
- Male informants needed!

Myles, BS, Trautman, ML, & Schelvan, RL (2004.) The Hidden Curriculum: Practical Solutions for Understanding Unstated Rules in Social Situations. Shawnee Mission, KS: Autism Asperger Publishing Company.

35

Stuff Happens!

What to do about accidents:

- ✓ Maintain a neutral stance
- ✓ Avoid punishment
- ✓ Change in the bathroom if possible
- ✓ Empty diaper in the toilet
- ✓ Have individual sit on the toilet
- ✓ Involve individual in clean-up

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Diapers vs. Underpants

- Not a matter of right or wrong
- Can make progress while wearing a diaper
- May be less stressful and frustrating to keep diapers
- Timing is key



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Bedwetting

- Primary vs. Secondary
- Chronological age
 - Girls: 6 years
 - Boys: 7 years
- Developmental level (at least 4 years)
- Family history
- Sleep issues

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First Steps

- Address constipation
- Lots of liquids during the day
- Restrict liquids 1.5 hours prior to bed
- Avoid bladder irritants:
 - Caffeine
 - Citrus
 - Carbonated beverages
 - Artificial red and purple dyes

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Other Strategies

- Wet alarm
- Arousal
- Behavioral strategies
- Retention control
- Pelvic floor exercises
- Biofeedback
- Medications

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Alarm Therapy



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Alarm therapy

- May take 6-8 weeks to work
- Some change after a week
- Can be very effective
- After 7 dry nights in a row, move to “overlearning”
 - Drink 16-32 ounces of fluid prior to bedtime
- www.bedwetting.com
- www.pottymd.com
- Wet Stop 3—combined auditory and vibratory component

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Alarm Therapy Tips

- Practice during the day
- Rehearse the routine
- Use social stories
- You may need to wake up a deep sleeper
- Use a reward system

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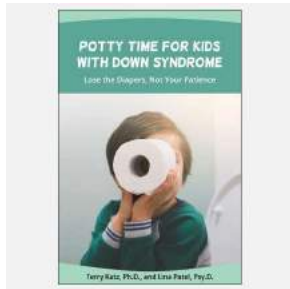
Realistic Expectations

- This is a difficult skill
- All individuals can make progress
- It will take time
- Avoid blame
- Celebrate all success!

“It’s a marathon, not a sprint.”
--Gary Heffner

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Resources



45

Down syndrome with comorbid (co-occurring) autism spectrum disorder:

Recognizing the signs, understanding the diagnostic process, and exploring options for behavioral supports

Nancy Raitano Lee, Ph.D.
Assistant Professor of Psychology

Taralee Hamner, Ph.D.
Postdoctoral Fellow




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1

Plan

Part 1: Background, diagnostic process, and overview of thinking about behavior problems

- Background on Down syndrome (DS) and autism spectrum disorder (ASD)
 - Common challenges in DS
 - Common challenges in ASD
 - Overlapping challenges of the two disorders
- Identification and diagnosis of ASD in children with Down syndrome
 - Symptoms and common behaviors
 - Diagnostic procedures
 - Developmental considerations
 - Additional learning & behavioral challenges in DS+ASD

2

2

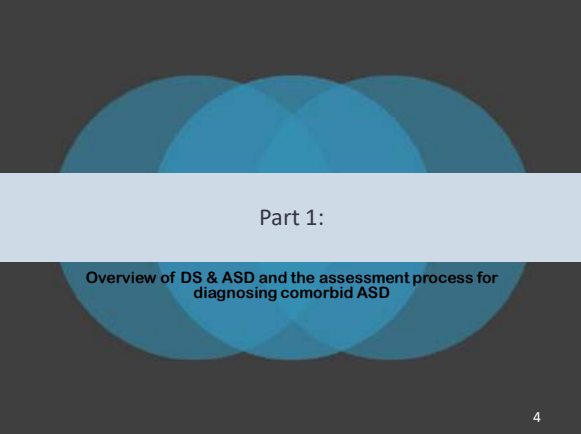
Plan

Part 2: Intervention strategies; general Q & A

- A summary of research on different interventions approaches for
 - DS
 - ASD
- General guidance on intervention strategies that may benefit children with DS+ASD.
- General Q & A

3

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Part 1:

Overview of DS & ASD and the assessment process for diagnosing comorbid ASD

4

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Part 1:

Overview of DS & ASD and the assessment process for diagnosing comorbid ASD

5

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Prevalence of DS

- ~1/700-800 [0.1% of population]
- Equally distributed between males & females
- Most common genetic cause of intellectual disability

Prevalence of ASD

- ~1/59 children [1.7% of population]
- More common in males than females (4:1)

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Prevalence of DS + ASD

- Comorbid ASD:
 - Estimated to be between 15 and 20% of children with DS
 - Recent meta-analysis: ~16% of kids with DS have ASD
- Prevalence of DS+ASD?
 - About .02% of population?
 - Approximately 1/5000?

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Down syndrome

8

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Common learning challenges associated with Down syndrome

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9

Nonverbal skills often > verbal

Nonverbal, visual-spatial problem solving

Expressing Verbal Knowledge

>



i.e., not always

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Receptive language often > expressive

Receptive Vocabulary Abilities

Expressive Vocabulary Abilities

>



i.e., not always

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Receptive > Expressive Vocabulary: Implications for Learning

- Balance the need for being able to articulate new concepts with the need to understand new concepts
- Ex: Evaluating vocabulary knowledge
 - Multiple choice or matching rather than oral/written expression of word meanings

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Verbal Learning Challenges

Picture schedule

- Visual strategies!
- Object or Picture schedules
- Picture books to support comprehension

13

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More on speech & language in DS

- Wide range of challenges
 - Delayed language acquisition
 - Articulation
 - Syntax or grammar (receptive & expressive)
 - Expressive vocabulary
- Hearing difficulties ~ likely to exacerbate language difficulties
- Discussion in second half of workshop about speech-language interventions

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Executive Function

- Children with DS have difficulties with
 - Working memory
 - Planning/organization
 - Shifting between ideas/mental sets

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Working Memory

- The ability to remember small amounts of information for short periods of time and simultaneously manipulate that information to perform some task

16

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Working Memory Difficulties: Everyday Examples

- Difficulties following multi-step directions
- Difficulties comprehending complex language
- Difficulties following assignment instructions

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Planning/Organizing

- The ability to prioritize and accomplish a goal efficiently

Everyday examples

- Putting on clothing
- Completing projects with multiple steps
- Knowing how to start something

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Shifting/Cognitive Flexibility

- The ability to flexibly change between thoughts or behaviors to complete a task.

Everyday examples

- Insisting that things be done the same way
- Having particular routines or rituals
- Difficulties doing something a new way

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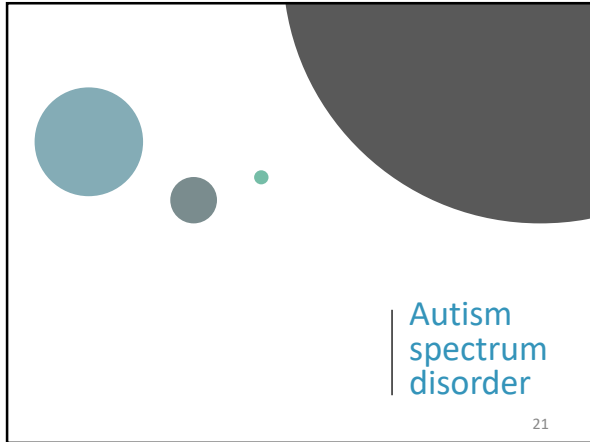
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Challenges with language & executive function are common in children with Down syndrome with and without autism.

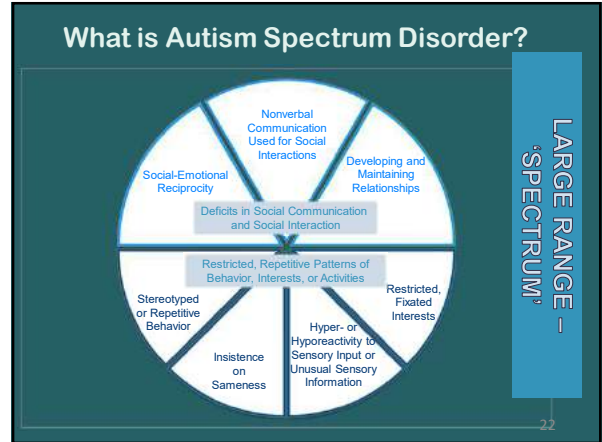
Difficulties in these areas are not red flags for autism

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Social:
Deficits in social-emotional reciprocity

Examples

- abnormal social approach
- failure of normal back-and-forth conversation
- reduced sharing of interests, emotions, or affect
- failure to initiate or respond to social interactions.




Symptoms directly from DSM-5 diagnostic criteria

23

Social:
Deficits in Nonverbal Communication

- poorly integrated verbal and nonverbal communication
- abnormalities in eye contact and body language
- deficits in understanding and use of gestures
- total lack of facial expressions and nonverbal communication.



Symptoms directly from DSM-5 diagnostic criteria

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Social:

Deficits in developing & maintaining relationships

Examples

- difficulties adjusting behavior to suit various social contexts
- difficulties in sharing imaginative play or in making friends
- absence of interest in peers



Symptoms directly
from DSM-5
diagnostic criteria 25

25

Restricted behavior, interests:

Stereotyped/repetitive behavior

Examples

- stereotyped or repetitive motor movements
- use of objects or speech
- e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases



Symptoms directly
from DSM-5
diagnostic criteria 26

26

Restricted behavior, interests:

Insistence on sameness

- insistence on sameness
- inflexible adherence to routines
- ritualized patterns of verbal or nonverbal behavior
- e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day



Symptoms directly
from DSM-5
diagnostic criteria 27

27

Restricted behavior, interests:

Fixated interests

- highly restricted, fixated interests that are abnormal in intensity or focus
- e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests



Symptoms directly
from DSM-5
diagnostic criteria 28

28

Restricted behavior, interests: Sensory hyper- or hyporeactivity

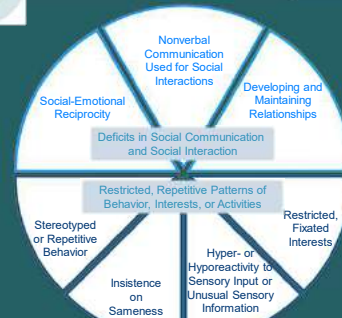
- hyper- or hyporeactivity to sensory input
- or unusual interest in sensory aspects of the environment
- e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement



Symptoms directly from DSM-5 diagnostic criteria 29

29

Which of these challenges might you see in children with DS without ASD?



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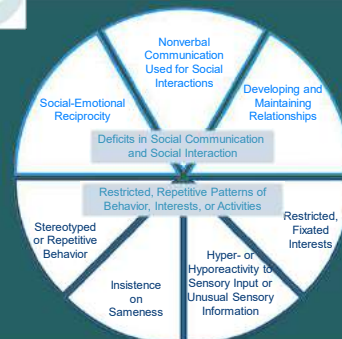
Which of these challenges might you see in children with DS without ASD?



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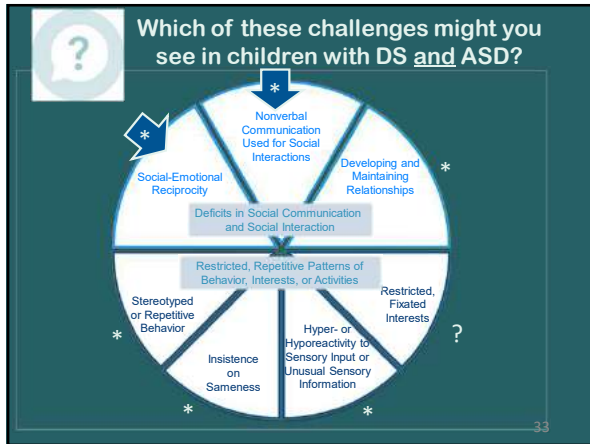
31

Which of these challenges might you see in children with DS and ASD?



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Part 1:

Overview of DS & ASD and the assessment process for diagnosing comorbid ASD

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What do features of ASD look like in children with DS?

What are we looking for during these evaluations?

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We are concerned about ASD when we see...

- Rare attempts to imitate others
- Tendency not to share emotions by directing facial expressions to others
- “Disconnect” between child’s emotions and what is going on around her
- Lack of understanding about the process of communication – “lack of intentionality”

Adapted from slide Courtesy of Susan Hepburn, Ph.D.

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We are concerned about ASD when we see...

- Social-communication skills that are below the child's other skills
- Lack of sharing enjoyment with others
- Few attempts to communicate

Adapted from slide Courtesy of Susan Hepburn, Ph.D.

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Let's talk about communication

- Communication ≠ talking

<https://www.buzzfeed.com/mikespohr/this-viral-video-of-a-dad-having-a-conversation-with-his>

38

38

We are concerned about ASD when we see...



Few attempts to communicate in (no matter what the verbal level)

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Diagnostic process

Thank you to our colleague, Susan Hepburn, Ph.D., for sharing her expertise on this process and presentation more generally



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What does a gold standard diagnostic evaluation involve?

- Child Component
 - Autism Diagnostic Observation Schedule (1 hour)
 - Cognitive assessment (1 hour)
- Parent Component
 - Autism Diagnostic Interview (2 hours)
 - Adaptive Behavior interview (1 hour)

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OBSERVING
FEATURES OF
AUTISM IN YOUTH
WITH DS



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42

Overview of key diagnostic tool & types of expected behaviors in DS

Adapted from slide Courtesy of Susan Hepburn, Ph.D.

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Behaviors that raise concern about ASD in a child with DS

1:16

Adapted from slide Courtesy of Susan Hepburn, Ph.D.

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Behaviors that raise concern about ASD in a child with DS

Adapted from slide Courtesy of Susan Hepburn, Ph.D.

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Behaviors that raise concern about ASD in a child with DS

Adapted from slide Courtesy of Susan Hepburn, Ph.D.

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Other challenges that may mimic ASD

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Children who are not behaviorally flexible...

Or those who insist on routines, get stuck, have a hard time transitioning, engage in repetitive behaviors a lot...

•Sometimes they don't meet the social criteria for ASD; however, interventions for people with ASD can work very well.

•Some professionals use the term "poor executive functioning" to describe this & have ideas on how to help from working with people with many different conditions

Adapted from slide Courtesy of Susan Hepburn, Ph.D.

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Adolescents who may be experiencing depression

- Stops showing pleasure in activities he used to love
- Shows sad, flat or serious affect all the time, with little variation, little joy
- Cries a lot or makes sounds or body movements that communicate agitation or discomfort without a known cause, (for some may be an increase in self-injury)
- Shows a change in their sleeping or eating habits
- Has a particularly hard time getting activated and/or tends to withdraw more
- Teenagers and young adults may be at increased risk for depression.

Adapted from slide Courtesy of Susan Hepburn, Ph.D.

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In conclusion...children with DS and ASD

- Have difficulties in core social relating that cannot be explained by their overall developmental level
- Have difficulty becoming intentional communicators
- Show reduced social orientation
 - Little sharing of enjoyment
 - May not seek parent for comfort
 - Affect may be either very flat or may not always fit context

Adapted from slide Courtesy of Susan Hepburn, Ph.D.

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Behaviors that don't help us figure out the autism question

- Repetitive motor behaviors
- Speech difficulties
- Behavioral rigidity

These behaviors can be seen in a person with DS with or without autism and more research is needed to understand if there are differences in intensity or pervasiveness of these behaviors in people with both conditions.

Adapted from slide Courtesy of Susan Hepburn, Ph.D.

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Common learning & behavior challenges for children with DS+ASD

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ASD Symptoms in DS+ASD– Atypical Presentation

Some research suggests that ASD profiles appear *less severe* in DS+ASD than peers with ASD in isolation

- lower severity in social symptoms
- lower severity in restricted & repetitive behaviors/interests

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Cognition in DS+ASD

Some research also suggests that children with DS+ASD have greater cognitive challenges than children with DS alone.

Does not appear to be evidence for specific strengths or weaknesses in verbal and nonverbal abilities

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Q&A



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Part 2:

Intervention strategies; general Q & A

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Research on Language Interventions for DS (with or without ASD)

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Research on Language Interventions for DS (with or without ASD)

- Growing body of research
- Two research-based interventions are
 1. Milieu Communication Teaching (MCT)/Enhanced Milieu Teaching
 2. Broad Target Speech Recasts

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Milieu Communication Teaching

Resource:

Pursuing Precision Speech-Language Therapy Services for Children with Down Syndrome
Ann McIvor, MEd,¹ and Paul J. Yoder, PhD,² 2016

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KidTalk ~ Enhanced Milieu Training

- Video:

<https://youtu.be/3HHcvMqIPp8>

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Broad Target Speech Recasts

- Involves clinician providing ‘speech recasts’
- Speech recasts:
 - accurately modeling words the child articulated incorrectly soon after the child states them
 - No requirement for child to imitate

Potentially helpful resource on this topic:
<https://ykc.vumc.org/assets/files/resources/yoderdsreport15.pdf>

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In addition to interventions to support DS-specific challenges...

Children with DS+ASD may need supports developed for children with autism

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Research on ASD Early Intervention Approaches

Thank you to our colleague, Giacomo Vivanti, Ph.D. for sharing his expertise on autism intervention strategies



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THE EVOLVING LANDSCAPE OF ASD EARLY INTERVENTION RESEARCH

MODELS SUPPORTED BY AT LEAST ONE RANDOMIZED CONTROLLED TRIAL

ESDM (Dawson et al., 2010; Rogers et al., 2019)
ABA/DTT (Smith et al., 2000)
ESI/SCERTS (Wetherby et al., 2014)
JASPER (Kasari et al., 2010, 2014)
PLAY (Solomon et al., 2014)
PACT (Pickles et al., 2016)
LEAP (Strain & Boverly, 2011)
TEACCH (Turner-Brown et al., 2016)
PRT (Hardan et al., 2015)
IMPACT (Ingersoll et al., 2016)
Adapted Responsive Teaching (Baranek et al., 2016)
Joint Attention Mediated Learning (Schertz et al., 2013)

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Adapted from slide courtesy of Giacomo Vivanti, Ph.D.



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Early Start Denver Model

Comprehensive early intervention for children with autism ages 12–48 months.




“Denver Model”
Sally Rogers and colleagues, 1984


“Early Start Denver Model”
Rogers & Dawson, 2010

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Critical Treatment Techniques In ESDM

- Child Motivation
- Child Attention
- Positive Affect
- Dyadic Engagement
- Joint Routine
- ABCs
- Instructional Techniques
- 1up Rule

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Critical Treatment Techniques In ESDM

Optimize **child motivation**:

- Follow the child’s lead
- Offer choices and build joint activities that expand on child goals (vs “imposing” activities based on unrelated goals)
- Monitor child’s cues to figure out what they want

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Critical Treatment Techniques In ESDM

Obtain **child’s attention**:

- Manage ‘competition’ with objects
- Position self in front of child (face to face)
- Use **positive affect**

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Critical Treatment Techniques In ESDM

Use **joint routines**:

- Child smiles, looks engaged and has **optimal positive arousal**)

69



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Critical Treatment Techniques In ESDM

Wait!

- Very important, but often hard
- Wait for the child to communicate they want you to do it again

70



70

Critical Treatment Techniques In ESDM

Wait!

71




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Critical Treatment Techniques In ESDM

1 Up Rule: Use language to narrate and expand child language

- Requesting
- Commenting
- Labelling
- Greeting
- Protesting



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PARTNERSHIP WITH FAMILIES

- Relevant across all effective interventions
- Parents are the number one experts on their child
- Parents are part of all activities and meetings
- Parents help set goals (negotiating priorities)
- Parents empowered to make informed decisions
- Parent coaching to support delivery of intervention at home (but do not replace therapists!). Child is part (not center) of family
- Parent/family needs (e.g. mental health) and priorities (e.g., employment) are part of plan

Adapted from slide courtesy of Giacomo Vivanti, Ph.D.



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What about interventions for older children & adolescents?

74

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Interventions for older kids with autism could provide some guidance

- This article may be helpful for educators:



Public School-Based Interventions for Adolescents and Young Adults With an Autism Spectrum Disorder: A Meta-Analysis
 Author(s) Catriona L. de Bruin, Jonathan M. Duppel, Dennis W. Moore and Neil T. Diamond
 Source: *Review of Educational Research*, December 2013, Vol. 83, No. 4 (December 2013), pp. 921-950
 Published by: American Educational Research Association
 Stable URL: <https://www.jstor.org/stable/24434221>

<https://www.jstor.org/stable/24434221>

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Emerging research on adolescents with autism suggests....

- Video modeling may be helpful for teaching skills

<https://youtu.be/w8Iv6Tt25u8>



- Types of behaviors that may benefit from video modeling
 - Vocational
 - Academic
 - Daily living skills
 - Conversation

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Antecedent-Based Approaches

- Focus on prompts/strategies to elicit the desired behavior
- Examples
 - Chaining – teaching tasks in steps & adding steps after mastering earlier ones
 - Prompting – providing consistent cues to elicit desired behavior

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Consequence-Based Approaches

- Focus on what happens after the behavior to increase or decrease the likelihood of occurrence
- Examples
 - Differential reinforcement of desired behavior
 - Praise

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**What about
problem
behaviors?**

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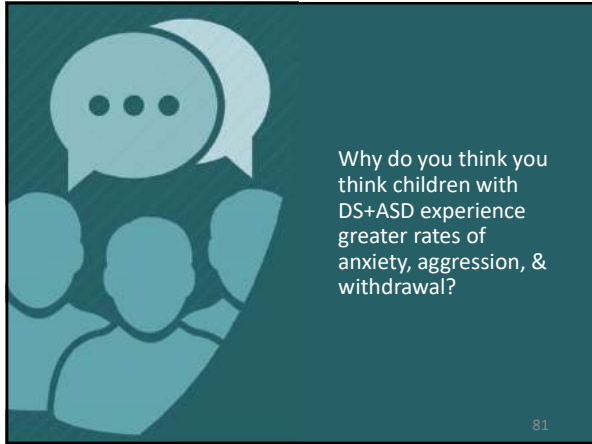
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Problem behaviors in DS+ASD

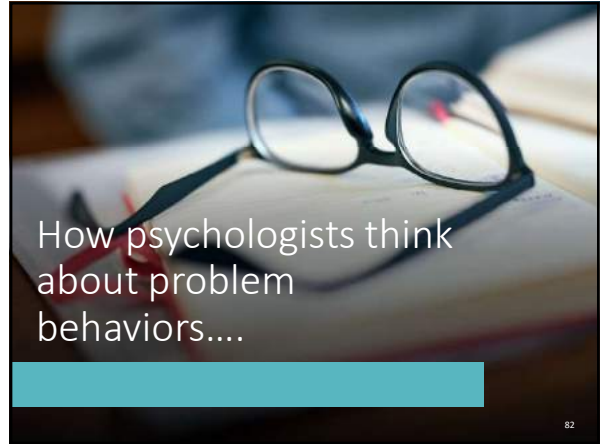
- Children with DS+ASD are more likely to experience
 - Anxiety
 - Aggression
 - Withdrawal

80

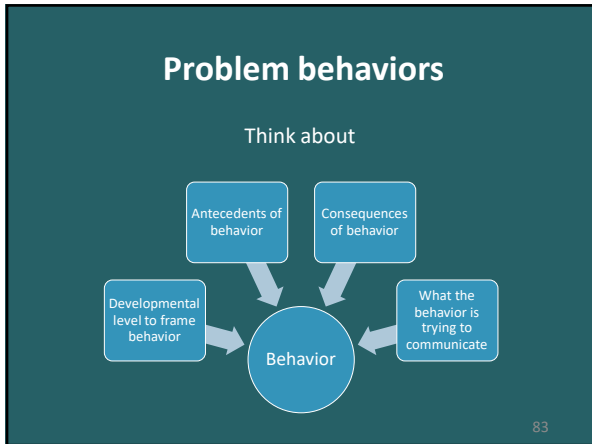
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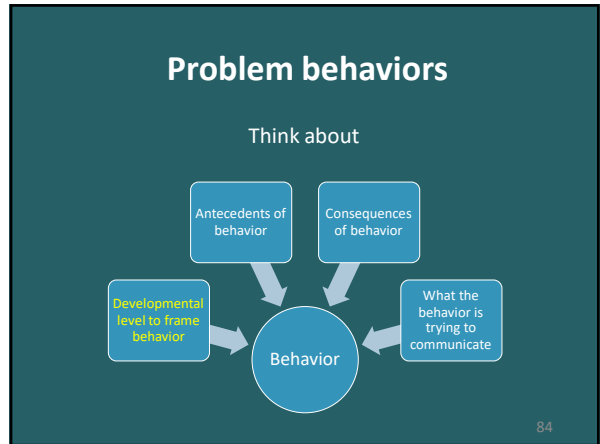
81



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Cognition + Problem Behavior

Important to “frame” behavior within context of *developmental level*

Expectations for 3-year-old

Expectations for 9-year-old

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Problem behaviors

Think about

Antecedents of behavior

Consequences of behavior

Developmental level to frame behavior

Behavior

What the behavior is trying to communicate

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Behavioral Assessment

Antecedent

Behavior

Consequence

87

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Problem behaviors

Think about

Antecedents of behavior

Consequences of behavior

Developmental level to frame behavior

Behavior

What the behavior is trying to communicate

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What is the child trying to communicate via the behavior?

COMMUNICATION-BASED INTERVENTION FOR PROBLEM BEHAVIOR
A User's Guide for Producing Positive Change
 Edward G. Carr
 Len Levin • Gene McConnachie
 Jane I. Carlson • Duane C. Kemp
 Christopher E. Smith
 Foreword by James W. Hall and David F. Winkler

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What is the child trying to communicate via the behavior?

Examples...

COMMUNICATION-BASED INTERVENTION FOR PROBLEM BEHAVIOR
A User's Guide for Producing Positive Change
 Edward G. Carr
 Len Levin • Gene McConnachie
 Jane I. Carlson • Duane C. Kemp
 Christopher E. Smith
 Foreword by James W. Hall and David F. Winkler

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Is there research on intervention for children with DS+ASD specifically?

- We are really just beginning to characterize the presentation of autism in children with DS
- So, we turn to clinical guidance from experts on DS+ASD to share ideas for intervention
- Research is needed on strategies to support individuals with DS+ASD across the lifespan

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Clinical Suggestions for Children with DS + ASD

Thank you to Susan Hepburn, Ph.D. & Debbie Fidler, Ph.D. for sharing their expertise on this topic.

92

Clinical recommendations for children with DS+ASD

- More direct intervention in social and communication, with an emphasis on functional, preverbal communication
- Active facilitated social support with peers

Hepburn & Fidler, 2012

Adapted from slide Courtesy of Susan Hepburn, Ph.D.

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Clinical recommendations for children with DS+ASD

- Planful approaches to teaching skills that fill in developmental gaps
- More time on teaching intentional requests
- Visual supports and predictable routines
- Overall, interventions designed for children with Autism are usually a better fit

Adapted from slide Courtesy of Susan Hepburn, Ph.D.

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Clinical recommendations for children with DS+ASD

- Development of leisure interests that they can look forward to and can encourage social engagement
- Active facilitated social support with peers, within highly preferred activities
- Consistent involvement in inclusive settings with predictable breaks that are long enough to be rejuvenating.

Adapted from slide Courtesy of Susan Hepburn, Ph.D.

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Clinical recommendations for children with DS+ASD

- Minimal distractors when learning a new skill – sometimes this means 1:1 or small group instruction is the appropriate format for learning new skills.
- A strength-based approach to learning new skills

Adapted from slide Courtesy of Susan Hepburn, Ph.D.

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Articulation/ Speech sound production

The screenshot shows the National Down Syndrome Congress website. The main heading is "Speech and Language". Below it, there is a paragraph of text and a list of resources. A URL <http://ndscenter.org/> is highlighted in blue. The website has a navigation menu at the top with categories like "ABOUT", "RESEARCH", "SELF-ADVOCATE", "AFFILIATE", "NEWS & EVENTS", "GOVERNMENT", and "OUR CHAIRS".

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Resource Guide to Oral Motor Skill Difficulties in Children with Down Syndrome

By Libby Kumin, Ph.D., CCC-SLP
Loyola College, Columbia, MD

Can be found on NDSC website: <http://ndscenter.org/>

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Resource for promoting intentional communication

The screenshot shows the website for The Hanen Centre, which has the tagline "HELPING YOU HELP CHILDREN COMMUNICATE". The article title is "Was That Intentional? Helping Young Children with Communication Delays Send Purposeful Messages" by Lauren Lowry, a Hanen Certified SLP and Clinical Staff Writer. The article includes a "PRINT" button and a small image of a woman and a child. The URL <http://www.hanen.org/helpful-info/articles/was-that-intentional--helping-young-children-with-.aspx> is visible at the bottom.

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What Happens When I'm Gone? Special Needs Planning for North Carolina Parents

Paul Yokabitus
Cary Estate Planning
919-659-8439
paul@caryestateplanning.com
www.caryestateplanning.com
Office in Cary and Wake Forest NC

1

What You'll Discover

- By the end of this webinar, you'll discover that:
 - Planning ahead for a child with Special Needs can be easy
 - Benefit Maintenance is Crucial
 - Trusted Individuals
 - Planning is important for YOU TOO
- Peace of Mind



2

This is For You if Your Are

- Frustrated with all the misinformation and confusion surrounding special needs planning and the conflicting advice you've been given
- Worried about staying involved in the conversation and decision making
- Worried about protecting benefits
- Worried about protecting assets for immature or young kids after you're gone
- Interested in making sure what you want WILL happen



3

Welcome, I'm Paul

- Just an average kid from Michigan
- Inspiration
- The System is Not Fair
- Beware of "Dabblers"



4

How You Can Protect Your Child and Their Public Benefits No Matter What

5

What is Special Needs Planning?

Estate Planning that uses unique tools designed to help disabled beneficiaries receive wealth while maintaining public benefits

6

What Do I Mean By “Special Needs?”

- Currently Eligible/Receiving Benefits
- May become eligible in the future
- No benefits? May still need asset management...



7

What Does Planning Look Like?

- Overall family planning (Estate Planning)
- Planning for “special needs” beneficiaries
- Common tools combined with specialized tools
- Minimizing or Eliminating Risks



8

Do All Individuals with Disabilities *Require* Special Needs Planning?

- Planning is needed for individuals who:
 - Are “disabled”, AND
 - Must maintain eligibility for means-tested programs



9

Which Benefits Need Protecting?

10

Types of Benefits

- Means-Tested Federal Programs
 - SSI
 - Medicaid
 - Section 8
- State-Based Programs
 - Food Stamps
 - NC Special Assistance
- NOT Entitlement Programs (**NOT** what we plan for)
 - SSDI (work credits)
 - Medicare

11

What Does SSI Provide?

- Monthly cash grant for food and shelter for:
 - Disabled
 - Blind, or
 - Aged (65+)
- 2020: maximum payment is \$783/month
- North Carolina supplement

12

Resource Caps: What We Plan For

Asset and income levels are critical for means-tested benefits

13

SSI Resource Test

- “Countable Resource” limits for SSI:
 - \$2,000 for an eligible individual
 - \$3,000 for an eligible couple
 - Measured on a month-by-month basis on the first day of each month
 - “Snapshot Test”

14

Countable Resources Under SSI

- Anything that’s not “non-countable” or “exempt”
- Examples:
 - Real Property other than a personal residence;
 - A second vehicle
 - Life insurance policies with a face value of >\$1,500
 - Cash
 - Stocks
 - Bonds
 - Bank Accounts
 - “Deemed Resources”

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Planning Tools

Special Needs Trusts and ABLE Accounts (it’s not one or the other)

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ABLE Accounts (529A)

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ABLE Accounts – the Newest Planning Tool

- ABLE Act
- Tax-advantaged savings accounts
- Beneficiary is account owner
- Income earned is not taxed.
- Contributions by anyone, not deductible

18

Why the Need for ABLE Accounts?

- Increase Access
- "secure funding ... [and] supplement but not supplant, public benefits."

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ABLE Account "Pros"

- Self-funded (of "First Party")
- Non-countable
- Autonomy
- Tax advantaged
- Easy set up

20

“Cons” of the ABLE Account

- < 26 years old.
- Potential predators
- Contribution limits:
 - \$15,000 per year
 - \$100,000 total
- Could still affect government assistance
- Only cash or securities, no tangible or real property
- Medicaid Payback

21

Special Needs Trusts (SNTs)

22

Special Needs Trusts – Total Protection w/o Limits

- Sole purpose: Protecting a beneficiary's government benefits
- Not an average trust
 - CANNOT STRESS THIS ENOUGH!!!!

23

Third Party Trusts

- Source of Funds: Anyone but the beneficiary
 - During Grantor's Life (gifted assets)
 - At Grantor's Death (life insurance, estate assets, retirement assets)
- Trustee(s)
- Remainder beneficiaries
- *No Medicaid Payback*
- Trustee: Absolute discretion
- Revocable

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Special Needs Trusts Created Before 2016

- Should be reviewed and (likely) updated because of the ABLE Act of 2016
- If your trust was not created by a Special Needs Planning lawyer, it should also be reviewed for fatal distribution language.

25

Adult Guardianship or POAs

Is it right for your child?

26

Incompetency: The Deciding Factor

- Clerk of Court
- Totality of Circumstances
- GAL
- Due Process

27

What Do We Do?

- Adult Guardianship can begin at 17 years and 6 months
- Alternatives
 - Powers of Attorney
 - Rep Payee for SSI

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How Does Special Needs Planning Work?

Meet the Jones Family

29

The Jones Family

- John (47) and Mary (45) Jones
- 3 Kids:
 - Jennifer (21) – College Senior, majoring in Accounting
 - Jason (17) – Senior in high school
 - Scott (14) – Diagnosed with Down Syndrome, parents plan to apply for SSI and Medicaid when Scott turns 18; they'll also make a plan for Guardianship or POAs when he's 17.

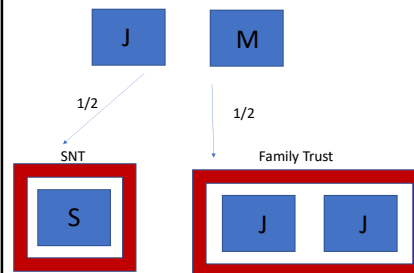
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Planning for the Jones Family

- Jennifer and Jason
- Scott's needs
- Planning for Now and Planning for the Future

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The Jones Family Plan



Key Points

- Intentional Planning
- Legal Poverty
- Supplemental Support
- Protects all Benefits
- Planning for Everyone
- Nothing to Fix Later

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What if They Had Planned Differently?

Regular Trust

- Held by a Trustee
- Immediately "Countable"
- Benefit Suspension
- Benefit Elimination
- Unintended Consequences
- First Party SNT

Just a Will

- Outright to Scott at 18
- Immediately "Countable"
- Benefit Suspension
- Benefit Elimination
- Guardianship?
- First Party SNT

No Plan At All

- Outright to Scott at 18
- Immediately "Countable"
- Benefit Suspension
- Benefit Elimination
- Guardianship?
- First Party SNT

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You Can't Just Do Nothing – A Lack of Intentional Planning Will Jeopardize Your Child's Future

34

You Can Protect Your Child and Their Public Benefits No Matter What

35

How Do I Make That Happen?

www.caryestateplanning.com/meeting

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The Down Syndrome Diet: Changing the 'Course' Through Nutrition

Jennifer L. Kimes, Psy.D.
Down Syndrome of Louisville, Inc.
Louisville, Ky

1

Common co-occurring issues for Individuals with DS

- Hashimoto Thyroiditis
- Diabetes
- Obesity
- Seizures
- Allergies
- ADHD
- Sleep problems
- Arthritis
- Celiac Disease
- Autism
- G I problems
- Alzheimer's
- Recurrent infections (suppressed immune system)

2

Shared Nutritional Deficiencies

Autism	Vitamin A	Down syndrome
Autism	Vitamin D	Down syndrome
Autism	Selenium	Down syndrome
Autism	B12	Down syndrome
Autism	Zinc	Down syndrome
Autism	Glutathione	Down syndrome
Autism	Digestive Enzymes	Down syndrome

3

Deficiency Comparison

Autism	EPA	
Autism	Taurine	
Autism	Folate	
Autism	Vitamin C	
Autism	B6	
Autism	Vitamin E	Down syndrome
Autism	Elevated antibodies to milk	
Autism	Elevated antibodies to grains	
Autism	Imbalance in bacterial flora in the gut	

4

Autism and GF/CF Diet

- 45% of people with Autism Spectrum Disorders have gastrointestinal problems.
- Caregivers have been utilizing GF/CF diet for the past several years with 40% reporting a reduction in symptomatology and even 'recovering' children from Autism.
- 3-6% prevalence rate of Celiac Disease in the DS population.

5

What is Celiac Disease?

An autoimmune disorder where the ingestion of gluten leads to damage in the small intestine.

It is estimated to affect 1 in 100 people worldwide.

Rate of celiac in the general population has quadrupled in the past 50 years.

Wheat has changed!

6

Leaky Gut/ Intestinal Permeability

- Gluten protein, gliadin triggers Zonulin.
- A protein that increases the permeability between cells of the wall of the digestive track.
- Leads to inflammation and can cause neurological, autoimmune and mental health problems.
- Gluten interferes with the breakdown and absorption of nutrients.

7

Gluten Sensitivity

- Antibodies to the gluten are activated and inflammatory cytokines begin collecting & attack the brain.
- Elevated cytokines are seen in Alzheimer's Disease, Parkinson's Disease, MS and Autism
- "Gluten sensitivity can be primarily, and at times, exclusively a neurological disease" – Dr. Hadjivassiliou
- Therefore, you can have issues with brain function without having any gastrointestinal problems.
- Gluten disables the immune system (Perlmutter)

8

What Else Can Gluten Do?

- Link between gluten sensitivity and Hashimoto's thyroiditis – Dr. Perlmutter
- Depression & anxiety are often severe in patients with gluten sensitivity.
- Cytokines block production of serotonin (essential for mood regulation)
- Elimination of gluten and often dairy, many patients have been freed from not just a mood disorder but other conditions caused by an overactive immune system, like allergies and arthritis.

9

Cognitive Impairment and Diet

- 2006 Mayo Clinic report – link between Cognitive impairment & Celiac Disease
 - Patients w/ sx's of dementia at a younger age (n=65 w/ range of 45 -79 years old).
 - Patients put on GF diet showed "significant improvement" in their cognitive decline.
 - Have researchers discovered a reversible form of cognitive impairment through diet?!

10

Inflammation

- Can have a positive side effect when it helps your body respond to illness, through a fever and eliminates the virus.
- However, chronic, low-grade inflammation is thought to be one of the leading causes of disease, premature aging, and illness.
- Inflammation is involved in virtually every chronic disease.

11

Oxidation and Antioxidants

- At the center of chronic inflammation is the concept of oxidative stress. Oxidation in the brain releases a chain of events that creates free radicals and stirs inflammation. Oxidized tissues and cells don't function normally & can lead to health issues.
- Conversely, reduced oxidation lowers inflammation - antioxidants are very important for this reason.

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Gluten-free Caution

- If going gluten-free, be careful of added sugars to help with taste and texture
- Avoid GMOs: 98% of soy, 88% of corn, and 98% of rice are GMO.
- Rice allowed in USA has high levels of arsenic.
- If using nut-based foods as a replacement, ensure a nut allergy has been ruled out.

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The Typical DS Diet

Infants: formula, filler cereals (rice or gluten-based), yogurt

Toddlers: puffs, cereal, crackers, juice, yogurt, milk, pasta, potatoes, Pediasure

Children: pizza, pasta, breads, breaded meats, cereal, crackers, cookies, french fries, sandwiches, juice, fruit punch

Adults: soda (diet or regular), fruit punch, potatoes, breads, breaded meats, pasta

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Sugar Count

- AHA daily limit of sugar for children (based upon a 1,000-1,200 daily calorie intake) is 4 teaspoons (16 grams).
- However the Ave. child age 1-3 years consumes approx. 13 tsp. of added sugar/day.
- Ave. child age 4-8 years consumes approx. 21 teaspoons.
- Teenagers 14-18 years consume 34.3 teaspoons.
- The average adult consumes 22.2 teaspoons.

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Sugar Content

- 12-oz can of soda = 39 grams
- 4 oz vanilla yogurt = 17 grams
- 8 oz applesauce = 36 grams
- 1 Poptart = 20 grams
- 5 oz package of fruit snacks = 10 grams
- 8 oz apple juice = 23 grams
- 8 oz Pediasure = 18 grams (chocolate = 23)

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Sugar & Alzheimer's

- ▶ Becoming diabetic doubles your risk of Alzheimer's disease.
- ▶ Diabetes has tripled in the past 40 years.
- ▶ Half the people with diabetes will develop Alzheimer's disease (2011 study)
- ▶ Alzheimer's is now being considered Type 3 Diabetes.

17

How does diabetes contribute to dementia?

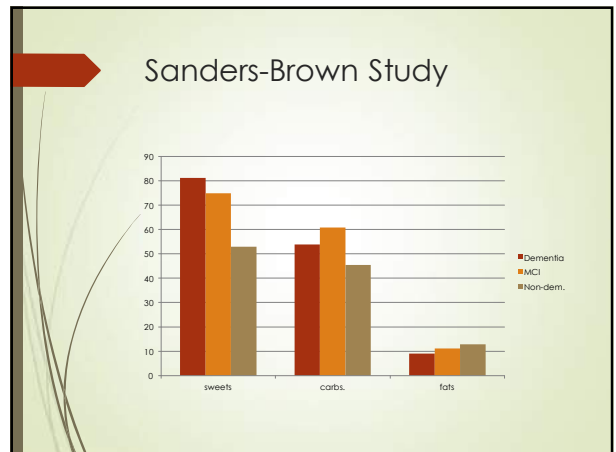
- 1) If you're insulin resistant your body may not be able to break down the protein (amyloid) that forms brain plaques associated with brain disease.
- 2) high blood sugar provokes the production of oxygen-containing molecules that damage cells and causes inflammation that can result in hardening and narrowing of the arteries in the brain.
- 3) This condition known as atherosclerosis can lead to vascular dementia which occurs when blockages and strokes kill brain tissue.

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Free Radicals & Oxidative Stress

- ▶ We know that oxidative stress is directly related to brain degeneration & cognitive decline.
- ▶ If you want to reduce oxidative stress and the action of free radicals from your brain, you have to reduce the glycation of proteins: You have to LIMIT your body's access to SUGAR.
- ▶ Most dangerous are refined sugars, which are packed in virtually all processed foods & hidden in "healthy" foods, especially fat-free foods.

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Bad Sugar – Good Fat

- LDLs (the so-called bad cholesterol) are an important carrier protein bringing vital cholesterol to brain cells.
- Problems arise when LDLs become oxidized.
- When LDLs become glycated (or mix with sugar) there is a dramatic increase in oxidation and a 50X increase in free radicals.
- Then, they cannot present cholesterol to brain cells and brain function suffer.

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We Need Brain Fat

- Obesity and its metabolic consequences has almost nothing to do with dietary fat consumption and everything to do with our addiction to carbohydrates .
- Eating high cholesterol foods has no impact on our actual cholesterol levels.
- The alleged correlation between high cholesterol and higher cardiac risk is an absolute fallacy.
-Dr. Perlmutter

22

Fat Brain


- Good fats like Omega-3s and monosaturated fats reduce inflammation.
- Modified hydrogenated fats dramatically increase inflammation.
- In addition, certain vitamins (A, D, E, and K) require fat so they can be absorbed properly.
- These fat-soluble vitamins need dietary fat to transport them through the body.
- Because vitamins do not dissolve in water they can only be absorbed from your small intestine in combination with fat.

23

Cholesterol Extends Longevity

- Correlation between higher cholesterol levels and decreased mortality.
- No difference in the risk of dying from coronary artery disease between the high versus low-cholesterol groups.
- Mortality from cancer & infection was significantly lower among the participants in the highest total cholesterol category.


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Protecting Your Brain

- DHA brain boosting molecule
- More than 2/3 of the dry weight of the human brain is fat. Of that fat, 1/4 is DHA.
- An important building block for the membrane surrounding brain cells, particularly the synapses.
- An important regulator of inflammation. It can fight back inflammation and it can block the damaging effects of a high sugar diet and help prevent metabolic dysfunction in the brain that can result from a high-carb. diet.


25



Fish Oil & Antioxidant Protection

- Decreased levels of free radical damage in individuals who consume fish oil (the source of EPA and DHA)
- Omega-3 fats EPA and DHA produce powerful antioxidants and detoxification enzymes.
- Consuming more than 2 servings of fish/week was associated with a 59% reduction in the occurrence of Alzheimer's disease.

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Increase Omega 3 Fatty Acids

Harvard Medical School Professor George Cahill - recent studies have shown that coconut oil:

- * improves antioxidant function
- * increases the number of mitochondria
- * stimulates the growth of new brain cells
- * helps repair myelin sheath


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Are All Oils Created Equal?

- Vegetable oil has omega 6 which is pro inflammatory.
- The recommended ratio of omega-6 to omega-3 is anywhere from 1: 1 to 4:1
- The typical American diet averages are 20:1.


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Casein

- Casein is the protein found in mammal's milk.
- A casein allergy occurs when your body's immune system mistakenly thinks the protein is harmful and inappropriately produces allergic antibodies for protection.
- The interaction between these antibodies and the specific protein triggers the release of body chemicals such as *histamine*.


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Reactions could include:

- Skin reactions: hives, rashes, red or itchy skin
- Nasal congestions, runny nose, coughing, sneezing, wheezing, itchy or watery eyes
- Swelling of the lips, tongue, mouth, face or throat
- Less severe reactions: cramping, flatulence, nausea, diarrhea and/or constipation

30



Dairy Sensitivity

- People can be lactose sensitive without having a full blown milk allergy.
- Recent estimates indicate that approximately 60 % of Americans and 75% of people world-wide are lactose sensitive.

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Foods that Contain Casein

- Milk, Cream, Half and Half, and Butter
- Yogurt, Puddings and Custards
- Sour Cream and Cheese
- Chocolate
- Baby Formula
- Ice Cream & Sherbert
- Soup Bases
- Whey
- Creamed Soups and Vegetables

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Milk Comparison

	2% cow	Skim cow	Unsweet Almond	Cocnut	Rice
Calcium	30%	30%	45%	45%	30%
Vitamin A	9%	10%	10%	10%	10%
Vitamin D	26%	25%	25%	25%	25%
Fat	3g	0.1g	3g	5g	2.5g
Sugar	12g	12g	0g	0g	10g
Calories	122	83	40	50	120

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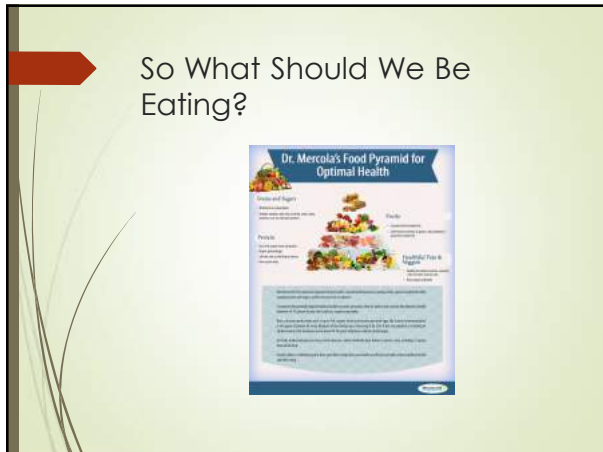
So What Should We Be Eating?

Medeterranean?
 Dr. Mercola?
 Keto?
 Paleo?
 Atkins?

↓
 ↓
 ↓

refined sugar & simple carbs
gluten & dairy
Healthy Fats

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35

Anti-Inflammatory Foods

- Fermented foods
- Lightly steamed broccoli
- Oils with Omega-3 fatty acids
- Wild fatty fish (salmon, cod, sardines)
- Tart cherries
- Soaked walnuts
- Onions and garlic
- Pineapple
- Spinach
- Turmeric and ginger


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Curcumin

- Curcumin (turmeric) and its impact on the brain is currently the subject of intense scientific inquiry especially.
- Has been used for thousands of years and traditional Chinese and Indian medicine.
- The prevalence of dementia is markedly reduced in communities where turmeric is used in abundance.
- Co q-10 has been proposed as a treatment for Alzheimer's disease.

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Low-Carb/High Fat Diet

- Consuming fats, such as MCT oil or coconut oil, has been shown to impart significant improving cognitive functioning in Alzheimer's patients.
- A very low carb. diet has been shown to reduce amyloids in the brain & increase glutathione (the body's natural brain protection).

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Glutathione

- One of the most important detoxification agents in the human body: made up of 3 amino acids: glutamine, glycine and cysteine.
- Serves as a major antioxidant - helping to protect the cell from free radical damage and protecting the mitochondria.
- Detoxification - renders various toxins less noxious & makes them more water soluble so they can be more easily excreted.
- To support Glutathione production, eat sulfur-rich foods, Vitamin C and Selenium-rich foods.

39



Fermented foods

Fermented foods are foods that have been through a process of lactofermentation in which natural bacteria feed on the sugar and starch in the food creating lactic acid.

This process preserves the food, and creates beneficial enzymes, b-vitamins, Omega-3 fatty acids, and various strains of probiotics.

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When Food May Not Enough

Supplementing with:

- * Antioxidants – CoQ10
- * Probiotics
- * Fish and/or mct oil
- * Multivitamin
- * Glutathione
- * Vitamins B, D, C, & E
- * Digestive enzymes
- * Calcium (if dairy-free)

Always consult your health-care provider

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Exercise

Exercise is a potent anti-inflammatory & it improves insulin sensitivity.

Dr. Aaron Buchanan (Rush University Memory and Aging Project) found that the risk of Alzheimer's was nearly tripled in people who exert themselves the least.

Daily 20 minutes moderately vigorous activity.

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Sleep

Sleep affects the hormone called leptin, which is a pro-inflammatory molecule & is negatively influenced by carbs with refined and processed carbs causing even greater imbalance to leptin levels.

Leptin also influences our cravings for carbohydrates.

Healthy levels of leptin prevent most diseases of aging.

No single drug or supplement can balance leptin levels; however better sleep & better dietary choices can.

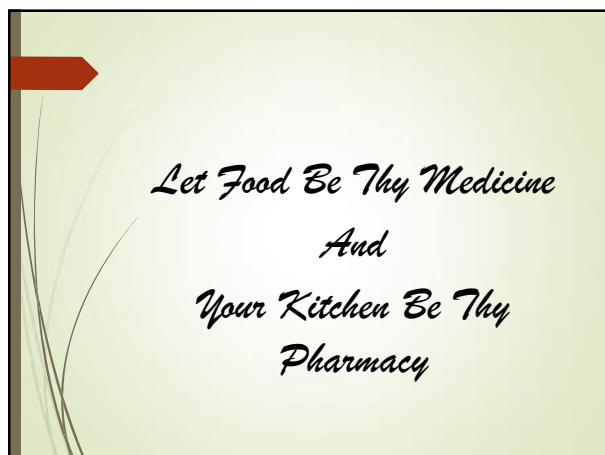
Consider the incidence of sleep apnea in the DS population.

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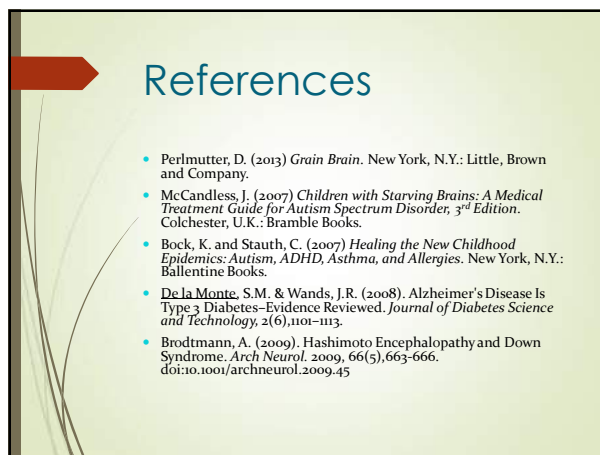
Take Away

- Impact of gluten and casein on health and increased sensitivities in DS population.
- Importance of processed sugar and healthy fats and the relationship to Alzheimer's disease.
- Can we reverse Autism or minimize the associated symptoms?
- Can we change the Course of the "inevitable" Alzheimer's disease for our members?

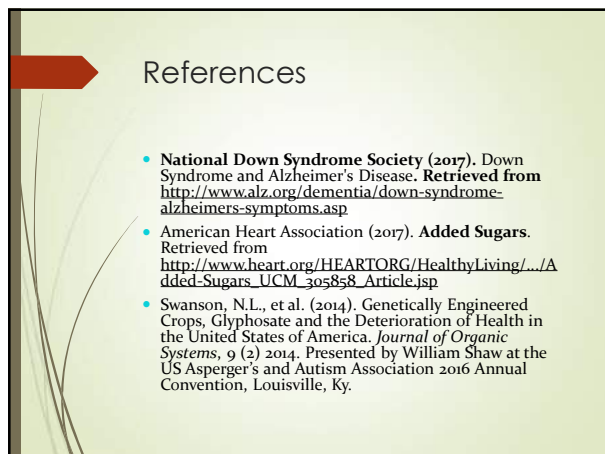
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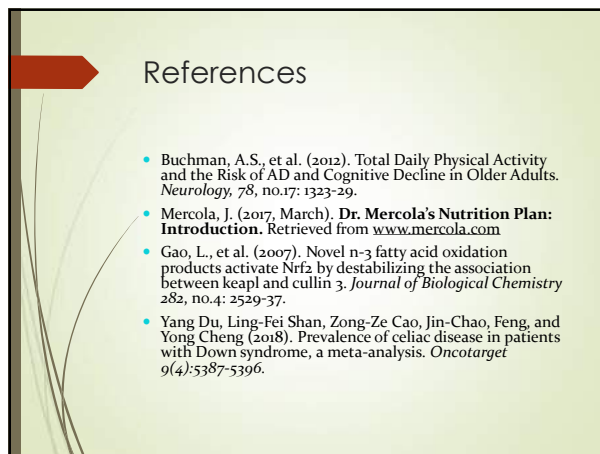
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**Alzheimer's and Dementia
in Down Syndrome**

Dr. Jim Hendrix
Chief Scientific Officer

November 13, 2021

1



Agenda

- Introduction to LuMind IDSC Foundation
- Advances in Down syndrome research
- What do we know about Alzheimer's in Down syndrome?
 - What is dementia and what are common symptoms?
 - What is the difference between regression and Alzheimer's disease?
 - Tips for caregivers
 - Free resources available to caregivers
- Research on Down Syndrome Associated Alzheimer's Disease
- What can you do to fight Alzheimer's and support research?
- Questions


2

**LuMind IDSC is Inspired
and Led by Families**



3

**Our Vision
& Mission**



LuMind IDSC Foundation envisions a world where every person with Down syndrome thrives with improved health, independence, and opportunities to reach their fullest potential.

Our mission is to accelerate research to increase the availability of therapeutic, diagnostic and medical care options, and to empower families through education, connections and support.


4

Focus Areas & Research Strategies

Focus Areas	Research Strategies
<ul style="list-style-type: none"> • Research Awareness • Accelerating Research • Empowering Families 	<ul style="list-style-type: none"> • Alzheimer's Disease • Sleep Apnea • Independence/Cognition • Gene Therapy • Access to Treatments

5

LuMind IDSC COVID-19 Family Resources



1. COVID-19 Resources on our website
2. COVID-19 Q&A
 - Co-led and disseminated with 7 DS organizations
3. T21RS/Emory survey on DS COVID-19 cases
 - Co-funded and disseminated by 8 DS organizations

All resources are available on LuMind IDSC's website in the COVID-19 Resources section (www.lumindidsc.org/covid19)

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Leveraging Partnerships for Community Impact

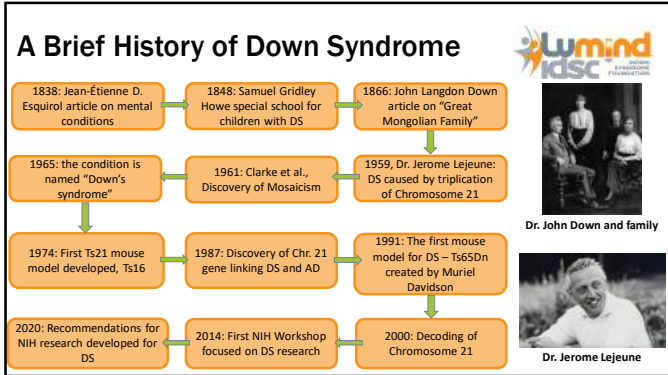


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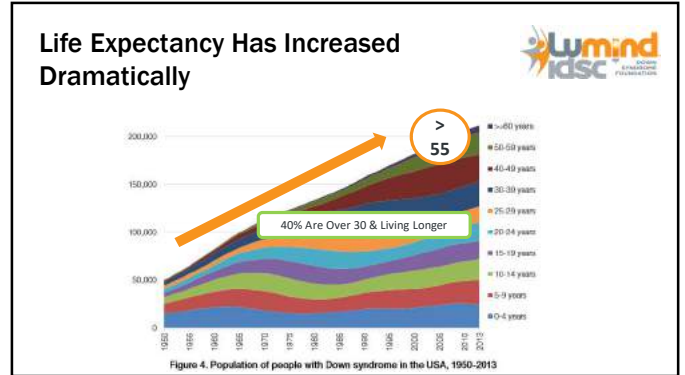
Advances in Down Syndrome Research



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10

What Has Increased Life Expectancy?

Medical Advances

- Heart Surgery
- Early Intervention
- Ear Tubes
- Glasses
- CPAP Mask
- Treatments for Thyroid Disorder
- Meaningful Inclusion

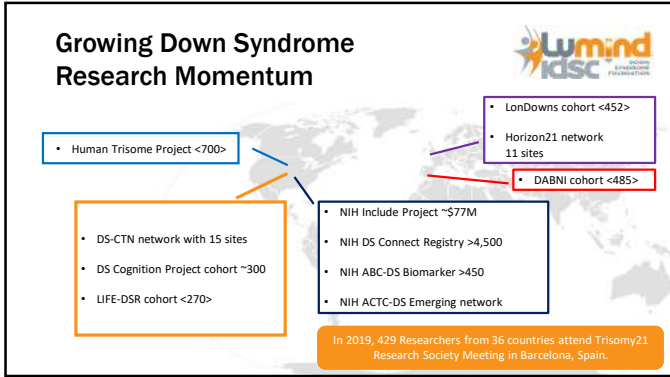
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What challenges are still unsolved?

Still Unmet Needs

- Forms of Leukemia
- Form of Immune Condition
- Sleep Apnea or Disorder
- Speech Difficulties (Nonverbal)
- Alzheimer's Disease

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Research & Trials Pipeline

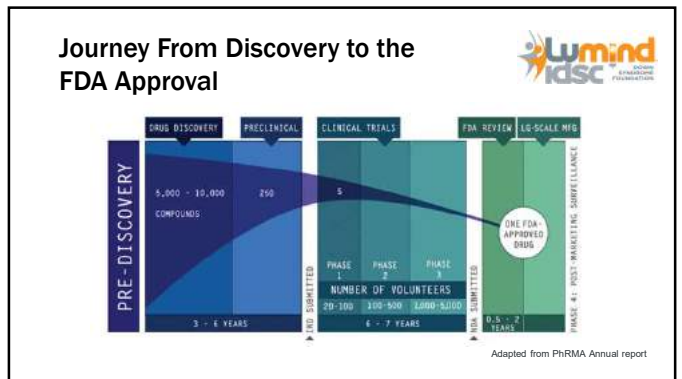
Approach	Potential Impact	Age Range of Therapy	Time to Trials
Hypoglossal Stimulation	Sleep, Speech, Cognition	Adolesc., adults	Ongoing
Infant Learning	Independence, learning	Infant/toddlers	Ongoing
Amyloid beta	Independence, Alzheimer's	Adults 30+	Ongoing
Drug combinations	Sleep, Cognition	Lifespan	2020
JAK Inhibitors	Immune, skin, alopecia, other	Lifespan	2020
Digital Medicines	Independence, speech, Executive Function	Lifespan	1+ years
Tau targeting	Independence, Alzheimer's	Adults 30+	1+ years
Gamma wave device	Independence, Alzheimer's	Adolesc., adults	1+ years
Dyrk1a target	Independence, Cognition	Early, Lifespan	3+ years
Meylination target	Independence, Communication	Early to Adult	3+ years
Gene therapies	Independence, Alzheimer's, Infection	Early, Lifespan	3+ years

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Drug Trials in Down Syndrome

Drug Name	Company	Population	Mechanism	Phase	Start Date	Expected Completion
AC Enzyme	ACT-24	24 adults age >50-65	Acetylcholinesterase	Phase 1	2019	June 2021
U. of Arizona	Acetylcholinesterase inhibitors	27 children 6-17 years of age	Acetylcholinesterase inhibitors	Phase 1	2019	September 2021
U. of Arizona	Acetylcholinesterase inhibitors	27 children 6-17 years of age	Acetylcholinesterase inhibitors	Phase 1	2019	September 2021
U. of Arizona	Acetylcholinesterase inhibitors	27 children 6-17 years of age	Acetylcholinesterase inhibitors	Phase 1	2019	September 2021
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U. of Arizona	Acetylcholinesterase inhibitors	27 children 6-17 years of age	Acetylcholinesterase inhibitors	Phase 1	2019	September 2021
U. of Arizona	Acetylcholinesterase inhibitors	27 children 6-17 years of age	Acetylcholinesterase inhibitors	Phase 1	2019	September 2021
U. of Arizona	Acetylcholinesterase inhibitors	27 children 6-17 years of age	Acetylcholinesterase inhibitors	Phase 1	2019	September 2021

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What Are Clinical Trials?

Lumind idsc DOWN SYNDROME RESEARCH FOUNDATION

- Clinical research that is performed on humans.
- **Double-blind placebo-controlled trials** are the gold standard for determining the safety and efficacy of a new treatment. **Be skeptical of results from other types of trials!**
- The **drug development process** is long, expensive and risky but still the best way to find new treatments.
- Typically **3 phases in clinical trials** in the drug development process.

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What Are Clinical Trials?

Lumind idsc DOWN SYNDROME RESEARCH FOUNDATION

- New **cognitive tests are needed** for Alzheimer's disease in Down Syndrome.
- Independent oversight of trials ensures high **ethical standards**.
- **Informed consent** is used to protect the rights of people participating in clinical trials.
- Clinical trial **results should be published** in a timely manner.

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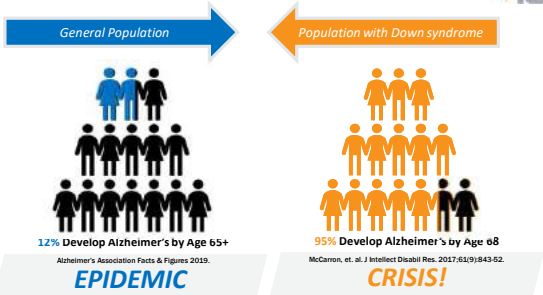
What Do We Know About Alzheimer's in Down Syndrome?

Lumind idsc DOWN SYNDROME RESEARCH FOUNDATION

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Risk Compared to General Population

Lumind idsc DOWN SYNDROME RESEARCH FOUNDATION

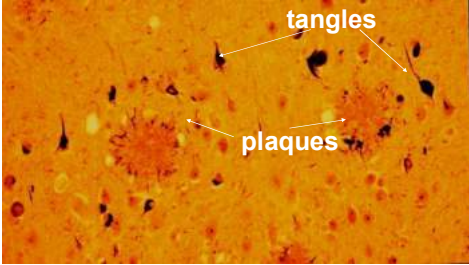


12% Develop Alzheimer's by Age 65+
Alzheimer's Association Facts & Figures 2019. **EPIDEMIC**

95% Develop Alzheimer's by Age 68
McCarroll, et. al. J Intellect Disabil Res. 2017;61(9):843-52. **CRISIS!**



20

History of Alzheimer's Disease



tangles

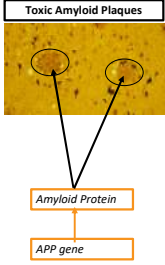

plaques

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Alzheimer's
Disease
Association

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Down Syndrome & Alzheimer's Genetics

Toxic Amyloid Plaques

Amyloid Protein

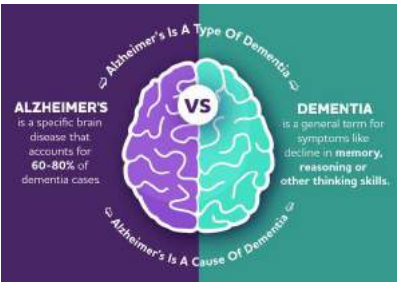
APP gene

The amyloid precursor protein gene (APP) is located on chromosome 21

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Alzheimer's vs. Dementia



ALZHEIMER'S is a specific brain disease that accounts for 60-80% of dementia cases.

VS

DEMENTIA is a general term for symptoms like decline in memory, reasoning or other thinking skills.

Alzheimer's Is A Type Of Dementia


Alzheimer's Is A Cause Of Dementia

Source: Alzheimer's Association

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Disease
Association

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Common Alzheimer's Symptoms





- Memory deterioration
- Loss of previously mastered skills
- Incontinence
- Unsteady gait
- Dysphagia (swallowing)
- Seizures
 - Higher rate (77% vs 2-25%)
- Weight loss
- Psychological changes

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Disease
Association

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Progression Over Time

- Alzheimer's is a disease of progressive decline
 - Rate of decline varies from person-to-person and over time
 - Plateaus, sudden drops, etc.
- Possible causes of sudden changes
 - Stroke
 - Infection
 - Depression
 - New onset or change in metabolic condition (e.g., diabetes)

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Alzheimer's or Regression?



What is similar?


- Both involve decline in skills
- Both are (probably) neurological conditions that often have psychological symptoms
- Both are challenging for the individual and families
- Both need more research, including ways to support the individual and family

What is different?

- Alzheimer's disease
 - Age of onset = > 40
 - Not reversible
- Regression syndrome
 - Age of onset = teens, early 20s
 - Sometimes reversible
- Not all decline in skills in those age ranges is either Alzheimer's disease or regression

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Alzheimer's Treatments



FDA Approved Drugs



- Cholinesterase inhibitors (e.g., donepezil / Aricept)
- NMDA receptor antagonist (memantine / Namenda)
- Anti-Amyloid Monoclonal Antibody: Aduhelm (aducanumab)

Non-Drug Strategies

- Create schedules and routines
- Promote lifestyle changes:
 - Sleep
 - Healthy eating
 - Physical activity
 - Encourage safe social interactions

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Tips for Caregivers

Communication

- Provide simple instructions
- Do not argue, you will not win
- Avoid asking them if they remember
- Smile
- Try not to raise your voice - speak calmly with a slow pace
- Get down on their level (eye-to-eye)

28

Tips for Caregivers




Home Safety

- Contrasting colors in the bathroom
- Adequate lighting in home
- Remove unnecessary furniture and mirrors
- Add handrails and ramps
- Add reflective tape on stairs
- Remove tripping hazards such as throw rugs
- Add a deadbolt out of reach or alarm on main doors and remove locks on interior doors to prevent person from locking themselves in
- Lock up medications and cleaning supplies

29

Resources for Caregivers




A free, online library of 700+ trusted resources and useful tools for people with Down syndrome and their families that can be personalized to each member's interests.

Registering is easy – and free - at www.myDSC.org






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Resources for Caregivers





DS-AD specific resources on LuMindIDSC.org

Guides, explainers, webinars, and more - in English and en Español

www.lumindidsc.org/alzheimersdisease





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Research on Down Syndrome Associated Alzheimer's Disease

32

Global Dementia May Be Preventable

Published in July 2018

➤ **Early life**

1. Education to age 15

➤ **Mid-life**

2. Hypertension
3. Obesity
4. Hearing loss


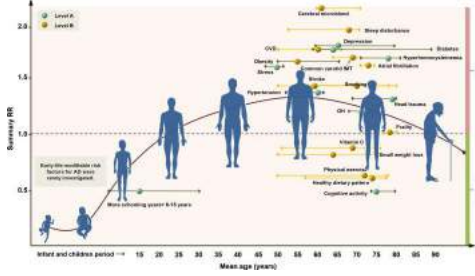
➤ **Later life**

5. Depression
6. Diabetes
7. Physical inactivity
8. Smoking
9. Low social contact

35%

33



Alzheimer's Prevention?

Yu, et al., Evidence-based prevention of Alzheimer's disease: systematic review and meta-analysis of 243 observational prospective studies and 153 randomised controlled trials. J Neurol Neurosurg Psychiatry, 2020 Nov;91(11):1201-1209.

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Diagnosis: What is a Biomarker?

- Biological marker to measure change
- Reliable predictor and indicator of disease and disease progression
- **Examples include:**
 - Glucose for insulin resistance and diabetes
 - T cell count for HIV/AIDS
 - Cholesterol for heart disease

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Diagnosis: What is a Biomarker?

- **Uses in Alzheimer's disease include:**
 - diagnostic – for determining diagnosis;
 - enrichment – for reinforcing entry criteria into a clinical trial;
 - prognostic – for determining course of illness and
 - predictive – for treatment outcomes and safety assessment

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The crisis of AD in DS is monumental with dementia prevalence nearing 100% by age 70




	Aβ 42	Aβ 40	
12 yo			<p>"Virtually all adults with DS develop neuropathology consistent with Alzheimer's by their 40s."</p> <p>Source: Lemere et al., Neurobiol Dis, 1996</p> <p>Clinical dementia in DS estimates:</p> <ul style="list-style-type: none"> - 50% by age 55 - 70% at age 55-60 - 95% by age 68 <p>Sources: McCarron, et. al. J Intellect Disabil Res. 2017;61(9):843-52. Harley et al., Alzheimer's Dementia, 2015; McCarron et. al. J Intellect Disabil Res. 2014;58(1):61-70.</p>
17 yo			
29 yo			

37

Five year, NIH Biomarker Study




NIA/NICHD funded \$46M ABC-DS biomarker study on ~500 participants over 5 years



- 1. Direct cognitive and functional measures** (tests of memory, visual spatial construction, language, executive processing and speed, mental status, and gait)
- 2. Caregiver questionnaires** (queries on functional abilities, mental status, neuropsychiatric symptoms, and dementia screening)
- 3. Medical and neurological assessments** (personal and family health history, medication usage, and a brief physical and neurological examination)

38

Five year, NIH Biomarker Study




NIA/NICHD funded \$46M ABC-DS biomarker study on ~500 participants over 5 years

- 4. Neuroimaging biomarkers** (MRI-based measures of cortical thickness and volume, white matter abnormalities and connectivity, as well as amyloid-, tau-, and FDG-PET)
- 5. Blood-based biomarkers** (proteomics panel with proinflammatory markers, metabolomics panel, and assay of plasma Aβ peptides—Aβ40, Aβ42, Aβ40/Aβ42 ratio)
- 6. Genetic studies** (candidate analysis focusing on variants in genes associated with AD and with individual differences in blood-based, imaging, and CSF biomarkers found to be associated with clinical disease progression including Aβ42, P181-tau, and total tau)

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PET Beta Amyloid Imaging

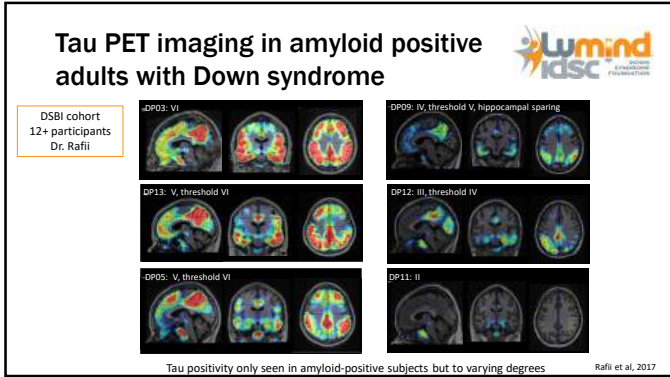


Normal Aging			
Alzheimer's Disease			

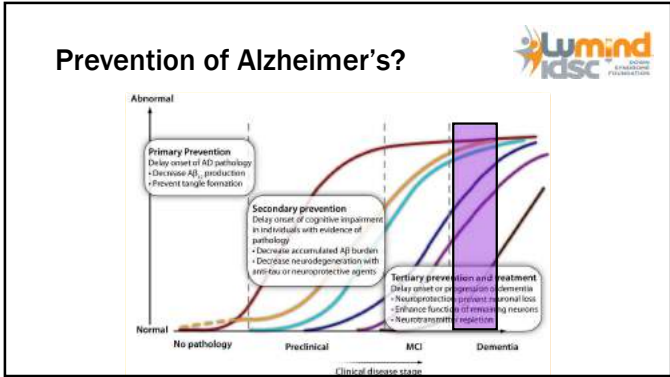
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Figures courtesy of Drs. Keith Johnson/Reisa Sperling

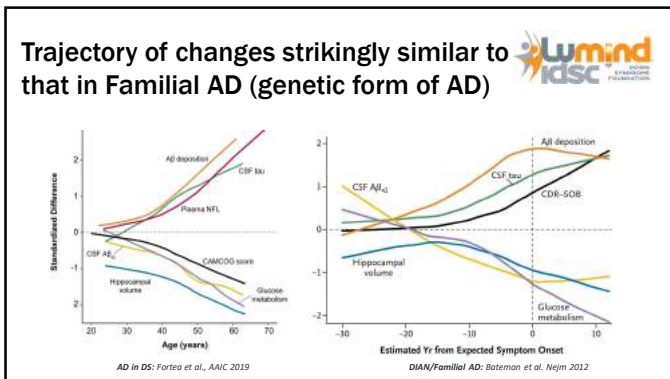
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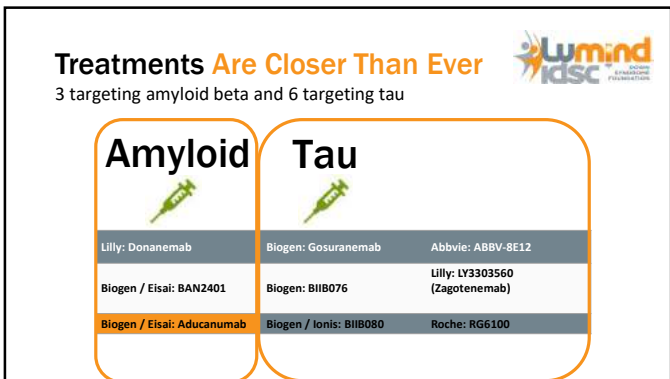
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Aducanumab (Aduhelm)



Early AD PET(+) Brain Imaging ↓ beta-amyloid(PET)
↑ cognition(CDRsb & MMSE)

Apr 2019 Futility Analysis Oct 2019 Data Shows Efficacy






FDA granted accelerated approval in June

Not one participant with Down syndrome. Will treatments work in people with Down syndrome if they are not part of trials?

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Aducanumab and Down syndrome?




EFFICACY
Aducanumab is a human monoclonal antibody reduces amyloid in the brain.
If aducanumab slows progression of sporadic AD, it may also slow AD in Down syndrome.

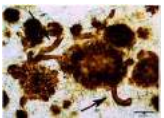

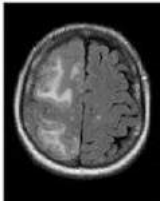
SAFETY
ARIA (Amyloid Related Imaging Abnormalities) is a known side effect. ARIA-E is edema (brain swelling) and ARIA-H is microhemorrhage (bleeding in the brain).
The incidence of ARIA is high.
25% of participants in the 6 mg/kg dose group and 33% of those receiving 10 mg/kg developed ARIA-E, compared with 10% in the placebo group.
17% of people on drug developed ARIA-H microhemorrhages, compared with 6% in the placebo group.
Microhemorrhages are more common in older adults with Down syndrome than the general population.
Will aducanumab increase this risk?

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Establishing Safety Through Trials



Lots of beta-amyloid on blood vessels in the brains of people with Down syndrome when they get older – and this may be more extensive than in people with Alzheimer’s disease without Down syndrome






Clinical trials in adults with Down syndrome with Aduhelm are needed to establish safety.




What is the safety profile of Aduhelm in people with Down syndrome?

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Immunotherapy for AD



- **Aduhelm (aducanumab) - Biogen**
 - FDA granted accelerated approval in June 2021
 - Biogen must conduct a Phase 4 post-marketing study to provide additional evidence, or the approval could be rescinded.
- **Other drug candidates in the same class in Phase 3 trials**
 - Donanemab – Eli Lilly
 - Gantenerumab – Roche
 - Lecanemab – Eisai & Biogen
- **The Centers for Medicare & Medicaid Services (CMS) will rule on reimbursement for all four drugs in early 2021.**
 - LuMind IDSC and other national Down syndrome organizations advocating for inclusion of Down syndrome in this decision.

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Immunotherapy for AD in DS




- Appropriate Use Criteria have been published- Recommend not prescribing for adults with DS at this time
- Safety studies will be needed to extend the label in persons with DS
- What stage of AD in DS? What age range should treatment start? How easily can they tolerate MRIs? How easily can they tolerate monthly intravenous infusions?
- Label extending studies have been done for other drugs into the pediatric DS population and can be designed for immunotherapy for AD in DS

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FDA/LuMind IDSC Meeting



March 12, 2021 - Critical Path Innovation Meeting (CPIM)




Advocates:
 Karen Gaffney, *Self Advocate*
 Taffy and Jeff Nothnagle, *Caregivers*

Key Opinion Leaders:
 Brian Chicoine, *Advocate Health*
 Elizabeth Head, *UC Irvine*
 Juan Fortea, *Hospital de la Santa Creu i Sant Pau, Barcelona*
 Judith Jaeger, *CognitionMetrics*
 Eric Siemers, *Siemens Integration*

Stakeholders:
 Key Academic Partners,
 National Institutes of Health (NIH)
 Pharma / Biotech Companies

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FDA/LuMind IDSC Meeting



PURPOSE

- Help de-risk Down syndrome associated Alzheimer’s disease (DS-AD) trials.
- Gain insights into clinical trial design issues including efficacy endpoints.
- Understand the FDA’s position on safety trials for approved Alzheimer’s drugs.

KEY TAKEAWAYS

- FDA supported LuMind IDSC’s efforts to collaborate with pharma companies.
- Biomarkers in DS-AD can be used as a bridge to AD biomarkers in the general population to better understand disease progression and drug effects.
- Consensus on the diagnosis of DS-AD is needed.
- More research is needed on cognitive and functional tests for DS-AD that could be used as efficacy endpoints.
- The FDA agreed that clinical trials of drug candidates in DS-AD will improve understanding of Alzheimer’s overall, drug safety, and speed new treatments.

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Down Syndrome Clinical Trial Network & LuMind IDSC

Alzheimer’s disease in Down syndrome projects





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LuMind IDSC has a 3-pronged transformational approach...

... to **accelerate** therapeutic, diagnostic, and medical care advances for people with Down syndrome

- 1 DS-CTN Maturity Plan
- 2 DS Community Education & Outreach
- 3 Translational Research

LIFE-DSR and the DS-CTN are central to LuMind IDSC's strategy!

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LuMind IDSC Vision to Tackle Alzheimer's

Advance effective treatments for people with DS

- Infrastructure to support trials
- Natural history study (LIFE-DSR)
- Develop assessment scales

Significantly and tangibly improve the care of those with DS

- Support families in studies and trials
- Connect to best medical health resources

Attract more public and pharmaceutical industry sponsors to clinical trials for DS

- Collaborate with NIH
- Engage with pharmaceutical industry

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Down Syndrome Clinical Trial Network

Logos of participating institutions:

- Advocate Medical Group Adult Down Syndrome Center
- Cincinnati Children's
- DukeHealth
- EMORY UNIVERSITY SCHOOL OF MEDICINE
- BARROW Neurological Institute
- CASE WESTERN RESERVE UNIVERSITY
- KU MEDICAL CENTER The University of Kansas
- MASSACHUSETTS GENERAL HOSPITAL
- UC San Diego SCHOOL OF MEDICINE
- Sanders-Brown Center on Aging Aging and Down Syndrome Study
- RUSH
- Down Syndrome Clinic and Research Center at Kennedy Krieger Institute

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LIFE-DSR Study

Longitudinal Investigation for Enhanced Down Syndrome Research (LIFE-DSR)

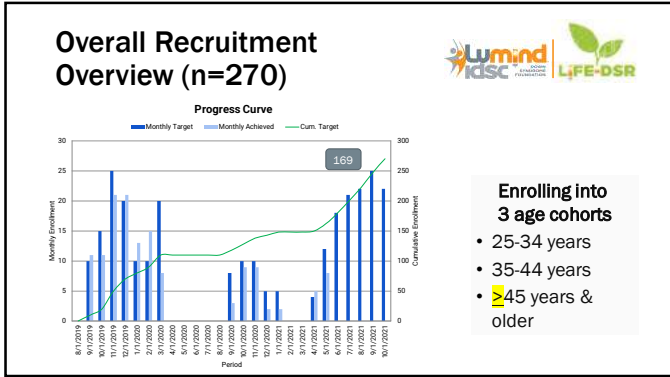
Goal: *To characterize a real-world adult DS population for future Alzheimer's prevention clinical trials in DS*

Aim A	Aim B	Aim C
Longitudinal Observational Cohort: 3 visits (Months 0,16, 32)	Develop a novel measurement instrument of cognition, behavior and function appropriate for clinical trials	Developing Blood Test for Alzheimer's

270 | **Age 25 and older (80% from 35-55)** | Few exclusions

lumindidsc.org/LIFE-DSR

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Launch of LuMind IDSC Research Consortium is next step forward

- Industry engagement to advance LuMind IDSC research priorities in Down syndrome
- Provide new funding and resources to expand the scope of research for LuMind IDSC and the LIFE-DSR study

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LIFE-DSR Interim Analysis

- Plasma samples from 90 baseline subjects were analyzed, in partnership with Eli Lilly, assessed associations of Alzheimer's disease at baseline
- The plasma biomarkers include Amyloid Beta (Ab₄₀ and Ab₄₂), Phosphorylated tau (P-tau181 and P-tau217), neurofilament light (NFL), Glial fibrillary acidic protein (GFAP) and APOE (e4 +/-) genotype.
- The biomarker data was combined with the clinical data collected in LIFE-DSR on medical history and results from cognitive (SIB, DS-MSE) tests.
- The P-tau217 test was recently featured in a NY Times story.

'Amazing, isn't it?' Long-Sought Blood Test for Alzheimer's In Reach
 July 26, 2020, NY Times
 Scientists say such tests could be available in a few years, speeding research for treatments and providing a diagnosis for dementia patients who want to know if they have Alzheimer's disease.

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AD Biomarkers Strongly Associated with Age in DS


Characteristic	Mean	Min, Max
Age	38.31	25, 69
Gender	40 (46.5%) Female	46 (53.5%) Male
APOE ε4	67 (74.4%) Non-Carrier	23 (25.6%) Carrier

Apolipoprotein E ε4 allele = APOE ε4





"Cross-Sectional Exploration of Plasma Biomarkers of Alzheimer's Disease in Down Syndrome: Early Data from the Longitudinal Investigation for Enhancing Down Syndrome Research (LIFE-DSR) Study"
 Hendrix, J.A., et al., *Clin. Med.* **2021**, *10*, 1907.

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LuMind IDSC Research Consortium




- Partners:** Funding from Merck & AbbVie
- Collaborators:** Lilly is providing in-kind support, Cerveau is providing tau PET tracer discount
- Studies:** Funding allows LIFE-DSR to launch new sub-studies in 2021
 - Tau PET imaging *30 participants at 2-time points*
 - CSF Biomarkers with PBMC (Peripheral Blood Mononuclear Cell) isolation *30 participants at 2-time points*
 - Goal Attainment Scale (GAS) feasibility study *45 caregivers at baseline, 12 wks. and 6 mos*
 - Strydom Composite Assessment *60 participants at 2-time points*


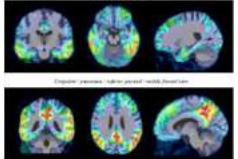





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LuMind IDSC Research Consortium: Tau PET Imaging




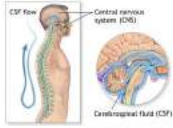

- Cerveau Technologies to provide tau PET tracer MK-6240 at a discount
- Perform tau PET scans with MK-6240 on 30 of the LIFE-DSR participants at 2 time points (60 total scans) to help define Alzheimer's progression.
- Launch targeted in 2021

¹⁸F-MK-6240 tau PET images from a neurotypical subject diagnosed with AD courtesy of Cerveau Image Core.

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LuMind IDSC Research Consortium: Cerebrospinal Fluid (CSF) Collection

- Will collect CSF samples from 30 LIFE-DSR participants at 2 time points to help define Alzheimer's progression
- Very safe procedure – most common side effect is a headache, but this is still rarely seen
- Will compare CSF biomarkers with blood biomarkers
- Launch targeted in 2021

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LuMind IDSC Research Consortium: Assessment Scales for DS-AD






1.DS-AD Composite Scale

- Collaboration with Andre Strydom, Kings College, London
- Data shared from 6 EU and 2 US sites
- Analysis performed by Jason Hassenstab & Andy Aschenbrenner (Wash U)
- Will recruit and consent a sub-group within the LIFE-DSR cohort for validation
- Timeline: Scale Validation in LIFE-DSR ready to begin in 2021

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LuMind IDSC Research Consortium: Assessment Scales for DS-AD

↳ The Goal Attainment Scale (GAS)

- Patients and/or families, usually in consultation with a clinician, set their own personalized treatment goals.
- Collaborators: Ken Rockwood, Dalhousie U. and Ardea Outcomes, Canada
- Ardea Outcomes and Dr. Rockwood have previously developed GAS for Alzheimer's in the general population.
- Timeline:
 - KOL meeting held July 29, 2019
 - 10 Caregiver interviews conducted in 4Q 2019
 - Feasibility sub-study of ~45 LIFE-DSR participants in 2021



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Next Steps





- Evaluate and select existing LIFE-DSR sites for participation in new sub-studies
 - Not all sites will conduct all sub-studies
 - Contracting will be at participating sites
- Launch Sub-Studies in 2021
- LuMind IDSC will continue to engage with industry to search for new consortia members
- DS-CTN in expanding to 15 sites

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What else can you do to fight Alzheimer's and support research?

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Participate in research.

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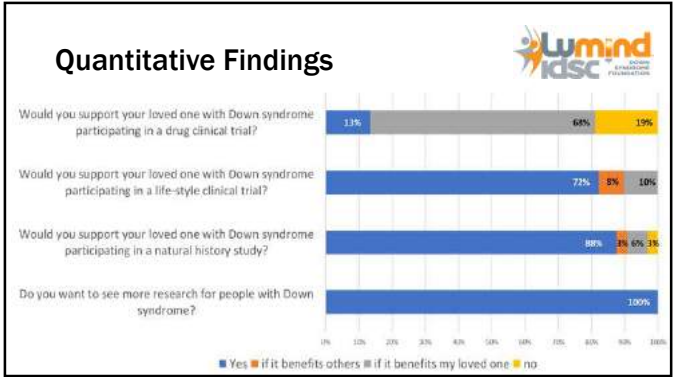
Comparing the Down Syndrome Community Experience with Sporadic AD Participant Insights: Overcoming Barriers to Clinical Trial Recruitment






 National Task Group on Intellectual Disabilities and Dementia Practices

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Insights: Comparisons & Differences

Late Onset AD Population	Down Syndrome Population
<ul style="list-style-type: none"> • Caregiving is a new role, and family members are often reluctant to play the role and/or change their role identity • Proactive patients and caregivers are seeking the top specialists for memory and cognition, incl. clinical trialists and researchers • Alzheimer's disease diagnoses are often avoided and rarely discussed in standard primary care medical visits • Clinical trial participants may have hope for individual benefit, but are more likely to mention a motivation to help their children or honor a loved one. 	<ul style="list-style-type: none"> • Caregiving and advocacy have become a lifetime identity and many have shifted to careers in the field • While Alzheimer's is a top concern, the first priority for a healthcare provider is Down Syndrome knowledge and experience • Alzheimer's disease is often the first assumed diagnosis in primary care for behavior changes, incl. regression • The stated goal of the clinical trial participation may include the community, but is primarily with the hope to benefit the individual.

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Recommendations for DS-AD Trials

A Clinical Trial Site staff with a "customer experience" mindset for a DS-AD population can have substantial benefit



Clearly Understood Expectations



- need to tailor patient education and informed consent for patients; ranging from pictures/illustrations to interactive Q&A
- create comfort with procedures (MRI, scans, lumbar puncture, blood draw)

No Surprises

- patient and caregiver need to have an understanding of each visit
- communication tools to be kept in home as a reminder of visits and expectations
- Offer a dry run to see location; have an on-location experience prior to an official visit

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Recommendations for DS-AD Trials

Personal Connection



- the first connection (often by phone) needs to be skilled at conversion
- relationships with site staff are meaningful, and should be personal and remain consistent whenever possible

Find and engage the 'seekers'

- Personal advocacy and volunteer work at school appear to be the initial experiences of "seeking" for better outcomes for their children with DS, a role they continue to play for life
- Frequently, these caregivers have networked beyond their communities to seek information and potential participation in new educational and vocational programs that reset the boundaries for people with DS
- They are trusted resources in their communities, perhaps leading orientation sessions for paperwork with state agencies

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Recommendations for DS-AD Trials

- Locate the 50+ DS population**, there appear to be generational differences that are not fully understood
- Determine whether state agencies/organizations** (ARC, Special Olympics, Case management) **can play a role**
- Explore a more formalized role for 'seekers,'** if identified early, can they become referral specialists
- Gain a deeper understanding of primary care role**, especially for the 50+ DS population
- Consider clinical trial participant testimonials**, since experience with DS is a primary influencer
- Gain a better understanding of motivating benefits including:** Benefit to the broader DS community; and Motivation by witnessing a family member with AD.
- Explore opportunities** to "bring the trial" to people with DS-AD vs. having them travel to CT sites

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Another Matter of Inclusion



Inclusion in clinical trials means that people with Down syndrome and their families have a voice in their health and medical care.



Education Employment Medical Care Clinical Trials

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Big Picture: Why Talk About Research?



What do we hear from the community?



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Big Picture: Why Talk About Research?




They can't do anything without research and trial participation, without YOU, without the greater US.



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Big Picture: Why Talk About Research?



Without participation in clinical trials →

- ⊘ No drug is approved.
- ⊘ No new treatments get to market.
- ⊘ IF new treatments do get to market in DS, most get to market *without ever having been tested in DS.*




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Clinical Trial Finder Online




LuMindIDSC.org/ClinicalTrialFinder

List of clinical trials that can be filtered by type, gender, age, category and recruitment status




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4 Ways You Can Rally Around Research!



1. **Get educated on research** – learn about the current status of Down syndrome research and stay updated (lumindisc.org/myDSmoment)
2. **Engage on research** – with other families, LuMind IDSC, NIH, other research organizations, researchers and clinicians ([follow LuMind IDSC on social media](#))
3. **Participate in research** – in surveys, observational studies and therapeutic clinical trials (lumindisc.org/research)
4. **Give to research** – your time, a donation, a fundraiser (lumindisc.org/donate)



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Alzheimer's Research




Down syndrome associated Alzheimer's disease

The Virtuous Cycle




- Late onset AD (older than age 65)
- ~6 million in US



- Early onset AD (younger than age 65)
- Genetic cause
- Rare

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Together, we can move mountains.




LuMindIDSC.org

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Please, keep in touch




- facebook.com/LuMindIDSC
- twitter.com/LuMindIDSC
- instagram.com/LuMindIDSC
- linkedin.com/company/LuMindIDSC
- youtube.com/c/LuMindIDSC
- LuMindIDSC.org/news

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ncdsa
North Carolina
Down Syndrome Alliance
empower connect support

Down Syndrome
The Early Years

Mahala Turner, Family Support Specialist
November 13, 2021

1

What We are Covering Today

- Myths and Truths about Down syndrome
- Medical Care and Guidelines
- Where to start
- Development
- Communication
- Behavior
- Transitions
- Benefits
- Advocacy



2



Myths and Truths

3

Truths

- The most common genetic condition
- Increased life expectancy
- Does not discriminate
- People with Ds have a full range of emotions

4

Maternal Age Statistics

Maternal Age	Incidence of Down syndrome	Maternal Age	Incidence of Down syndrome	Maternal Age	Incidence of Down syndrome
20	1 in 2,000	30	1 in 900	40	1 in 100
21	1 in 1,700	31	1 in 800	41	1 in 80
22	1 in 1,500	32	1 in 720	42	1 in 70
23	1 in 1,400	33	1 in 600	43	1 in 50
24	1 in 1,300	34	1 in 450	44	1 in 40
25	1 in 1,200	35	1 in 350	45	1 in 30
26	1 in 1,100	36	1 in 300	46	1 in 25
27	1 in 1,050	37	1 in 250	47	1 in 20
28	1 in 1,000	38	1 in 200	48	1 in 15
29	1 in 950	39	1 in 150	49	1 in 10

North Carolina Down Syndrome Alliance

5



Common Medical Issues

6

Most Common Health Concerns

- Heart
- Vision
- Ear, Nose & Throat Issues
- Obstructive Sleep Apnea
- Hypotonia
- Blood disorders
- Thyroid
- Leukemia
- Dual Diagnosis
- Dental

7



Where to Start?

8

Healthcare Guidelines

- Define the standards of quality care for individuals with Down syndrome
- Provide specific recommendations for screening tests
- Include information about the medical conditions that individuals with Down syndrome are at risk for
- Provide suggestions for early intervention, diet, exercise, and other issues across the lifespan

[Health Care Information for Families of Children with Down Syndrome](#)

[Down Syndrome Healthcare Guidelines Record Sheet](#)

[Growth Charts](#)

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Children's Hospital Charlotte
 Anne and John T. Lee Center for Down Syndrome

Down Syndrome Healthcare Guidelines (2011 Revision) Record Sheet*

	Birth	6 Mo	1	2	3	4	5	6	7	8	9	10	11	12	15	18	21	24	27	30	36	42	48	54	60	66	72	
Parent Coaching, Education, Parent Group Info and Support																												
GC to AGC transition																												
Cardiology																												
Audiological Evaluation																												
Genetic Counseling																												
Orthopedic Evaluation																												
Other (Hemoglobin, Thyroid, TSH, T4)																												
Speech Therapy																												
Early Intervention																												
IFSP																												
Transition																												

1. Given for a maximum of 4 years prior to age 4 years.
 2. 24 months prior to age 4 years or previously stated.
 3. Add one and a half months age (18) in months if negative response symptoms. * Ages: 18, 24, 30, 36, 42, 48, 54, 60, 66, 72, 78, 84, 90, 96, 102, 108, 114, 120, 126, 132, 138, 144, 150, 156, 162, 168, 174, 180, 186, 192, 198, 204, 210, 216, 222, 228, 234, 240, 246, 252, 258, 264, 270, 276, 282, 288, 294, 300, 306, 312, 318, 324, 330, 336, 342, 348, 354, 360, 366, 372, 378, 384, 390, 396, 402, 408, 414, 420, 426, 432, 438, 444, 450, 456, 462, 468, 474, 480, 486, 492, 498, 504, 510, 516, 522, 528, 534, 540, 546, 552, 558, 564, 570, 576, 582, 588, 594, 600, 606, 612, 618, 624, 630, 636, 642, 648, 654, 660, 666, 672, 678, 684, 690, 696, 702, 708, 714, 720, 726, 732, 738, 744, 750, 756, 762, 768, 774, 780, 786, 792, 798, 804, 810, 816, 822, 828, 834, 840, 846, 852, 858, 864, 870, 876, 882, 888, 894, 900, 906, 912, 918, 924, 930, 936, 942, 948, 954, 960, 966, 972, 978, 984, 990, 996, 1002, 1008, 1014, 1020, 1026, 1032, 1038, 1044, 1050, 1056, 1062, 1068, 1074, 1080, 1086, 1092, 1098, 1104, 1110, 1116, 1122, 1128, 1134, 1140, 1146, 1152, 1158, 1164, 1170, 1176, 1182, 1188, 1194, 1200, 1206, 1212, 1218, 1224, 1230, 1236, 1242, 1248, 1254, 1260, 1266, 1272, 1278, 1284, 1290, 1296, 1302, 1308, 1314, 1320, 1326, 1332, 1338, 1344, 1350, 1356, 1362, 1368, 1374, 1380, 1386, 1392, 1398, 1404, 1410, 1416, 1422, 1428, 1434, 1440, 1446, 1452, 1458, 1464, 1470, 1476, 1482, 1488, 1494, 1500, 1506, 1512, 1518, 1524, 1530, 1536, 1542, 1548, 1554, 1560, 1566, 1572, 1578, 1584, 1590, 1596, 1602, 1608, 1614, 1620, 1626, 1632, 1638, 1644, 1650, 1656, 1662, 1668, 1674, 1680, 1686, 1692, 1698, 1704, 1710, 1716, 1722, 1728, 1734, 1740, 1746, 1752, 1758, 1764, 1770, 1776, 1782, 1788, 1794, 1800, 1806, 1812, 1818, 1824, 1830, 1836, 1842, 1848, 1854, 1860, 1866, 1872, 1878, 1884, 1890, 1896, 1902, 1908, 1914, 1920, 1926, 1932, 1938, 1944, 1950, 1956, 1962, 1968, 1974, 1980, 1986, 1992, 1998, 2004, 2010, 2016, 2022, 2028, 2034, 2040, 2046, 2052, 2058, 2064, 2070, 2076, 2082, 2088, 2094, 2100, 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10068, 10074, 10080, 10086, 10092, 10098, 10104, 10110, 10116, 10122, 10128, 10134, 10140, 10146, 10152, 10158, 10164, 10170, 10176, 10182, 10188, 10194, 10200, 10206, 10212, 10218, 10224, 10230, 10236, 10242, 10248, 10254, 10260, 10266, 10272, 10278, 10284, 10290, 10296, 10302, 10308, 10314, 10320, 10326, 10332, 10338, 10344, 10350, 10

Acronyms

- EI – Early Intervention
- CDSA – Children’s Developmental Services Agency
- IFSP – Individualized Family Service Plan
- ST – Speech Therapy
- OT – Occupational Therapy
- PT – Physical Therapy
- IDEA – Individuals with Disabilities Education Act
- FAPE – Free and Appropriate Public Education
- IEP – Individualized Education Plan
- LRE – Least Restrictive Environment

13



Development

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Strengths

Social development

Visual learners

Whole word reading

Difficulties

Motor development

Expressive language/speech clarity

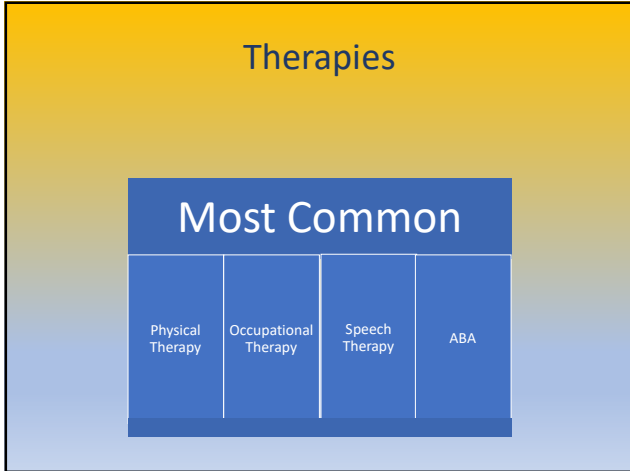
Math concepts

15

Milestone	Range for Children with Down Syndrome	Typical Range
GROSS MOTOR		
Sits Alone	6 – 30 Months	5 – 9 Months
Crawls	8 – 22 Months	6 – 12 Months
Stands	1 – 3.25 Years	8 – 17 Months
Walks Alone	1 – 4 Years	9 – 18 Months
LANGUAGE		
First Word	1 – 4 Years	1 – 3 Years
Two-Word Phrases	2 – 7.5 Years	15 – 32 Months
SOCIAL/SELF-HELP		
Responsive Smile	1.5 – 5 Months	1 – 3 Months
Finger Feeds	10 – 24 Months	7 – 14 Months
Drinks From Cup Unassisted	12 – 32 Months	9 – 17 Months
Uses Spoon	13 – 39 Months	12 – 20 Months
Bowel Control	2 – 7 Years	16 – 42 Months
Dresses Self Unassisted	3.5 – 8.5 Years	3.25 – 5 Years

Source: NDSS

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- ## Other Therapies
- Music Therapy
 - Hippotherapy
 - Aquatic Therapy
 - Play Therapy
 - Developmental Therapy
 - Feeding Therapy

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- ## Total Communication Approach
- Using ALL available means of communication including:
- Speech
 - Sign language
 - Gestures
 - Pictures
 - And/or simple voice output communication aides

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Communication

Speech Language

Communication
Sending and receiving messages

Language
The way in which we communicate thoughts, feelings, and needs with each other.

Speech
Vocalized form of communication (i.e. spoken words). Speech production is a complex process that involves many systems in the body.

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The Challenges

Several issues can affect speech and language development for children with Down syndrome:

- Cognitive development
- Hearing problems in some children
- Decreased muscle tone, strength and coordination in mouth and throat

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Resources & Tools

- [Signing Savvy](#)
- Signing Time
- Talk Tools

22



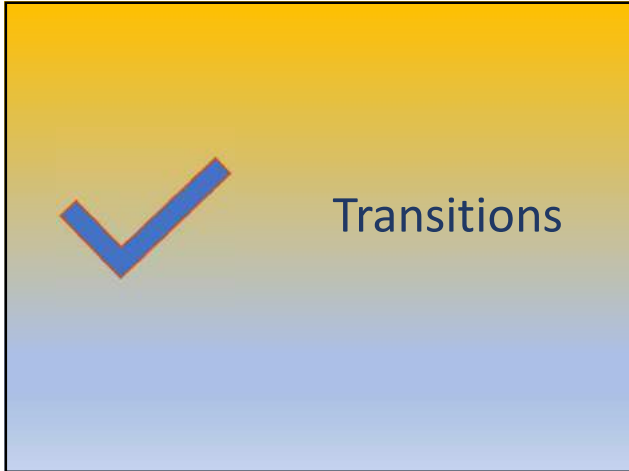
Behavior

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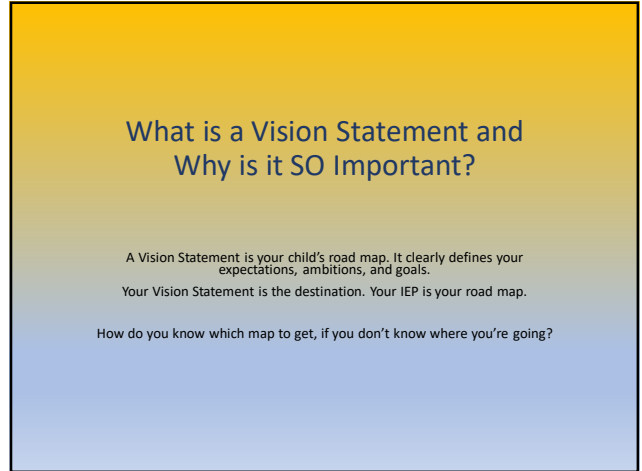
Positive Behavior Support

- High Expectations
- Everyone on board
- Modeling
- ABC – Antecedent, Behavior, Consequence
- Sensory
- Consistency

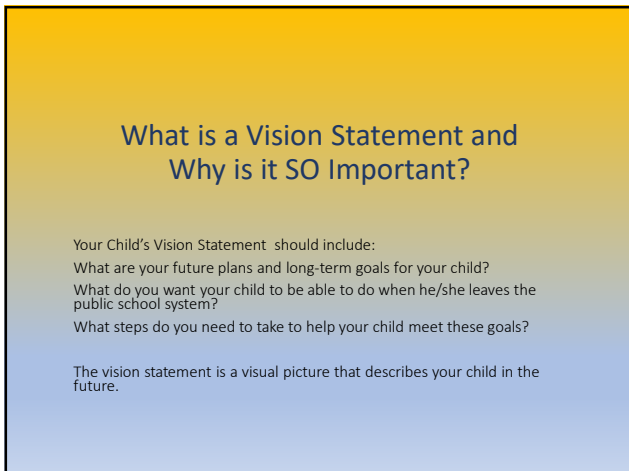
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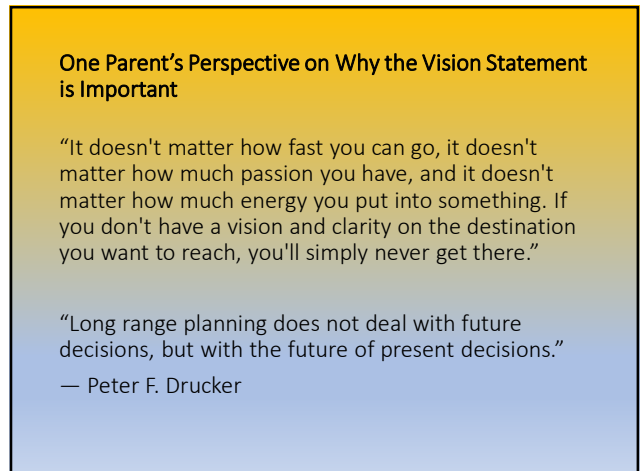
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Examples of Effective Vision Statements

We want to raise Susan to live in the real world, not the special needs world and not a world that especially centers around her or her disability. We want her to be confident. We want her to feel equal to her typical peers. We are setting the bar high and would like for her to have the opportunity to drive, graduate high school with a diploma, and go onto college- the same opportunities afforded to her brother and sister. We want her to be educated and independent in an inclusive general education setting where she will develop friendships and model appropriate behavior. We want her to feel and be loved. We do not want to place limitations that restrict her unmet potential, at 5 years old, we have no idea what she is capable of achieving and we will not settle for less than every appropriate opportunity. In order for her to be a successful, accepted member of her community as an adult, we will teach her self-help and independent living skills at home. We want her to receive the same educational opportunities as typically developing peers & her siblings in the least restrictive environment.

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Examples of Effective Vision Statements

We want Madelyn to be integrated into society where she excels and is accepted by her peers. We want her to be confident and independent. We want her to have equity among her peers. Our intention is for her to graduate high school with a High School Diploma and go onto post-secondary education. We want her to be educated in a general education setting where she will model after other students. We do not want to limit her ability to reach her highest potential and will not allow for her to grow stagnant. We want her to be placed in a inclusive general education classroom where she will be in the least restrictive environment and have access to her typically developing peers..

Concern:

We are concerned that by placing Madelyn in a self-contained preschool classroom that we are starting with the most restrictive environment. This does not align with our vision for Madalyn. An inclusive classroom would offer the ability for Madalyn to be educated alongside her typically developing peers.

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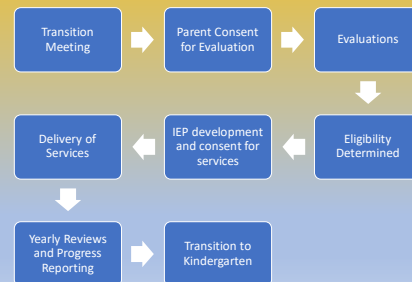
Transition to Pre-K

IFSP	IEP
Birth through age 3	Age 3-21
Is inclusive of the family's needs	Focuses on the child's needs
Services provided in natural environments	Services provided at school
Families are assigned a service coordinator	No service coordinator
Generally reviewed every 6 months	Generally reviewed 1x per year
IFSP Team makes decisions	IEP Team makes decisions
Governed under Part C of IDEA	Governed under Part B of IDEA

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Process

Transition out of EI by age 3
Transition process begins at 2 1/2



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Questions for Transition Meeting

- What are the differences between early intervention and preschool services?
- How will my child's eligibility be determined?
- What are the different ways services can be provided?
- Who do we contact to visit a program or classroom?
- How can we help the professionals understand the unique strengths and needs of our child?
- When will we meet next?

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Questions for Evaluation Team

- What tests and other evaluation tools are being considered?
- How will this information be used to plan my child's education?
- Will my child's disability interfere with obtaining valid test scores in any area?
- What will be done to help my child feel comfortable during the testing session?
- What kind of information will I be asked to contribute to the evaluation?

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A Note on Timelines

The school system has 90 *calendar* days to act on the referral

By the 90th calendar day, the following things must have happened:

- Evaluation
- Eligibility
- IEP

*timeline starts when the written referral is made by letter or email for evaluation, not the consent for evaluation

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Eligibility Determination

There are 14 categories of disability.

DEVELOPMENTAL DELAY - delay in one or more of the following areas:

- (A) Cognitive Development
- (B) Physical Development
- (C) Communication Development
- (D) Social-Emotional Development
- (E) Adaptive Development.

The specific level of delay shall be:

- (A) documented by scores of 2.0 standard deviations below the mean in at least one of the above areas or
- (B) documented by a 30 percent (30%) delay on instruments which determine scores in months in at least one of the above areas of development, or
- (C) documented by scores of 1.5 standard deviations below the mean on standardized tests in at least two of the above areas of development
- (D) documented by a 25 percent (25%) delay on instruments which determine scores in months in at least two of the above areas of development.

Established Conditions. A child is considered to have an established condition if the child has a diagnosed physical or mental condition which has a high probability of resulting in developmental delay.

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Inclusion Matters

All relevant research indicates that students with extensive and pervasive support needs, their general education peers, and both general and special education teachers benefit from inclusive education.

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Special Education is a SERVICE Not a PLACE!

? Does the student need to leave the general education environment for this instruction?

? If the student leaves the classroom for instruction, what will he or she gain? What will he or she lose?

? Can the student get the content or strategies he or she needs without losing access to the general education classroom?

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Benefits

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- Medicaid
- NC Health Choice (Previously CHIP)
- Care Coordination for Children (CC4C)
- CAP/C Waiver
- Innovations Waiver
- SSI
- SSDI

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Medicaid

Basic Eligibility Requirements

Medicaid or Health Choice may be available to people who are:

- Blind or disabled and your income and resources are under certain limits
- Infants and children under the age of 21
- Low-income individuals and families
- In need of long-term care

You also must:

- Be a US citizen or provide proof of eligible immigration status. Live in North Carolina, and provide proof of residency
- Have a Social Security number or have applied for one

You are automatically eligible for Medicaid if you receive any of the following:

- Supplemental Security Income (SSI)
- Work First Cash Assistance
- State/County Special Assistance for the Aged or Disabled (i.e.: Innovations Waiver)

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Monthly Income Limits: Medicaid for Infants & Children

Family Size	Age 0-5	Age 6-18
1	\$2,233	\$1,415
2	\$3,017	\$1,911
3	\$3,801	\$2,408
4	\$4,585	\$2,904
5	\$5,369	\$3,401

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GROUP	BENEFITS	BASIC MEDICAID ELIGIBILITY				SPECIAL PROVISIONS (Updated 07/16)	
		BASIC ELIGIBILITY REQUIREMENT	WHICH INCOME AND RESOURCES COUNT	MONTHLY INCOME LIMIT (spouse/parent)	RESOURCE LIMIT (spouse/parent)		
S-ARR, SSI cases	Full Medicaid coverage only, if a Medicaid applicant is submitted	Identifications meeting Supplemental Security Income (SSI) Federal cash assistance program for the aged blind and disabled, or a determination not to be Medicaid, the respective application or Medicaid determination is required.	Identifications meeting State/County Special Assistance (SA) program for aged and disabled individuals who are eligible for adult care facilities, include Medicaid eligibility.	Identifications meeting Special Assistance in Home - the individual must be determined Medicaid categorically needy.			
Age 65 or older	Full Medicaid Coverage	Age 65 or older	Spouse's income and resources if one together	100% of Poverty Level 1 - \$1,064 2 - \$1,437	SSI Limits 1 - \$2,000 2 - \$3,000	YES	If income exceeds SSI limits and the individual is not eligible for a waiver, the individual is ineligible for Medicaid. If the individual is eligible for a waiver, the individual is eligible for Medicaid. The amount of the waiver is based on the amount of the individual's income up to a limit specified by federal law, 42 CFR 435.115. There are not to be more than \$2,000 in assets for the individual.
Age 65 or older	Full Medicaid Coverage	Blind by Social Security Standards	Spouse's income and resources if one together. Parents' income and resources if under age 18 and live with parent.	100% of Poverty Level 1 - \$1,064 2 - \$1,437	SSI Limits 1 - \$2,000 2 - \$3,000	YES	Individuals in nursing facilities generally do not have to meet the asset test for Medicaid. However, they must pay all of their own personal needs allowance and the cost of medical expenses not covered by Medicaid or other insurance in the community. Medicaid will not pay for care in a nursing facility if the individual is not eligible for Medicaid. The amount of the waiver is based on the amount of the individual's income up to a limit specified by federal law, 42 CFR 435.115. There are not to be more than \$2,000 in assets for the individual.
Childen	Full Medicaid Coverage	Disabled by Social Security Standards	Spouse's income and resources if one together. Parents' income and resources if under age 18 and live with parent.	100% of Poverty Level 1 - \$1,064 2 - \$1,437	SSI Limits 1 - \$2,000 2 - \$3,000	YES	Individuals in nursing facilities generally do not have to meet the asset test for Medicaid. However, they must pay all of their own personal needs allowance and the cost of medical expenses not covered by Medicaid or other insurance in the community. Medicaid will not pay for care in a nursing facility if the individual is not eligible for Medicaid. The amount of the waiver is based on the amount of the individual's income up to a limit specified by federal law, 42 CFR 435.115. There are not to be more than \$2,000 in assets for the individual.
Health Care for Working Low-income (H-CWLI) (MSL)	Full Medicaid Coverage	See Footnote	Spouse's income and resources if one together. Parents' income and resources if under age 18 and live with parent.	100% of Poverty Level 1 - \$1,064 2 - \$1,437	MSL, CSIF 1 - \$1,395 2 - \$2,100	NO	Individuals in nursing facilities generally do not have to meet the asset test for Medicaid. However, they must pay all of their own personal needs allowance and the cost of medical expenses not covered by Medicaid or other insurance in the community. Medicaid will not pay for care in a nursing facility if the individual is not eligible for Medicaid. The amount of the waiver is based on the amount of the individual's income up to a limit specified by federal law, 42 CFR 435.115. There are not to be more than \$2,000 in assets for the individual.
Classified Medicaid Beneficiaries (MSB)	Payment of Medicare Part A and Part B	Eligible to receive Medicare Part A and B	Spouse's income and resources if one together. Parents' income and resources if under age 18 and live with parent.	100% of Poverty Level 1 - \$1,064 2 - \$1,437	1 - \$7,960 2 - \$11,068	NO	Individuals in nursing facilities generally do not have to meet the asset test for Medicaid. However, they must pay all of their own personal needs allowance and the cost of medical expenses not covered by Medicaid or other insurance in the community. Medicaid will not pay for care in a nursing facility if the individual is not eligible for Medicaid. The amount of the waiver is based on the amount of the individual's income up to a limit specified by federal law, 42 CFR 435.115. There are not to be more than \$2,000 in assets for the individual.
Special Low Income Medicaid (MSL)	Payment of Medicare Part A and Part B	Eligible to receive Medicare Part A and B	Spouse's income and resources if one together. Parents' income and resources if under age 18 and live with parent.	100% of Poverty Level 1 - \$1,064 2 - \$1,437	1 - \$7,960 2 - \$11,068	NO	Individuals in nursing facilities generally do not have to meet the asset test for Medicaid. However, they must pay all of their own personal needs allowance and the cost of medical expenses not covered by Medicaid or other insurance in the community. Medicaid will not pay for care in a nursing facility if the individual is not eligible for Medicaid. The amount of the waiver is based on the amount of the individual's income up to a limit specified by federal law, 42 CFR 435.115. There are not to be more than \$2,000 in assets for the individual.
Qualifying Individual MSIG	Payment of Medicare Part B Premiums	Eligible to receive Medicare Part B	Spouse's income and resources if one together. Parents' income and resources if under age 18 and live with parent.	100% of Poverty Level 1 - \$1,064 2 - \$1,437	1 - \$7,960 2 - \$11,068	NO	Individuals in nursing facilities generally do not have to meet the asset test for Medicaid. However, they must pay all of their own personal needs allowance and the cost of medical expenses not covered by Medicaid or other insurance in the community. Medicaid will not pay for care in a nursing facility if the individual is not eligible for Medicaid. The amount of the waiver is based on the amount of the individual's income up to a limit specified by federal law, 42 CFR 435.115. There are not to be more than \$2,000 in assets for the individual.
Working Children MWC	Payment of Medicare Part B Premiums	Eligible to receive Medicare Part B	Spouse's income and resources if one together. Parents' income and resources if under age 18 and live with parent.	100% of Poverty Level 1 - \$1,064 2 - \$1,437	2X SSI Limits 1 - \$2,107 2 - \$3,160	NO	Individuals in nursing facilities generally do not have to meet the asset test for Medicaid. However, they must pay all of their own personal needs allowance and the cost of medical expenses not covered by Medicaid or other insurance in the community. Medicaid will not pay for care in a nursing facility if the individual is not eligible for Medicaid. The amount of the waiver is based on the amount of the individual's income up to a limit specified by federal law, 42 CFR 435.115. There are not to be more than \$2,000 in assets for the individual.

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NC Health Choice

NC Health Choice is a health insurance program for children of families who make too much to qualify for Medicaid, but too little to afford private insurance. NC Health Choice does not include long-term care services or Early and Periodic Screening, Diagnosis and Diagnosis Testing (EPSDT).

Basic Eligibility Requirements

- Children ages 6 – 18
- Low Income

You also must:

- Be a US citizen or provide proof of eligible immigration status. Live in North Carolina, and provide proof of residency
- Have a Social Security number or have applied for one

You are automatically eligible for Medicaid if you receive any of the following:

- Supplemental Security Income (SSI)
- Work First Cash Assistance
- State/County Special Assistance for the Aged or Disabled (i.e.: Innovations Waiver)

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Monthly Income Limits: NC Health Choice		
Income must fall between the 2 columns.	133% of the Poverty Level	211% of the Poverty Level
Family Size	Monthly Income	Monthly Income
1	\$1,415	\$2,244
2	\$1,911	\$3,032
3	\$2,408	\$3,820
4	\$2,904	\$4,607
5	\$3,401	\$5,395
6	\$3,897	\$6,183
7	\$4,394	\$6,972

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Care Coordination for Children (CC4C)

Basic Eligibility Requirements

- Children from birth to age three years who are at risk for developmental delay or disability, long-term illness and/or social, emotional disorders and children ages birth to five years who have been diagnosed with developmental delay or disability, long-term illness and/or social, emotional disorder may be eligible for the program.

CC4C Care Managers:

CC4C care managers can help find medical care, transportation, childcare and financial aid. They can also provide you with information about a wide variety of family resources. Your care manager will:

- Discuss family strengths and concerns through home visits, telephone calls and other personal contacts
- Identify programs, services, and resources that meet your family's needs
- Serve as a link between you and your child's doctor or nurse
- Identify ways you can strengthen parent-child relationships
- Introduce you to parent support programs when available

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Cap-C Waiver- Community Alternatives Program for Children

Basic Eligibility Requirements

- Medically fragile and medically complex children who are age 0 through 20 years of age.
- Is determined to require a level of institutional care under the State Medicaid Plan.
- Need at least one or more CAPC home-and community-based services based on a reasonable indication of need assessment that must be coordinated by a CAP/C case manager.

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Cap-C Waiver- Community Alternatives Program for Children

What are some of the home and community-based services for the CAP-C Waiver?

Assistive technology;
 CAP/C in-home aide (IHA);
 Care advisor;
 Case management;
 Community transition service;
 Financial management services;
 Home accessibility and adaptation;
 Goods and services – Participant, Individual-directed, Pest eradication, Nutritional services and Non-medical transportation; Vehicle modification;
 Participant goods and services;
 Pediatric nurse aide services;
 Respite care (institutional and in-home);
 Specialized medical equipment and supplies;
 Training, education, and consultative services; and
 Consumer directed services

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Innovations Waiver

The NC Innovations Waiver is a Federally approved 1915 C Medicaid Home and Community-Based Services Waiver (HCBS Waiver) designed to meet the needs of Individuals with Intellectual or Development Disabilities (I/DD) who prefer to get long-term care services and supports in their home or community, rather than in an institutional setting.

The Innovations Waiver supports individuals with I/DD to live the life they choose.

Basic Eligibility Requirements

- Meet the requirements for Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF-IID) level of care
- Live in an ICF-IID or be at risk of being placed in an ICF-IID
- Be able to stay safe, healthy and well in the community while using [NC Innovations Waiver services](#)
- Need and use NC Innovations Waiver services listed in your person-centered plan at least once a month
- Want to use NC Innovations Waiver services instead of living in an ICF-IID

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Social Security Income (SSI):

Many children born with Down syndrome receive SSI, which provides monthly cash payments to children and adults with disabilities from lower-income households. This financial assistance is to help pay for medical care, housing costs, caretakers, and other daily living needs.

Basic Eligibility Requirements if your Child is under 18 years of age:

- You must meet the very limited income and resource requirement.
- Down Syndrome is a listed condition under 110.00 Congenital Disorders that Affect Multiple Body Systems.
- You must provide the Social Security Administration a copy of the Karyotype analysis signed by a physician.
- <https://www.ssa.gov/pubs/EN-05-10026.pdf>

You also must:

- Be a US citizen or provide proof of eligible immigration status. Live in North Carolina, and provide proof of residency
- Have a Social Security number or have applied for one

If you are eligible for Social Security Income you are automatically enrolled in Medicaid.

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SSI Income Scenarios:

Maximum family income levels requirements can be confusing for families of children with Down Syndrome. Here are a few examples.

Single/Earned

If you are a single parent whose income is all earned (your income is from your job), then your child can qualify for SSI benefits if you make \$3,158 a month or less. For each additional child in the household, you are allowed to make an additional \$337 per month. The higher your income, the less SSI benefit your child will receive because a portion of your income is considered available to your child.

Single/Unearned

If your income is unearned (Social Security, unemployment compensation and Temporary Assistance for Needy Families are a few examples) as a single parent, then you can receive \$1,725 a month in income. Each child living in the household will allow you to make an additional \$337 a month without decreasing benefits to your disabled child.

Couple/Earned

In a two-parent household, an earned family income of \$3,832 can be made and your child will still receive disability benefits from SSI. An additional \$337 a month income is allowed per child without affecting the benefits of your disabled child. For example, a couple with three children can make \$4,506 a month and still receive SSI benefits for their disabled child.

Couple/Unearned

A couple with an unearned income and a disabled child will receive SSI benefits for their disabled child if they make \$2,062 a month or less. An additional \$337 income is permitted for each additional child in the household without reducing the SSI benefit to the child with a disability.

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Social Security Income (SSDI):

SSDI is a commonly used acronym for **Social Security Disability Insurance**, a program that offers monthly Social Security Disability payments to people under age 65 who have qualifying disabilities and sufficient work credits or pays benefits to individuals who have Down syndrome. The SSDI benefit is paid based on a parent's Social Security earnings.

Basic Eligibility Requirements:

The Social Security Disability Insurance (SSDI) program pays benefits to adults who have a disability that began before they became 22 years old. We consider this SSDI benefit as a "child's" benefit because it's paid on a parent's Social Security earnings record.

For a disabled adult to become entitled to this "child" benefit, one of his or her parents must:

- Be receiving Social Security retirement or disability benefits.
- Have died and have worked enough to qualify for Social Security.

Children who were receiving benefits as a minor child on a parent's Social Security record may be eligible to continue receiving benefits on that parent's record upon reaching age 18 if they are disabled. We make the disability determination using the disability rules for adults. SSDI disabled adult "child" benefits continue as long as the individual remains disabled. **Marriage of the disabled adult "child" may affect eligibility for this benefit.** Your child doesn't need to have worked to get these benefits.

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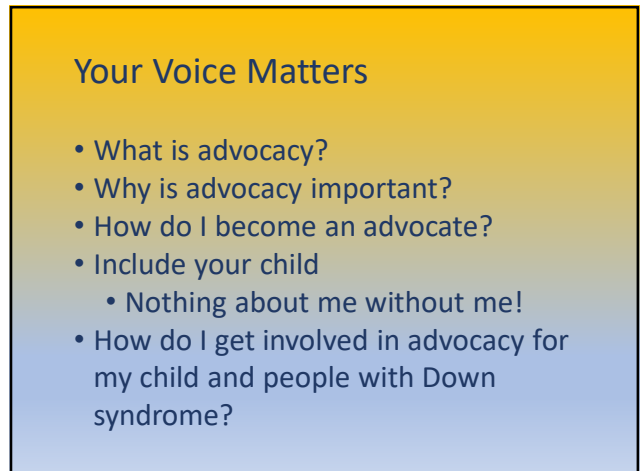
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Start Here

North Carolina Down Syndrome Alliance

- [Donna Beckmann](#), Advocacy and Outreach Director
- NC Down Syndrome Advocacy Day

[North Carolina Council on Developmental Disabilities \(NCCDD\)](#)

[Disability Rights North Carolina \(DRNC\)](#)

National Down Syndrome Congress (NDSC)

- [National Down Syndrome Advocacy Coalition](#)

National Down Syndrome Society (NDSS)

- [NDSS DS-AMBASSADOR® Program](#)

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Final Thoughts

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“There is no way to be a perfect parent, but there are a million ways to be a great one.”

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Questions

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