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

ncdsalliance.org/conference

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

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.

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 Yokabitis 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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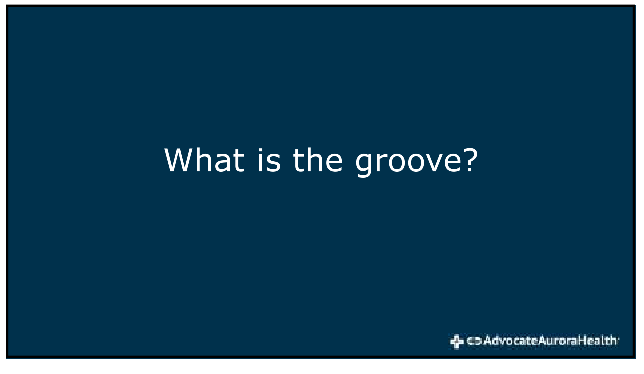

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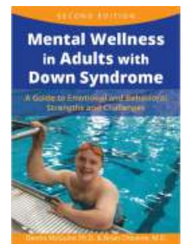
Definition

- "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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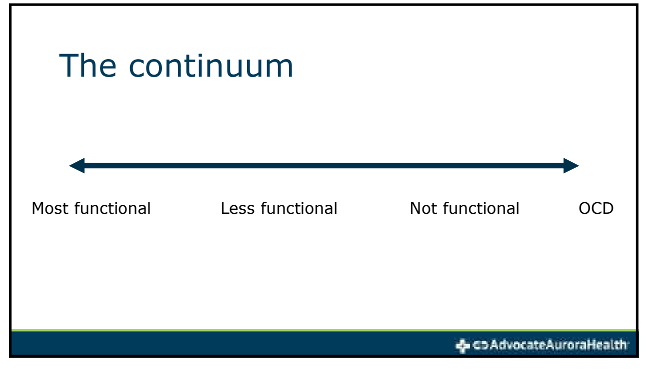

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Strategies to address problematic grooves and/or establish new grooves

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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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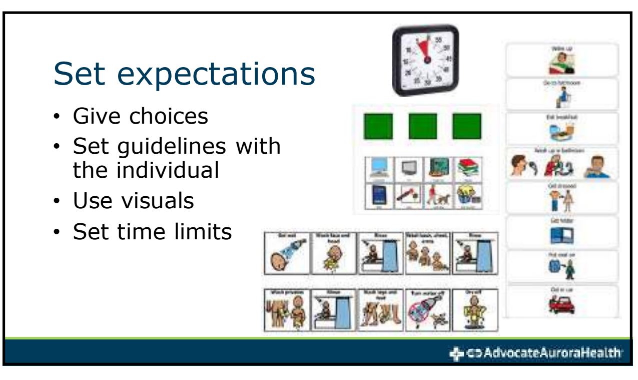

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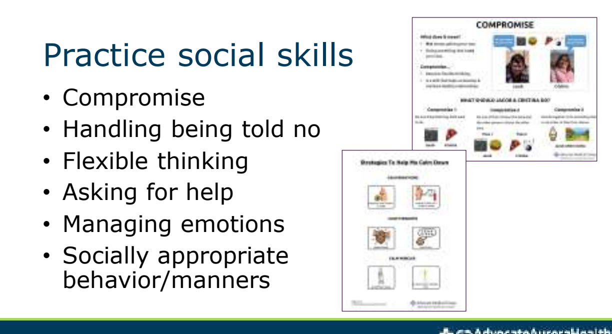

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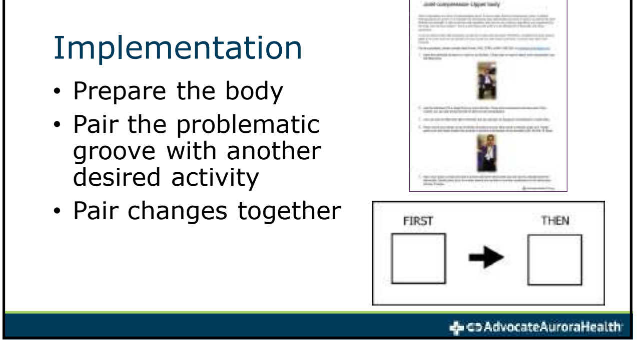

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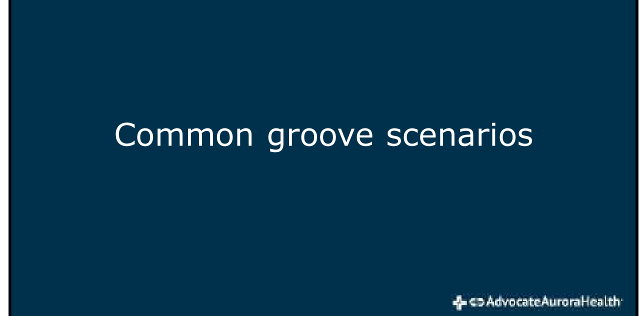

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Lengthy routines

- 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-medicinal 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-medicinal 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:
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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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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.

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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.

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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?

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"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?

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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.

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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.

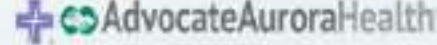
Sensory modulation problems

- 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 bothered 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)

- Doesn't cry 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.

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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

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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.

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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.

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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

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Who can help?

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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.

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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)

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 or 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 need 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.

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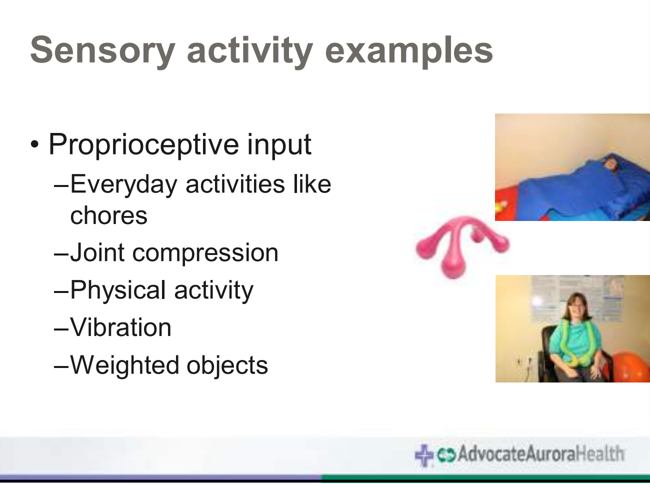
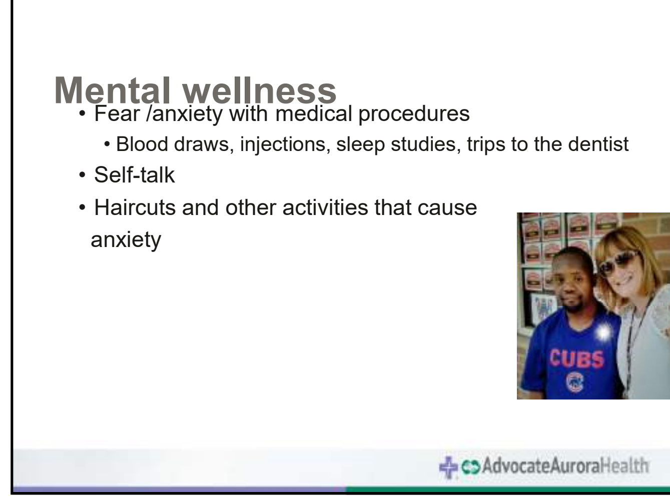
Sensory diet

- Sensory accommodations
  - –Used to address difficulties with sensations involving sight, sound, touch, taste, and smell
- Sensory activities
  - –Used to address input to the muscles and joints

Sensory accommodation examples

- Sunglasses, dim lighting, study corral
- Headphones
- Gloves, clothing without labels, fidget
- Bland foods for flavor vs spicy foods or soft/pureed foods vs crunchy foods
- Air purifiers, limiting perfume/lotion scents and air fresheners or aromatherapy





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.

Books

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- http://sensoryfun.com/home
- http://www.asensorylife.com
- https://sensationalbrain.com/
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- https://www.amctheatres.com/programs/sensory-friendly-films

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Websites-Sensory Diet

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- http://www.developmental-delay.com/page.cfm/286
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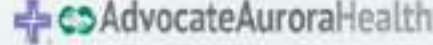
- http://www.alertprogram.com/index.php



Websites-Equipment

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

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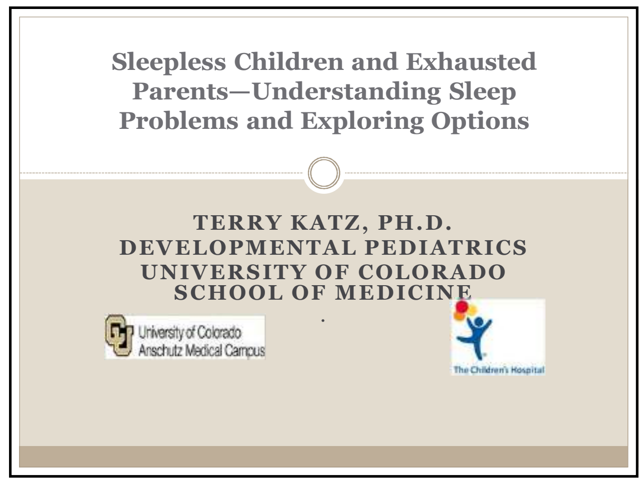

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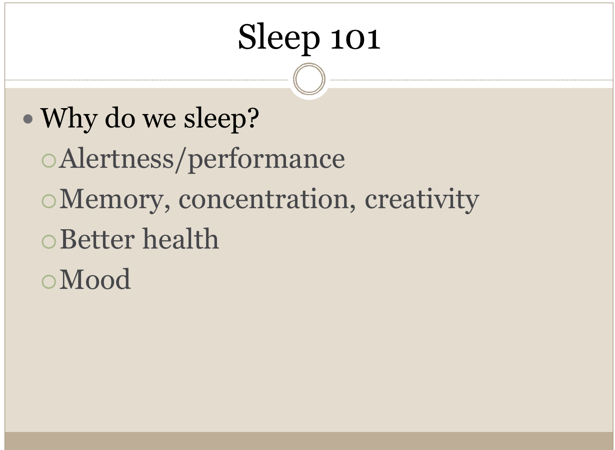

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Sleep Is Needed To:

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

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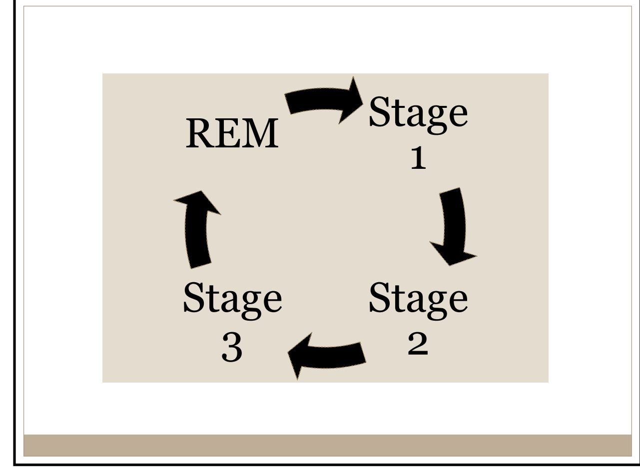

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Circadian Rhythms

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

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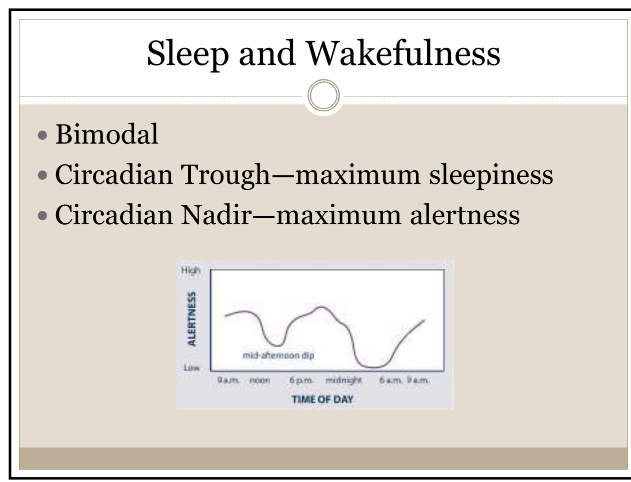

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Zeitgebers

- Social Demands
- Time Cues
- Light

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Melatonin

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

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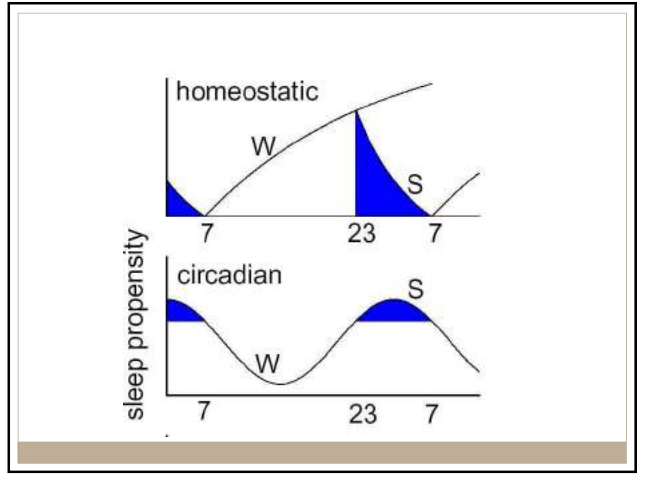

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Descriptive Category	Age Range	Recommended	May be Appropriate	Not Recommended
Preschool	3-5	10-13	(8-9) or (14)	Less than 8 hours; More than 14 hours
School Age	6-13	9-11	(7-8) or (12)	Less than 7 hours; More than 12 hours
Teenager	14-17	8-10	(7) or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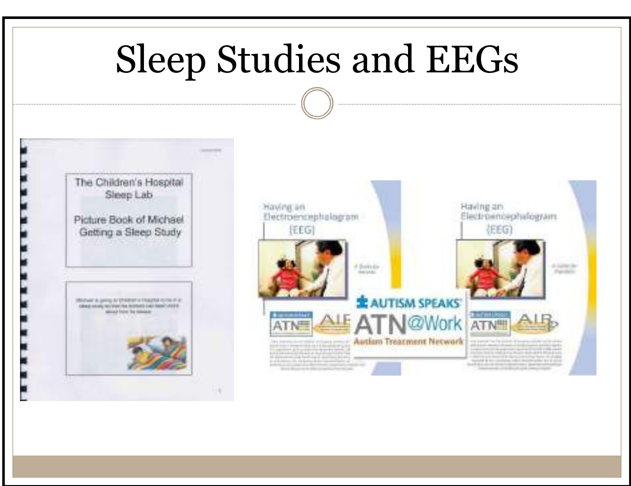
Sleep Studies and EEGs



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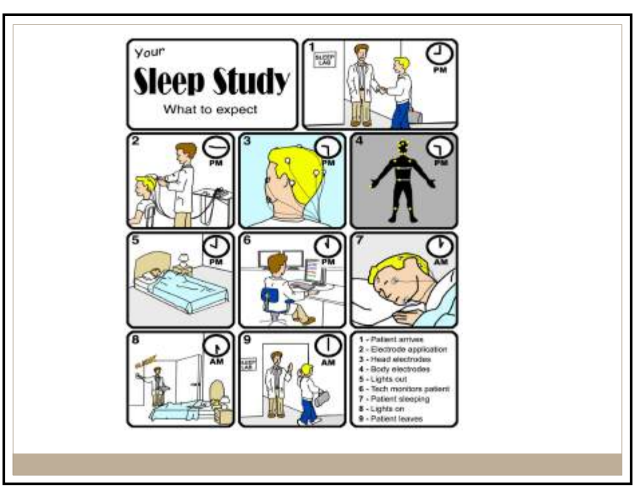

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Sleep Disordered Breathing

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

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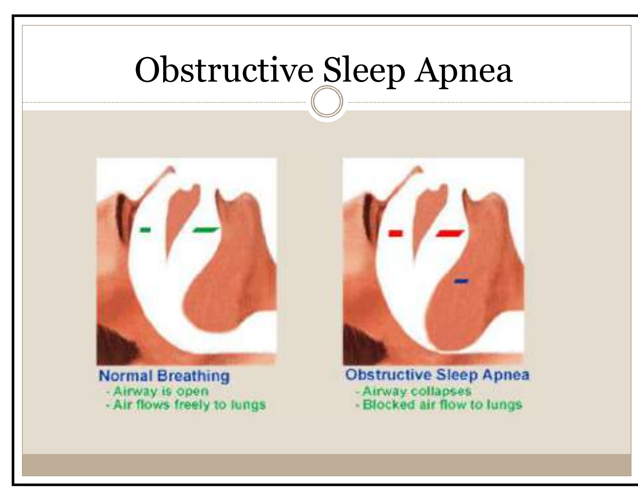
Obstructive Sleep Apnea



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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

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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

20

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

21

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

23

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

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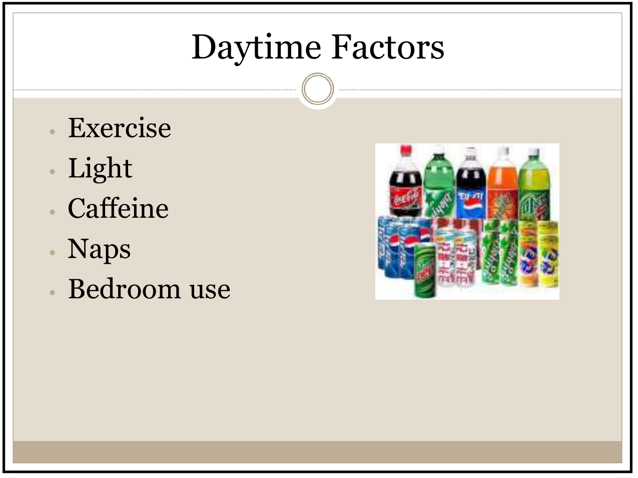

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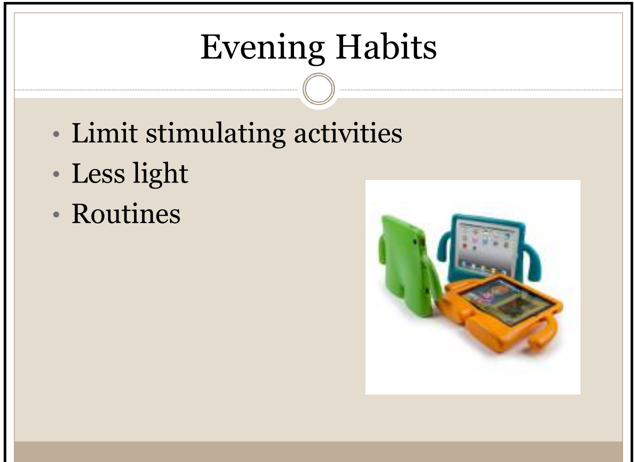

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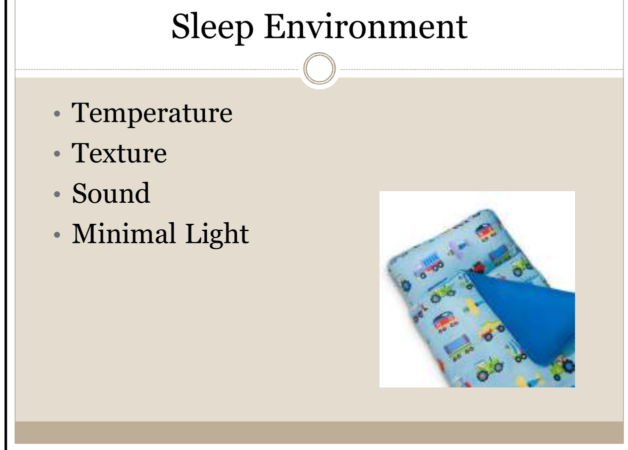

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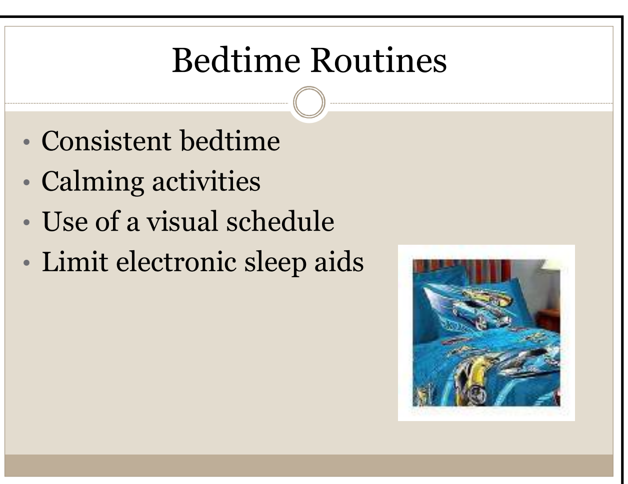

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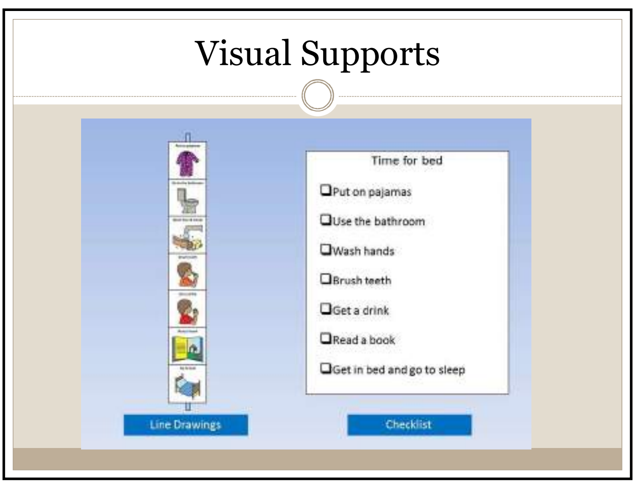

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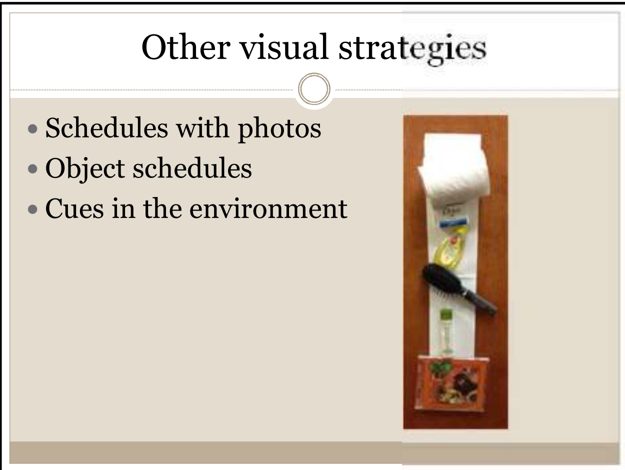

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Sensory Strategies

- 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

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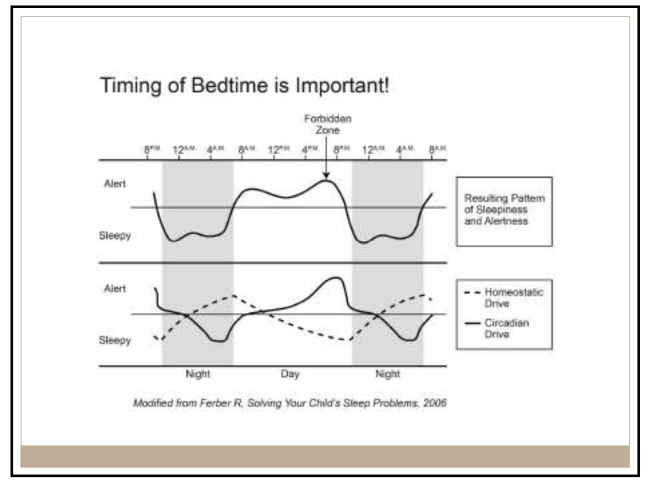

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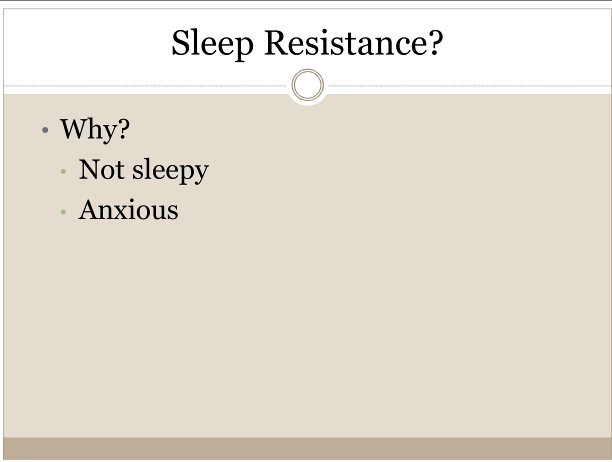

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Nighttime Fears

Common Characteristics:

--Fearful Behaviors

--Bedtime Resistance

--"Curtain Calls"

--Need to be with a parent or family member at bedtime

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Strategies for Sleep Resistance

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

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Understanding Night Wakings

Begin at bedtime (Durand, 1998)
- Learning how to fall asleep
- Falling asleep while drowsy

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What to do?

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

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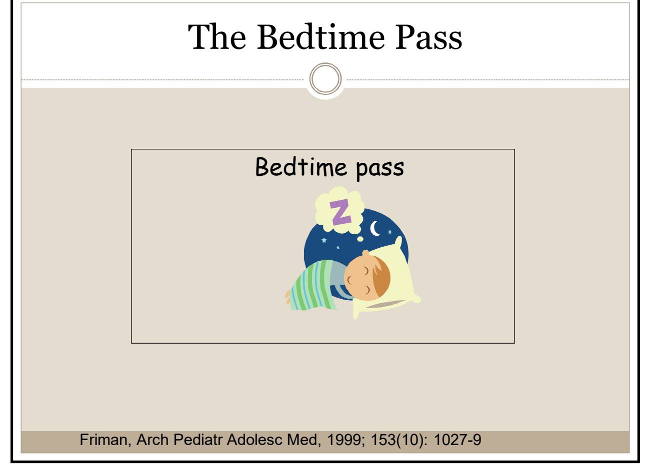

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Bedtime Pass Social Story

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 or to 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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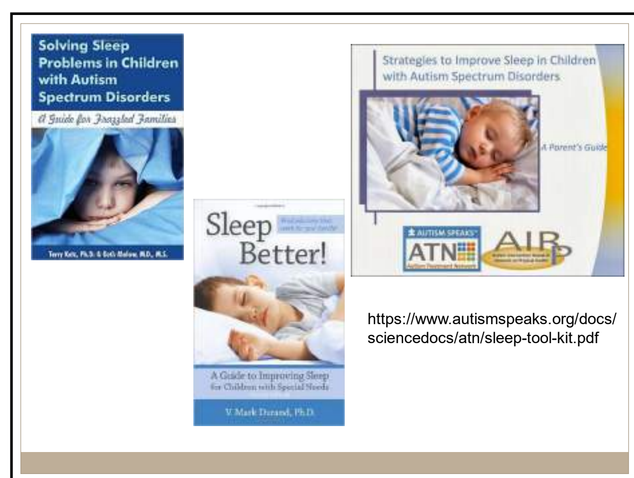

https://www.autismspeaks.org/docs/sciencedocs/atn/sleep-tool-kit.pdf

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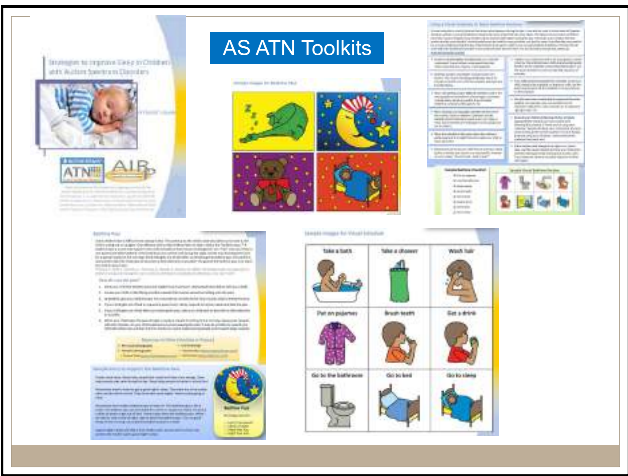

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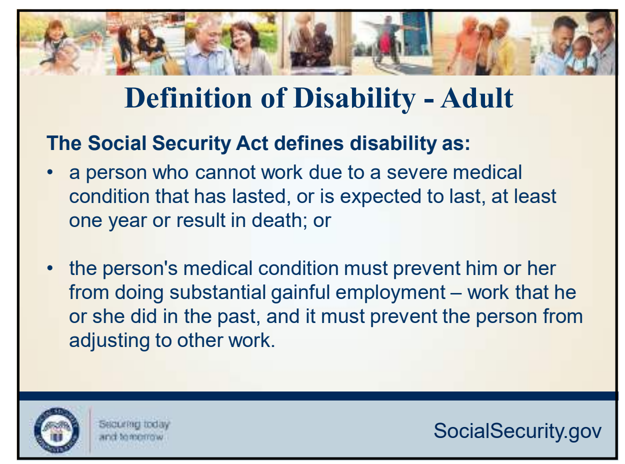

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Rules for Recent Work Test

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.

Securing today and tomorrow

SocialSecurity.gov

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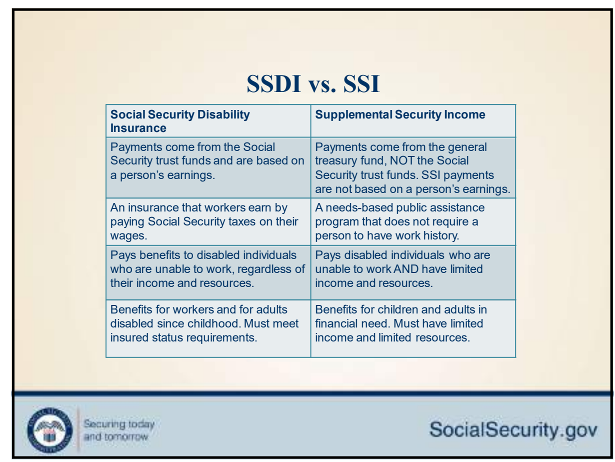
SSDI vs. SSI

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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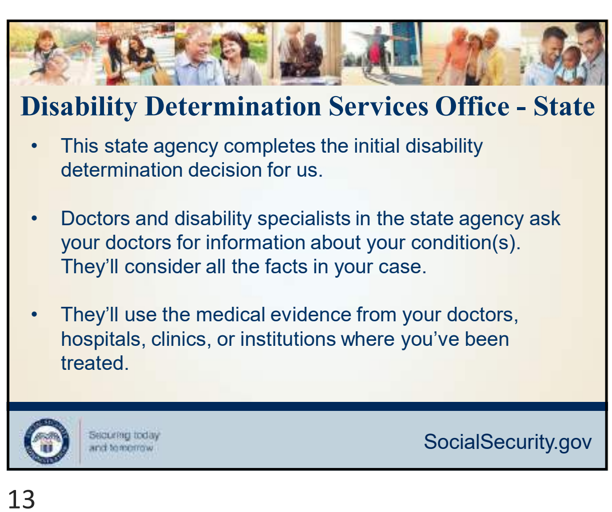

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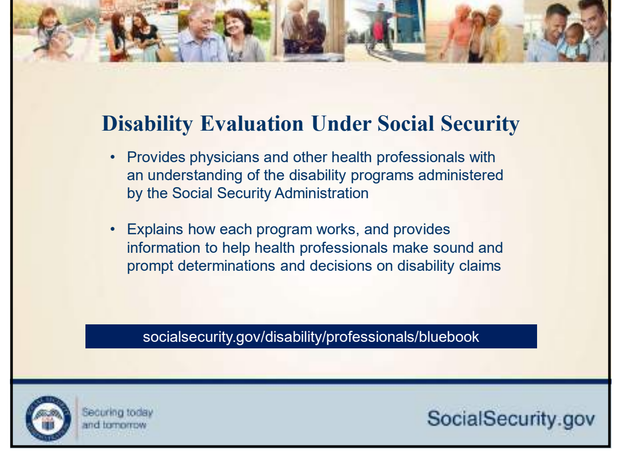

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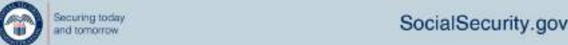
What evidence do we need to document non-mosaic Down syndrome?

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.

Securing today and tomorrow

SocialSecurity.gov

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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

Securing today and tomorrow

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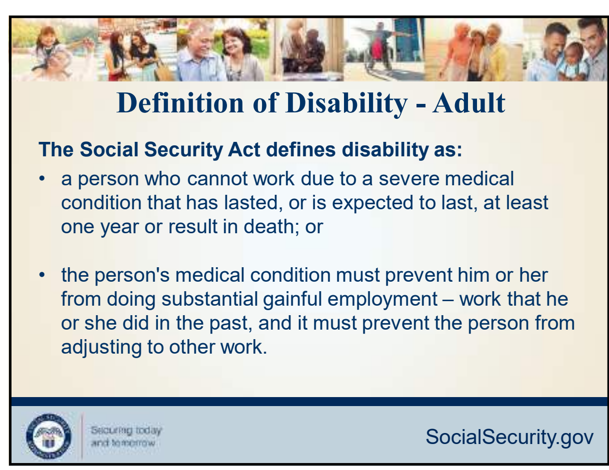

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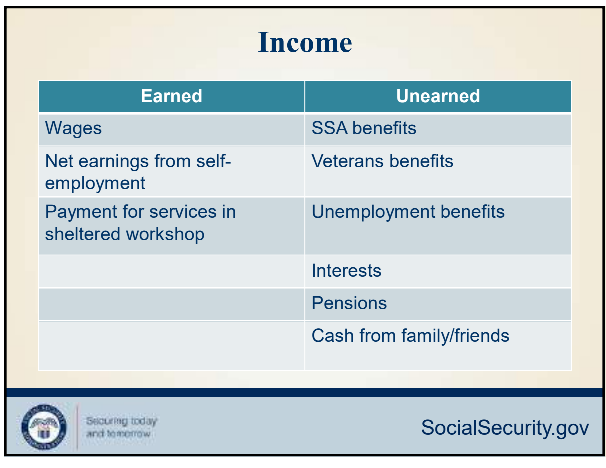

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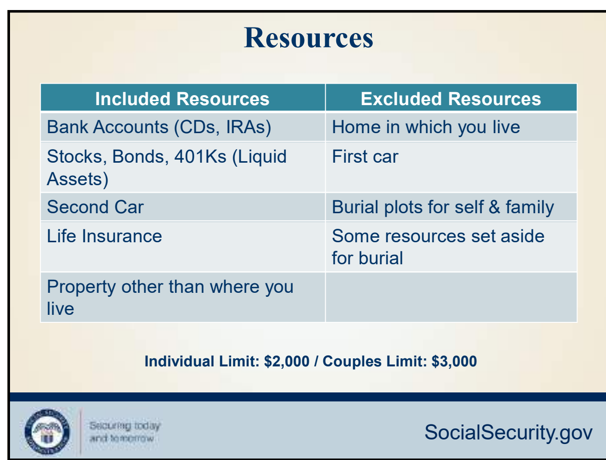

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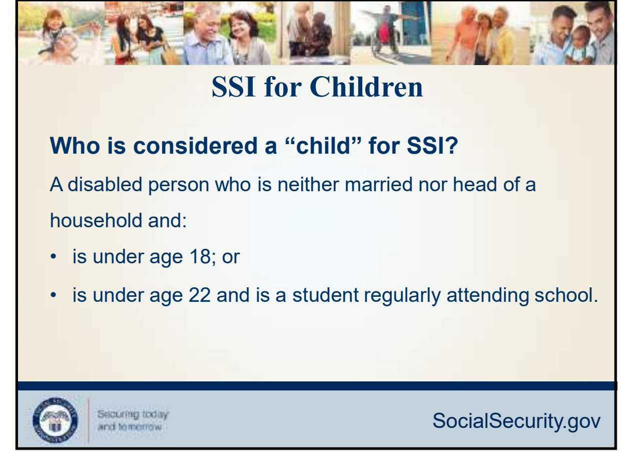

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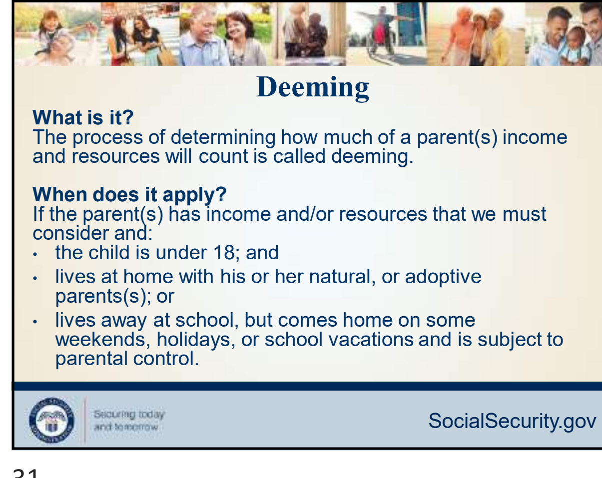

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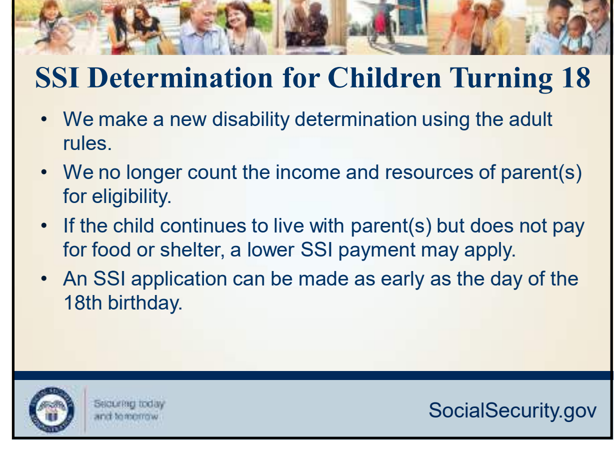

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TOILET TRAINING FOR INDIVIDUALS WITH DOWN SYNDROME

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

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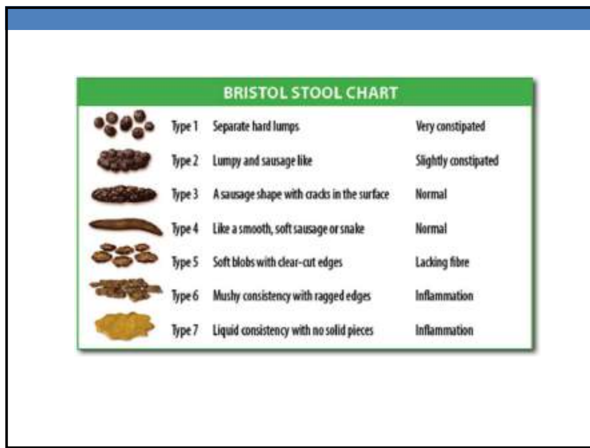

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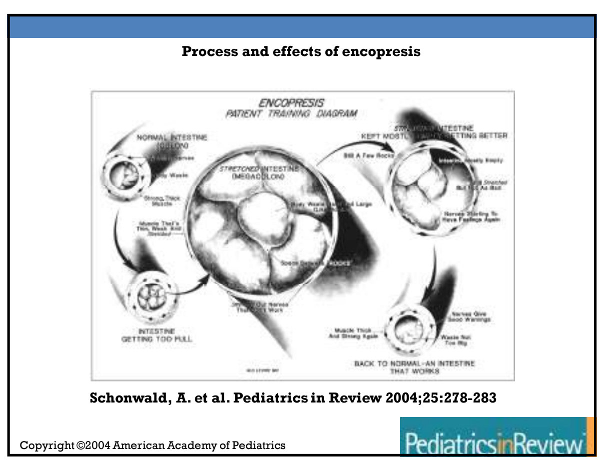

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Voiding Dysfunction

- Incontinence
- Irritative symptoms
- Recurrent UTIs
- Pain
- Can be related to constipation

6

Working Together

- Team approach
  - Family, school, therapists, healthcare provider
- Small steps
- Trouble-shooting

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Get the facts!

- Eating
- Drinking
- Peeing
- Pooping

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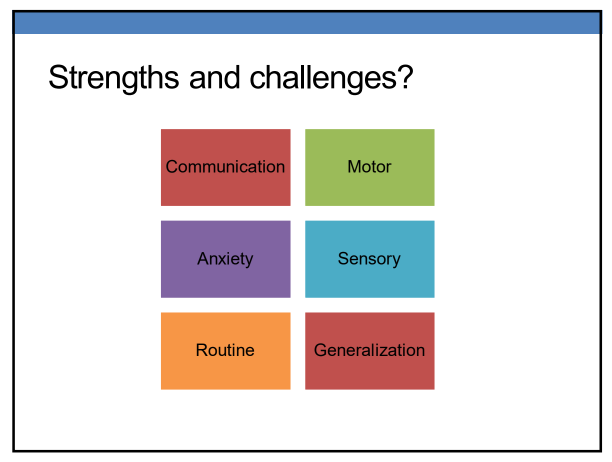

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Diet and Exercise

- Fluids
- Fiber
- Physical activity

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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

13

Exercise

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

  by Missy Chase Lapine and Larysa Didio

14

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

15

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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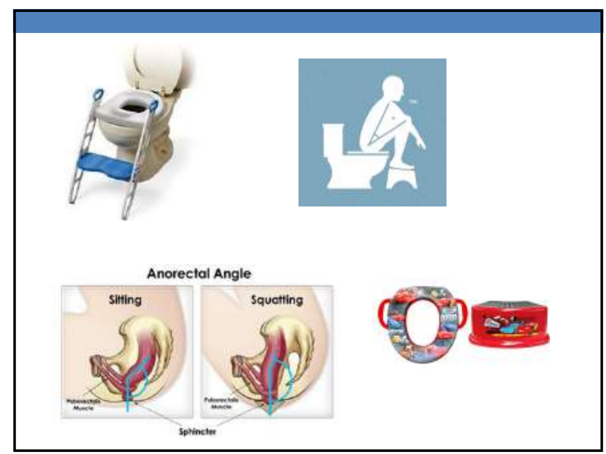

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Visual Supports

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

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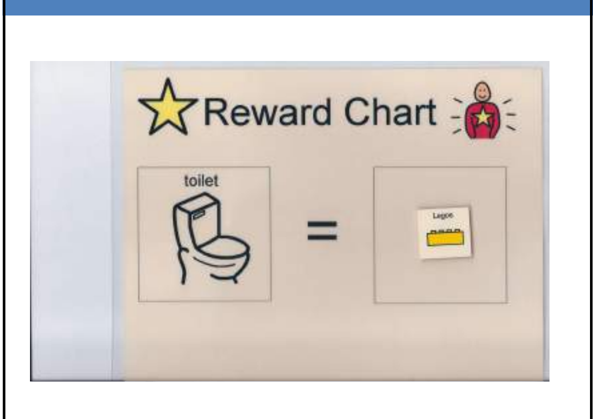

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Routines

- 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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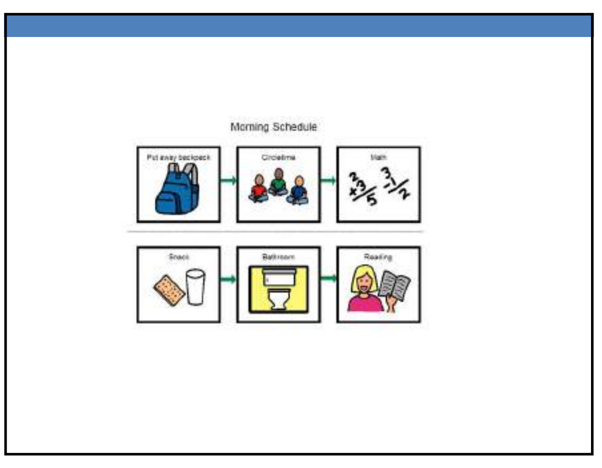

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Using a Visual Schedule

- 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

29

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

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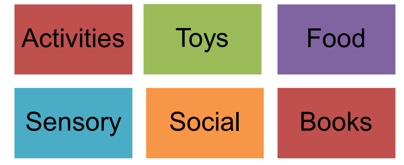
Reinforcement

- 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

32

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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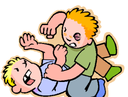
Diapers vs. Underpants

- 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

38

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

39

Other Strategies

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

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Alarm Therapy

41

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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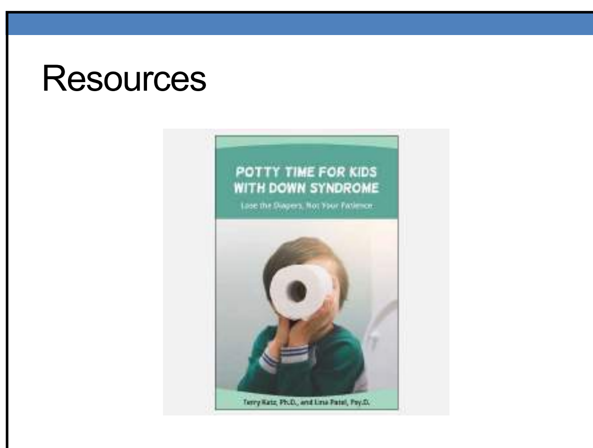

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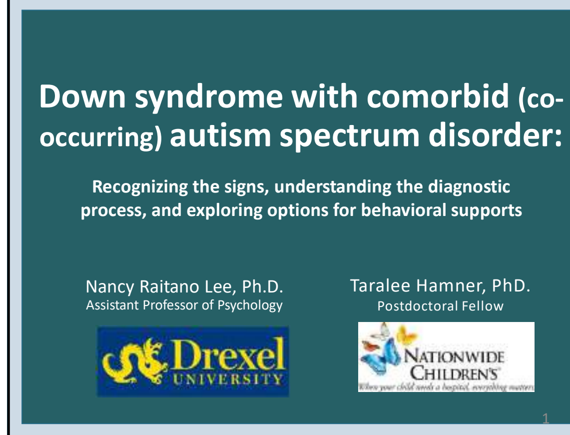

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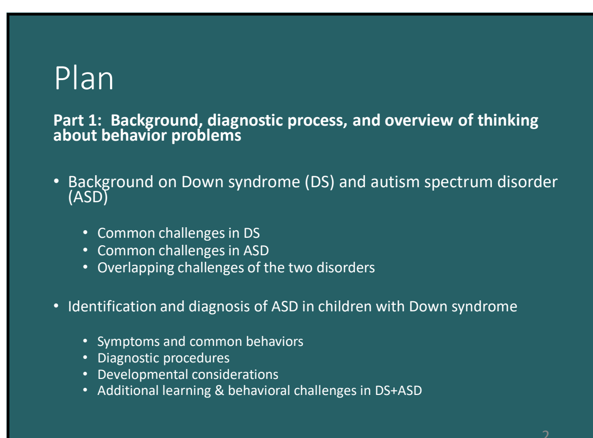

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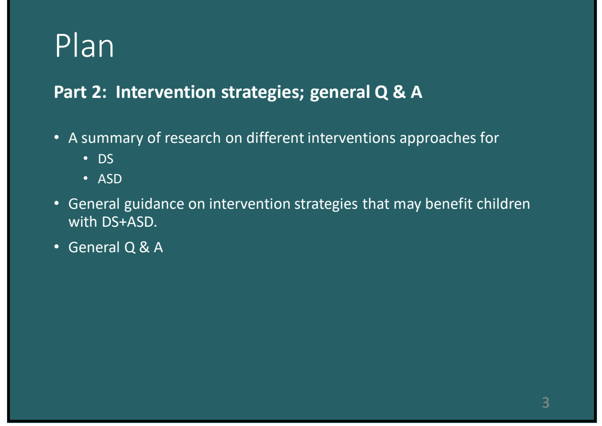

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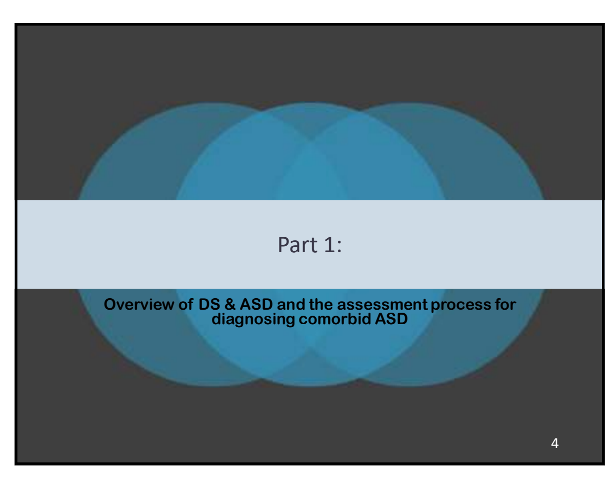

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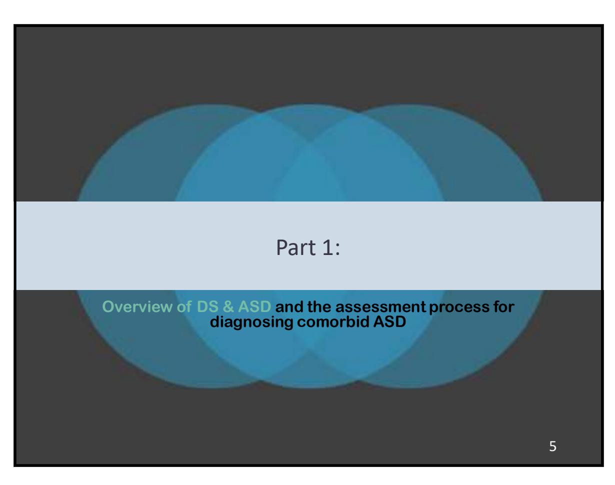

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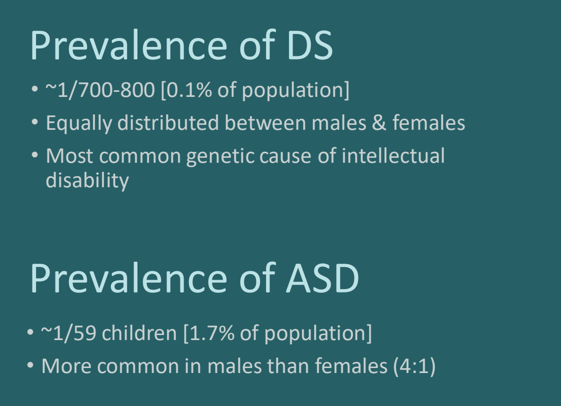

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Prevalence of DS + ASD

- 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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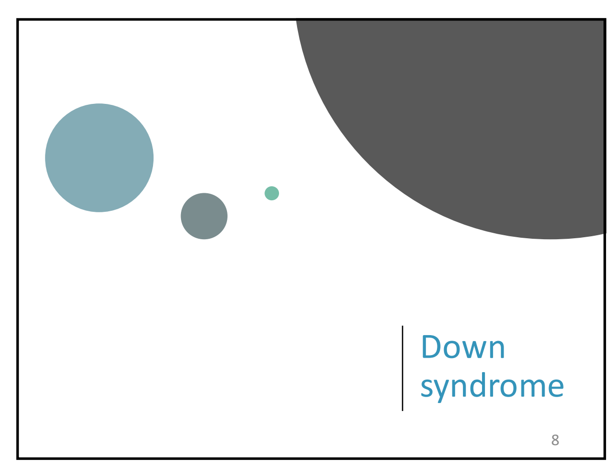

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Common learning challenges associated with Down syndrome

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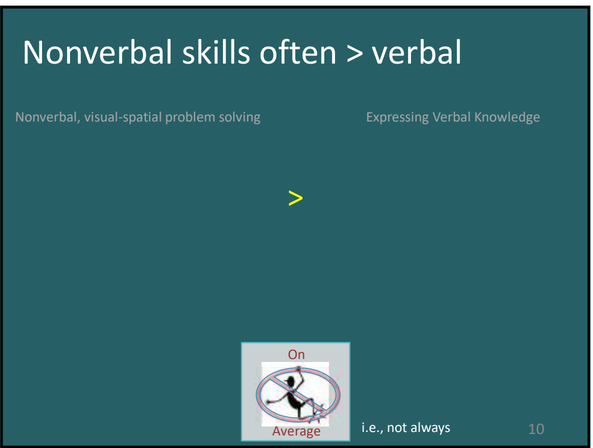

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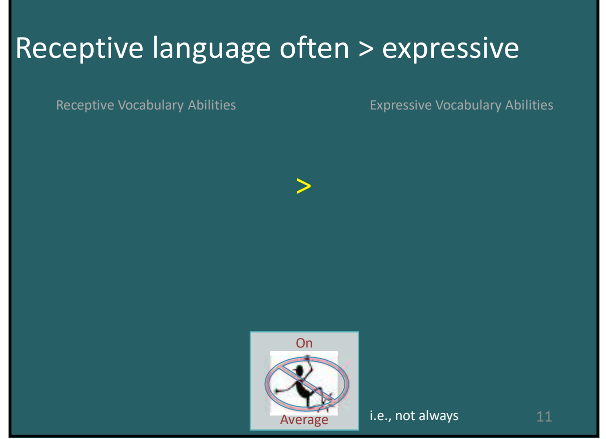

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Receptive > Expressive Vocabulary: Implications for Learning

- 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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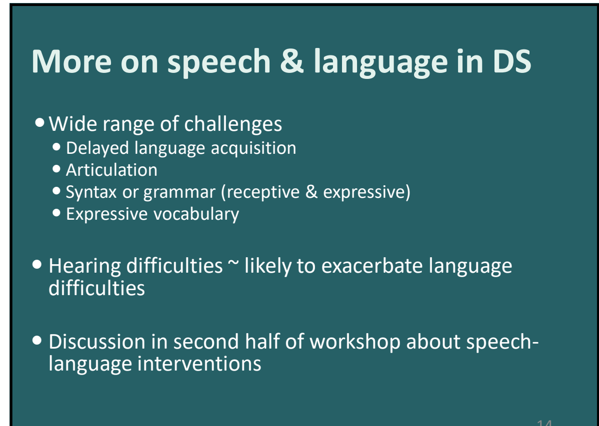

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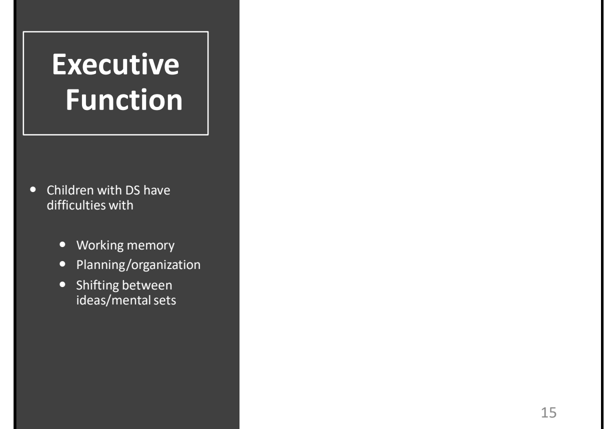

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Working Memory

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

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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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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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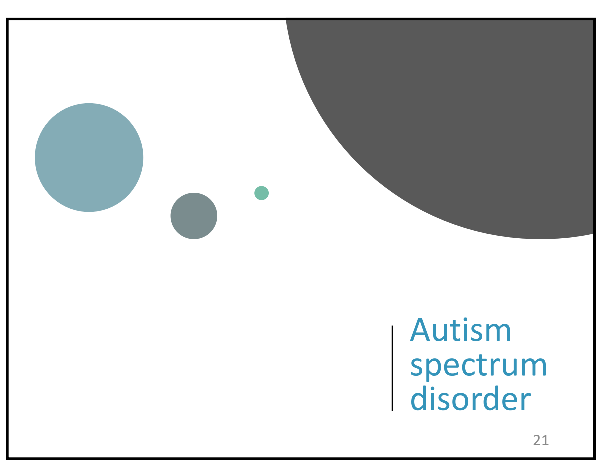

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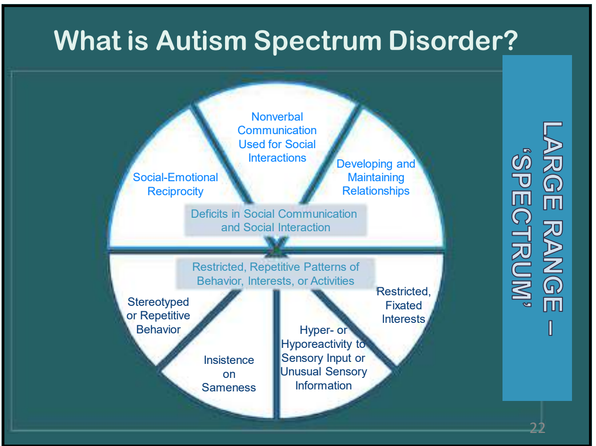

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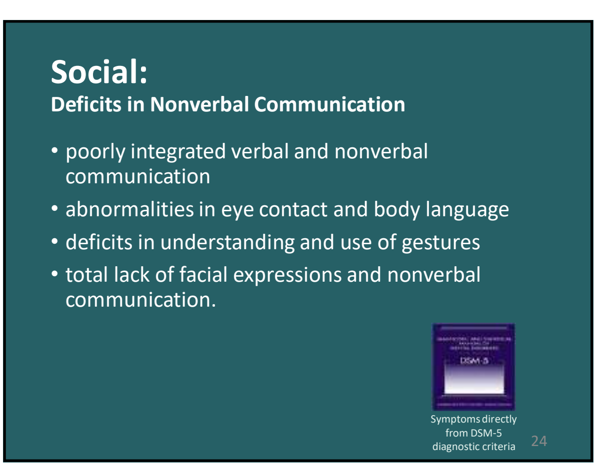

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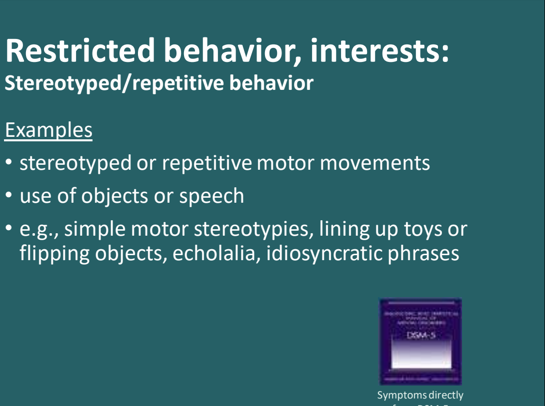

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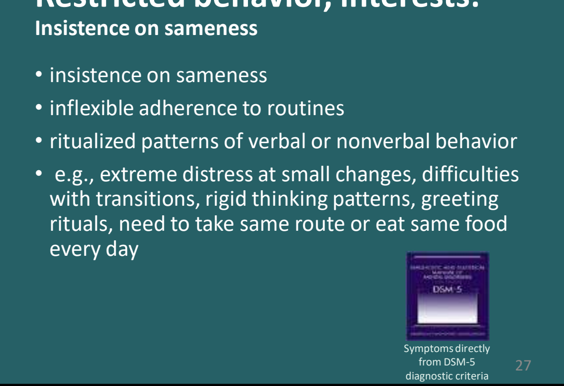

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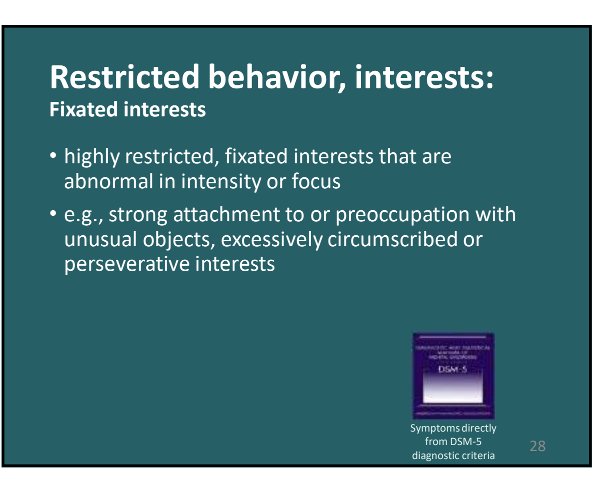

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Restricted behavior, interests:
Sensory hyper- or hyporeactivity

- 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

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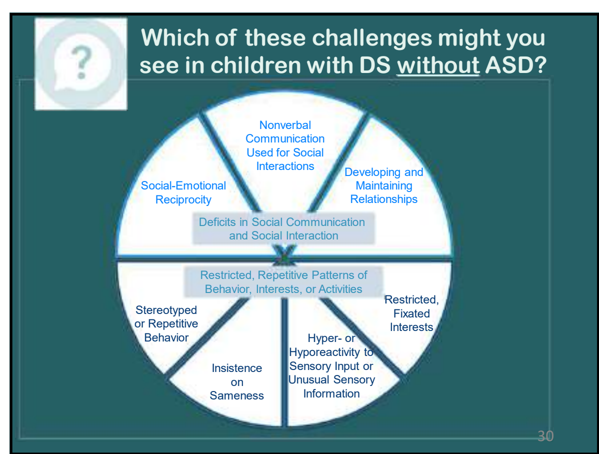

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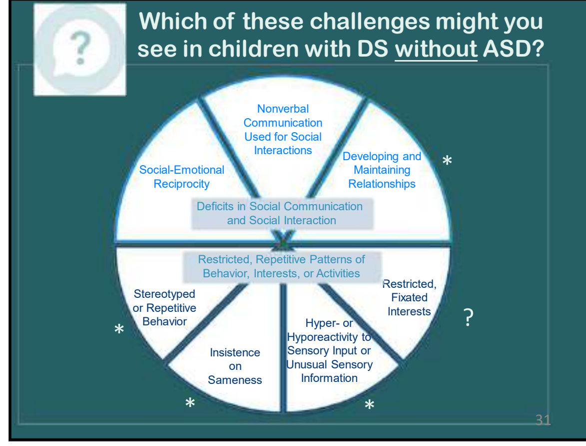

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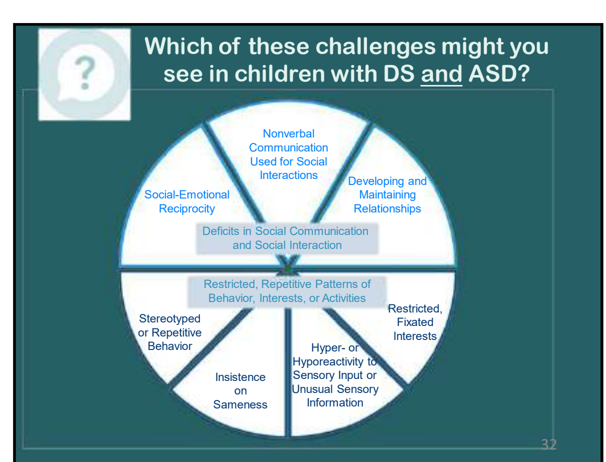

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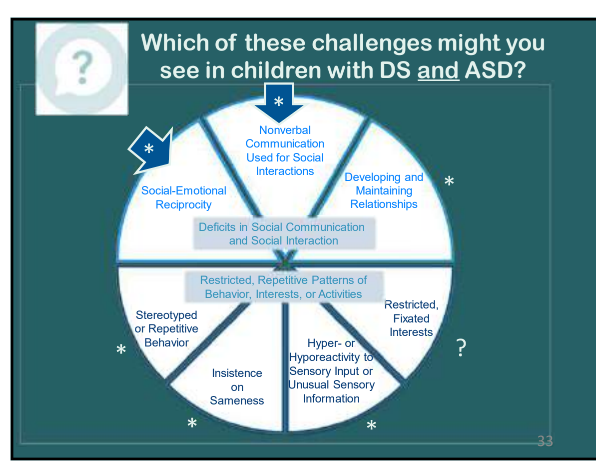

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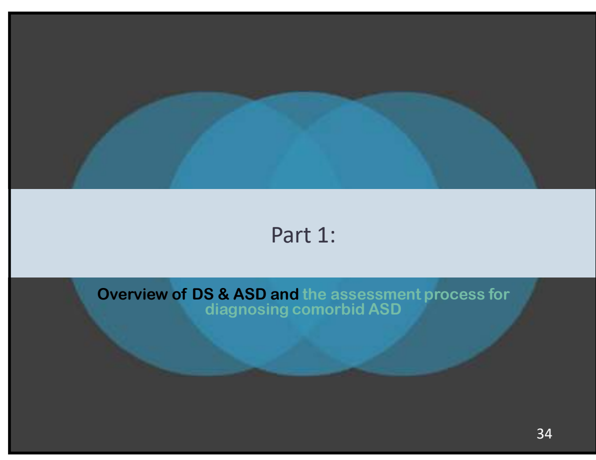

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We are concerned about ASD when we see…

- 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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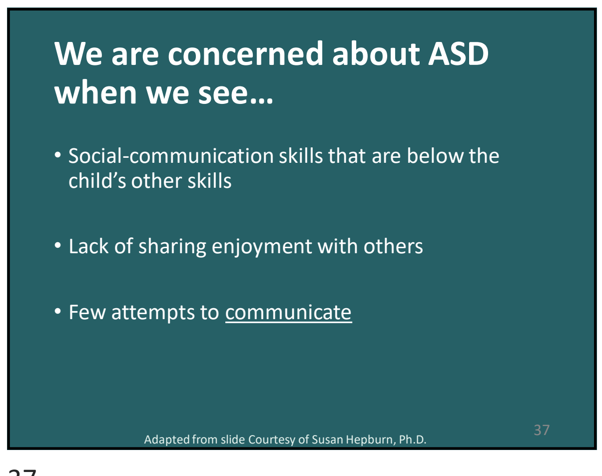

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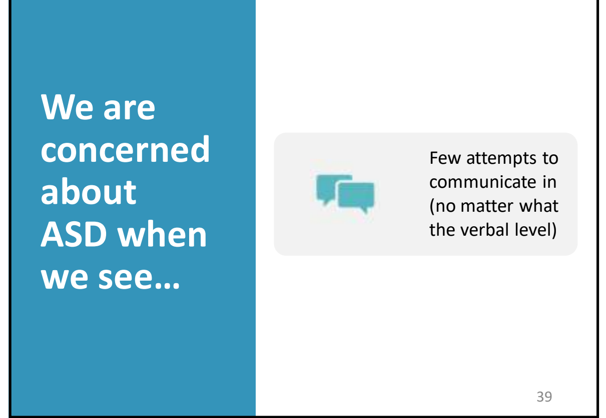

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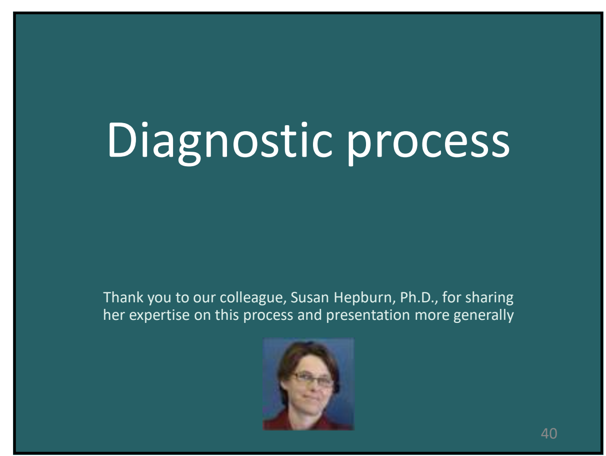

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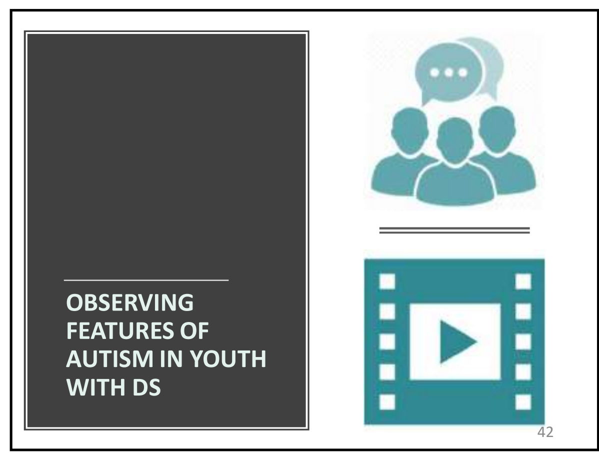

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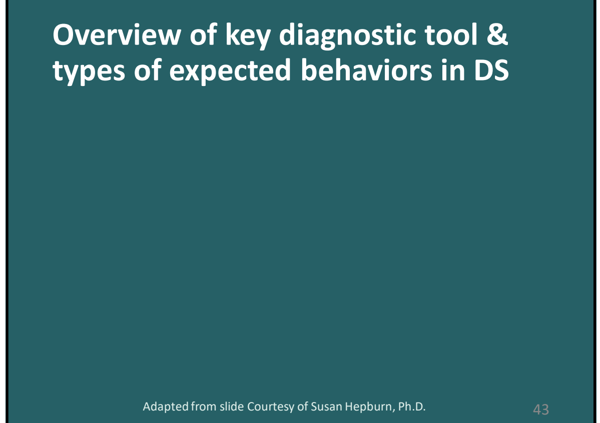

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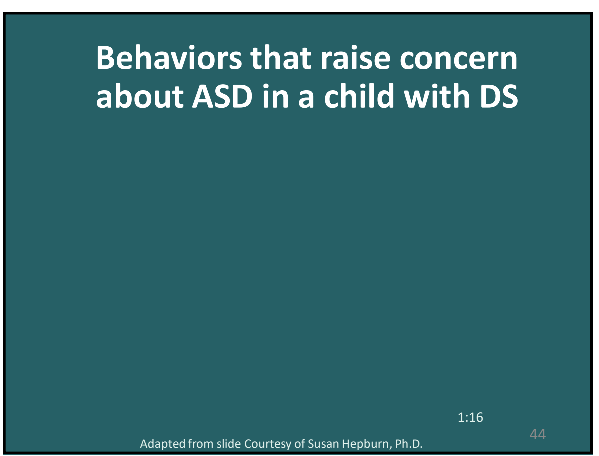

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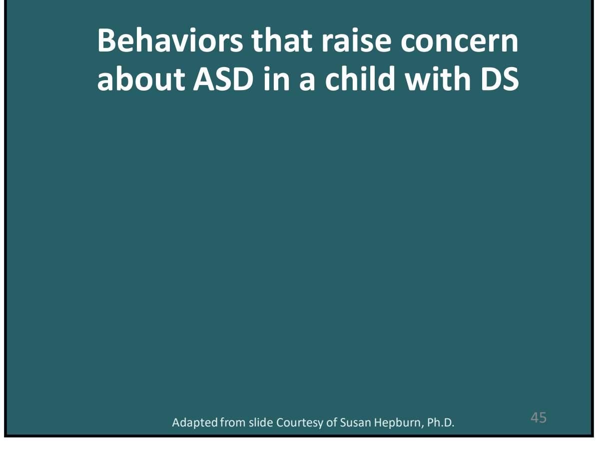

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Behaviors that raise concern about ASD in a child with DS

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

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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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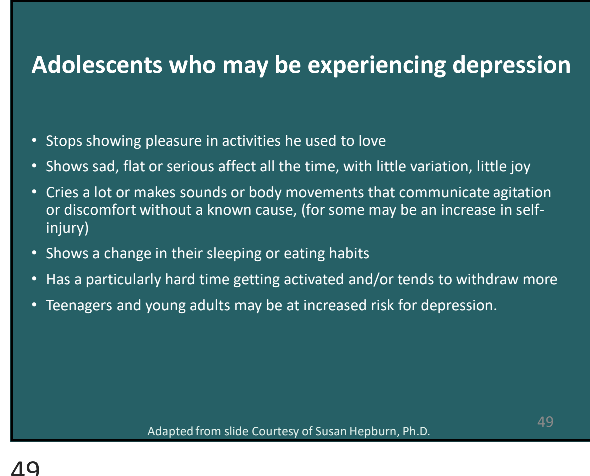

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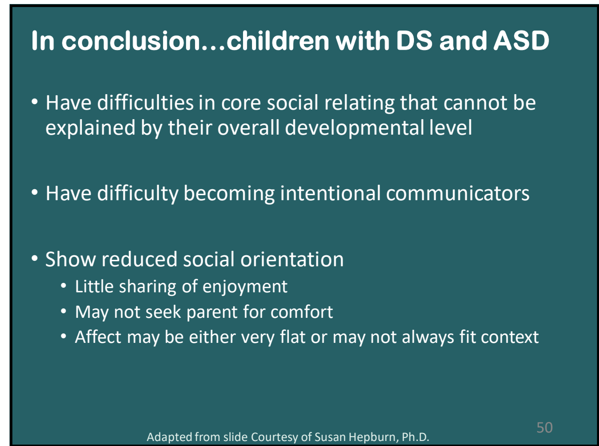

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Behaviors that don't help us figure out the autism question

- 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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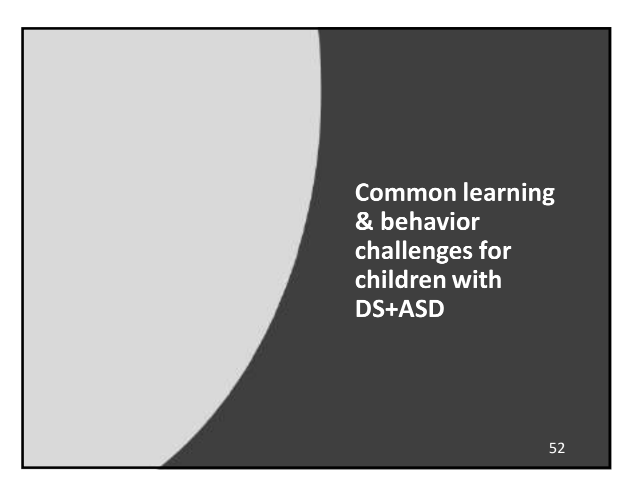

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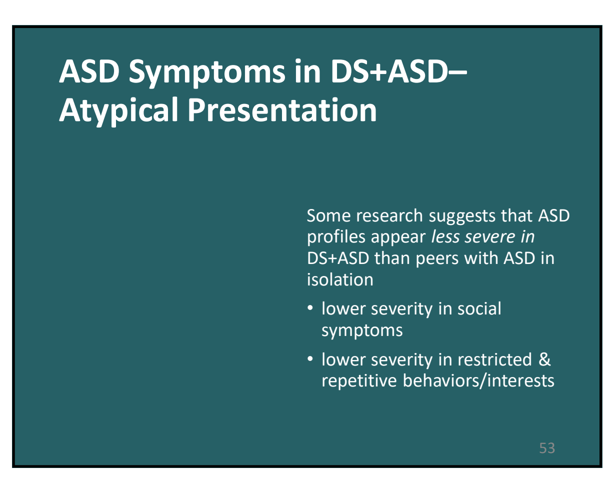

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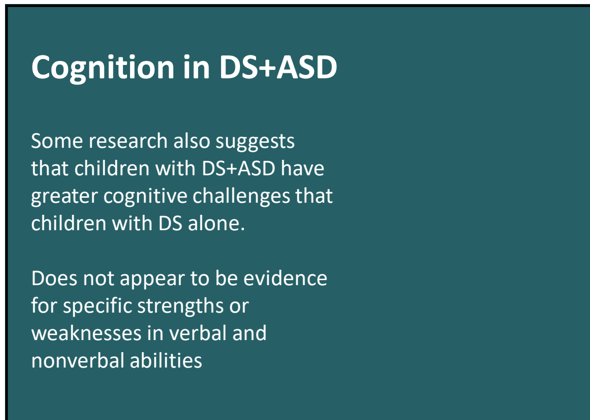

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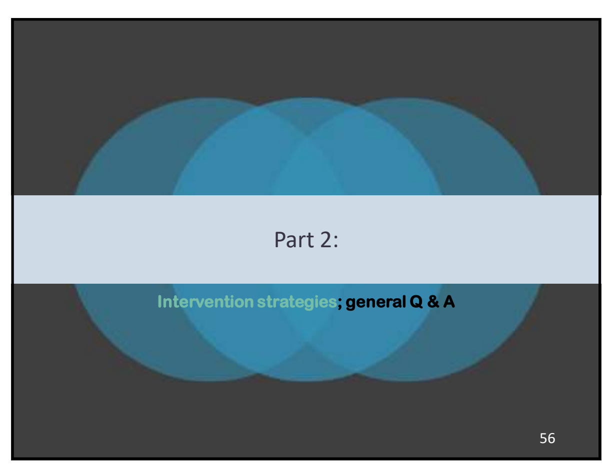

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Research on Language Interventions for DS
(with or without ASD)

57

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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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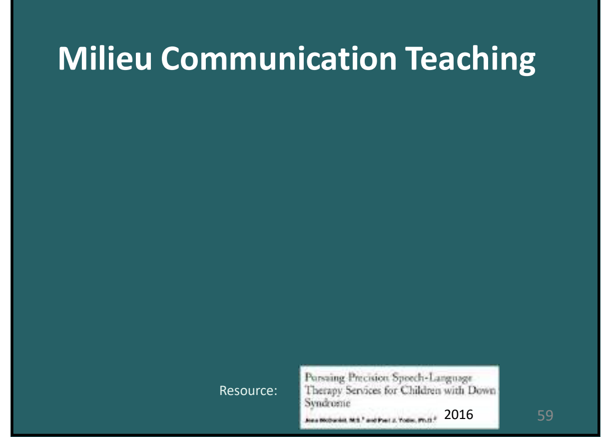

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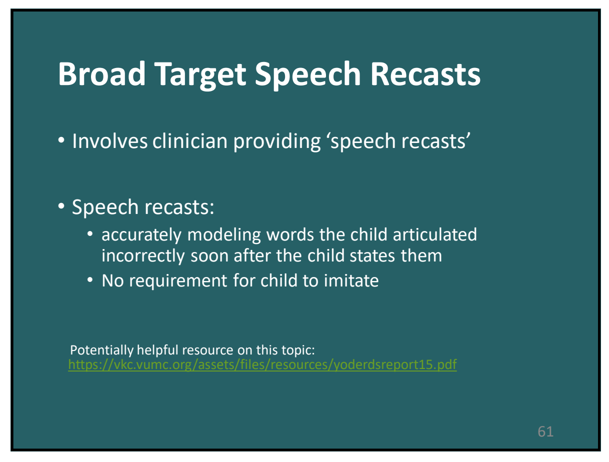

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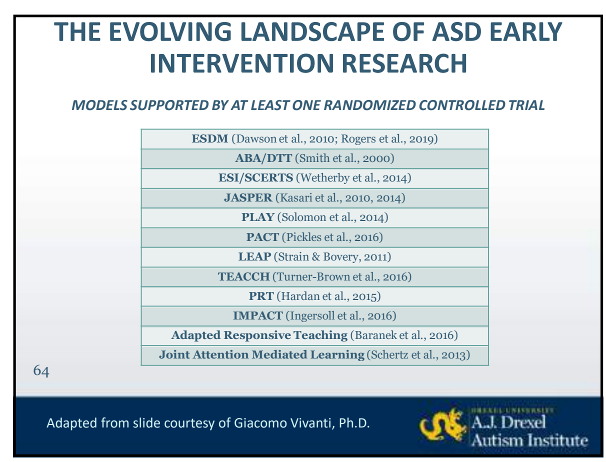

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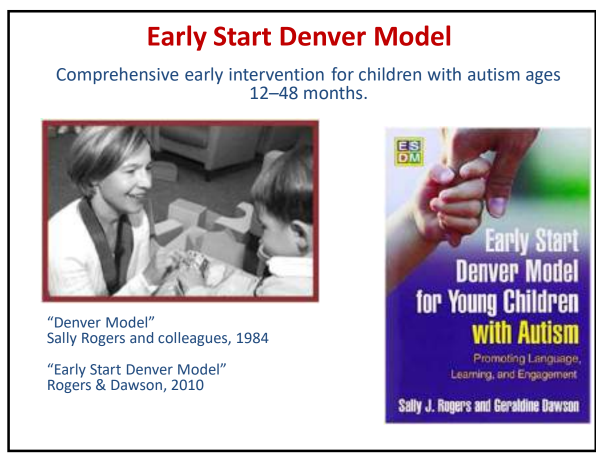

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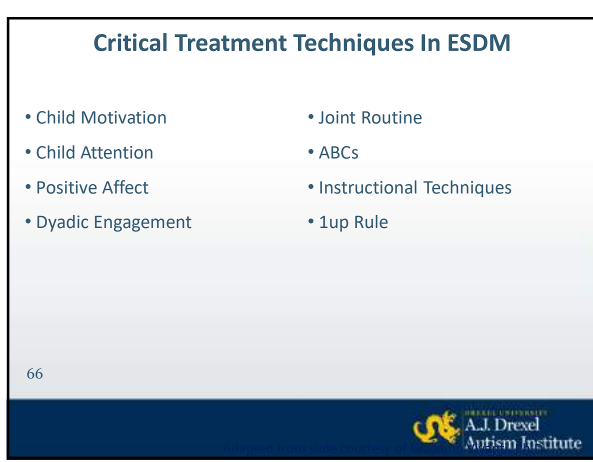

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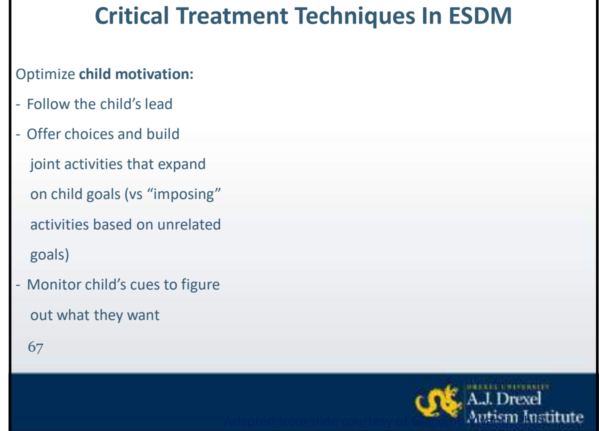

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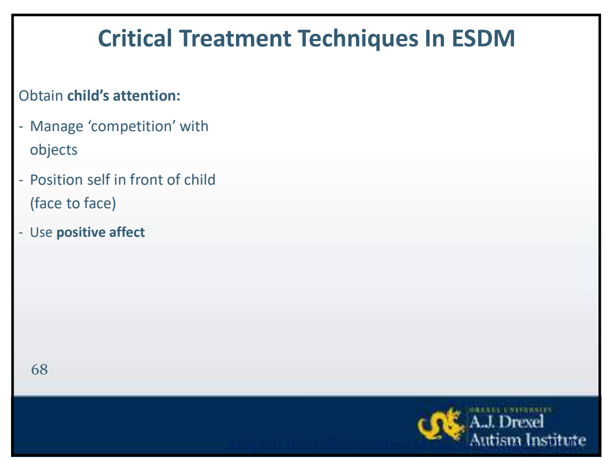

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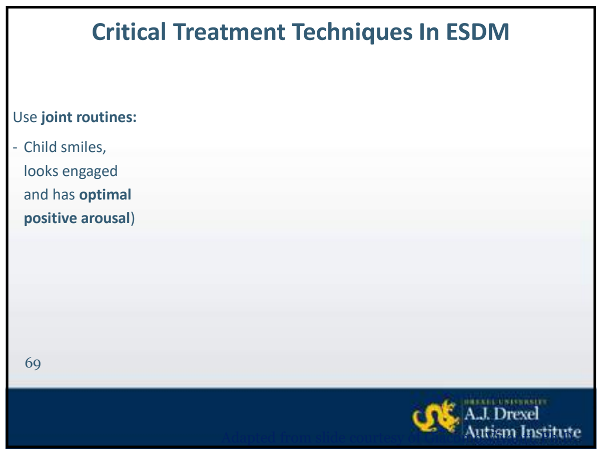

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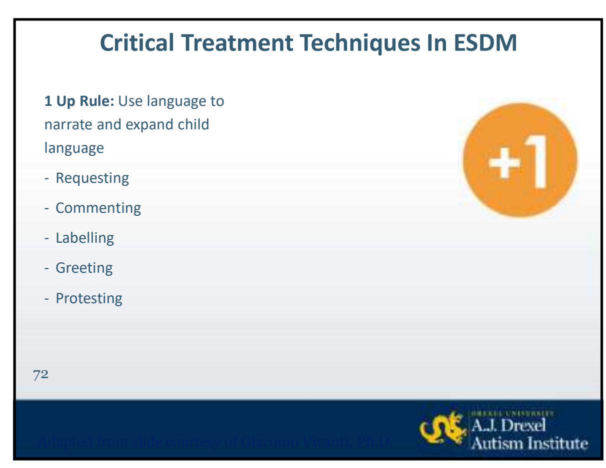

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Emerging research on adolescents with autism suggests….

- Video modeling may be helpful for teaching skills

  https://youtu.be/wBlvbTJz5u8

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

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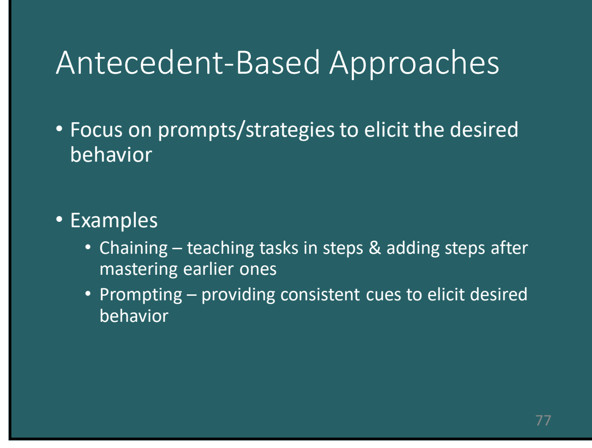

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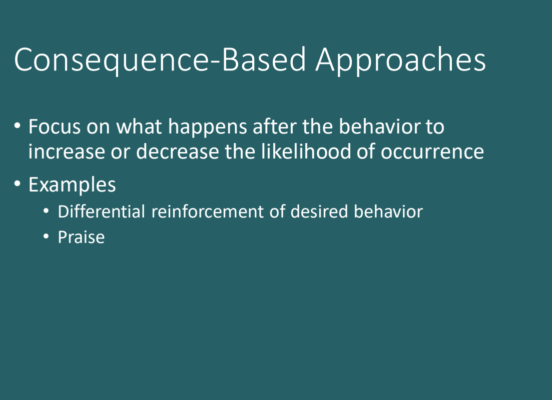

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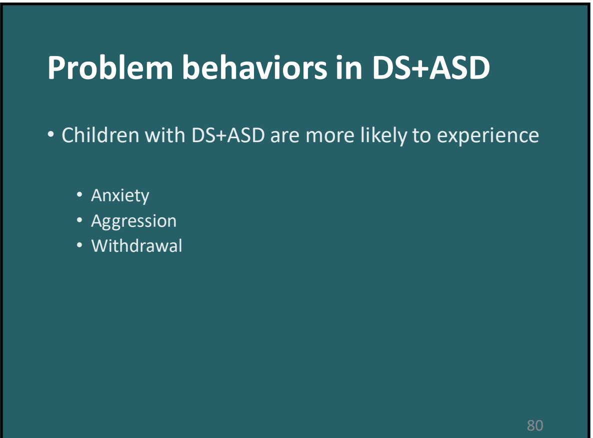

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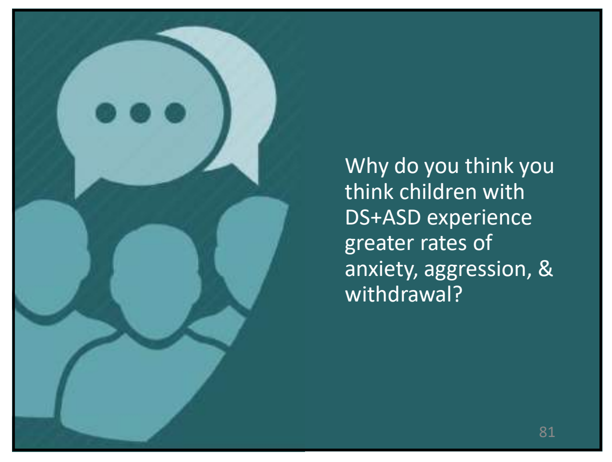

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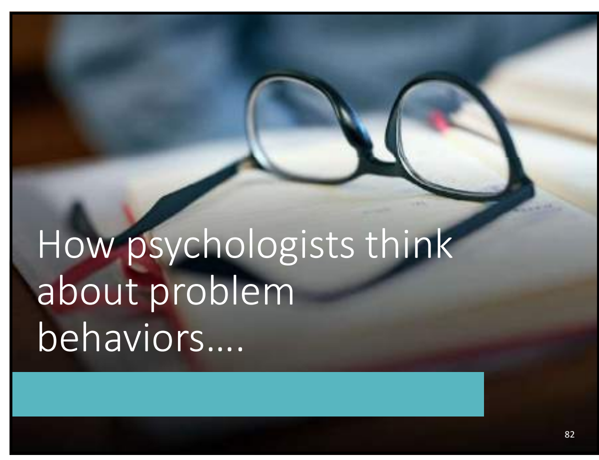

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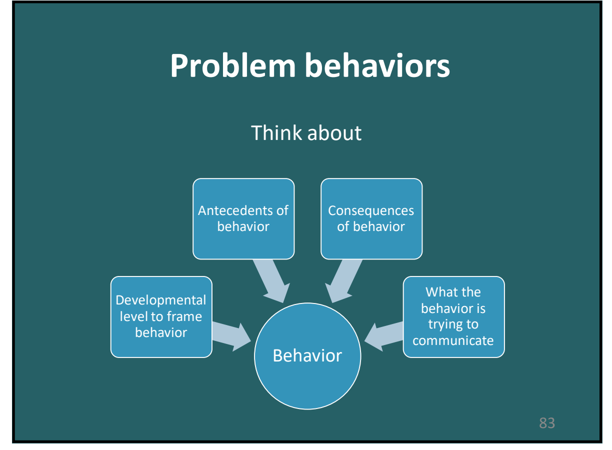

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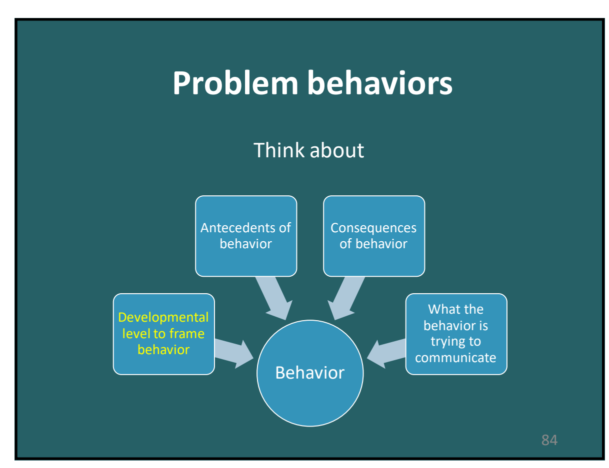

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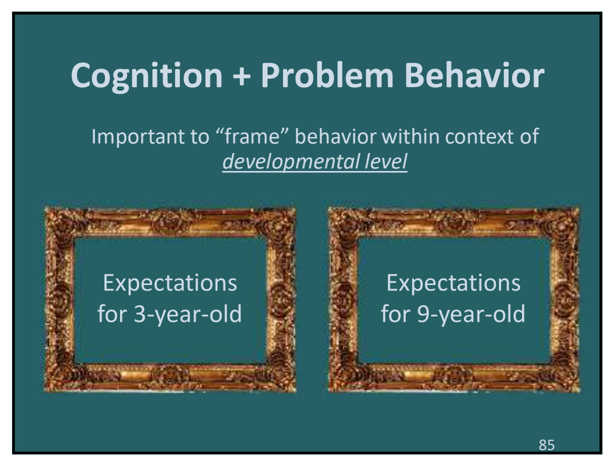

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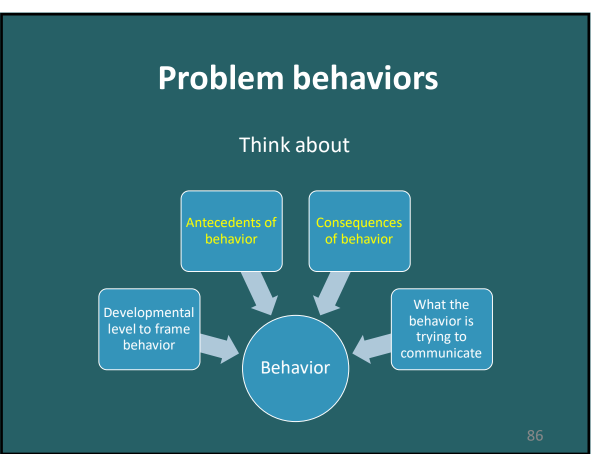

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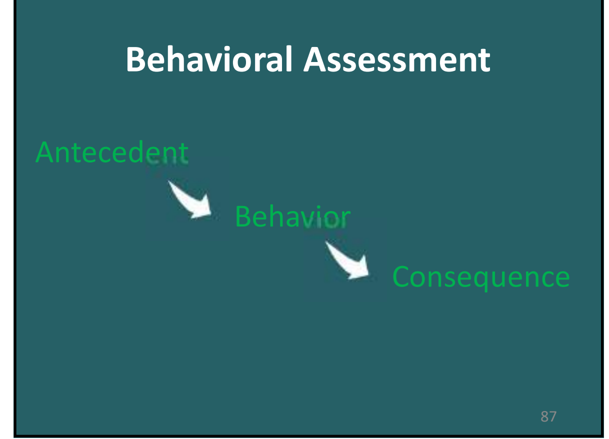

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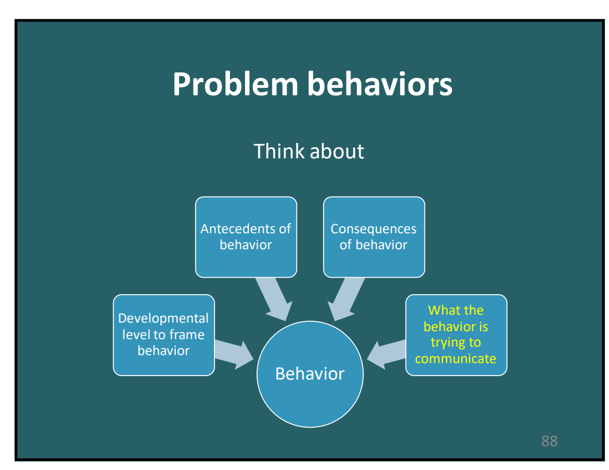

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What is the child trying to communicate via the behavior?

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

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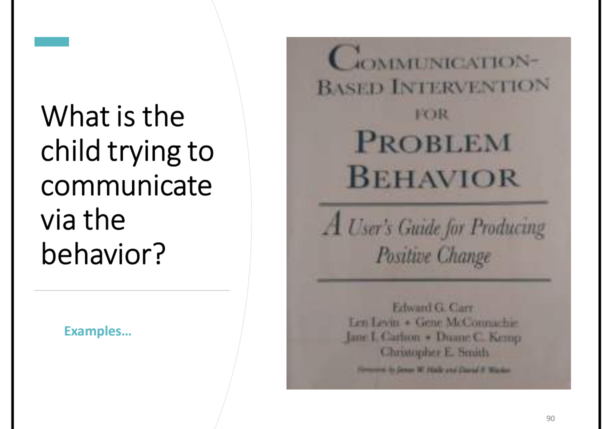

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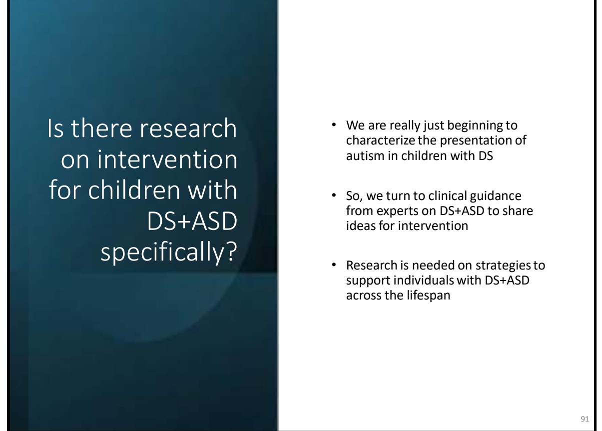

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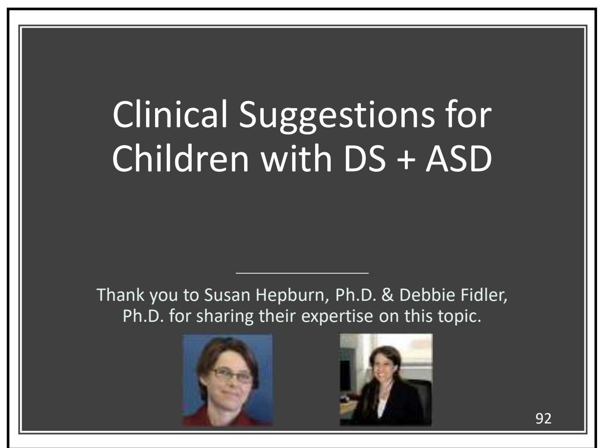

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Clinical recommendations for children with DS+ASD

- 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. 93

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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. 94

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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. 95

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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. 96

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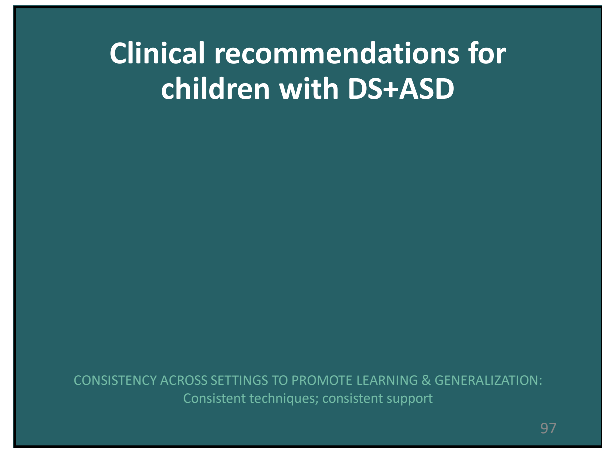

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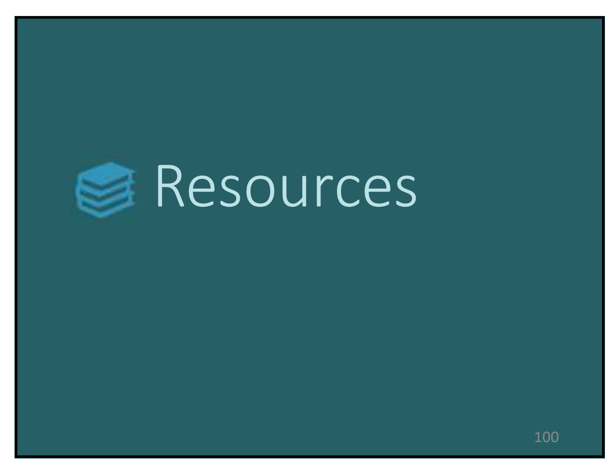

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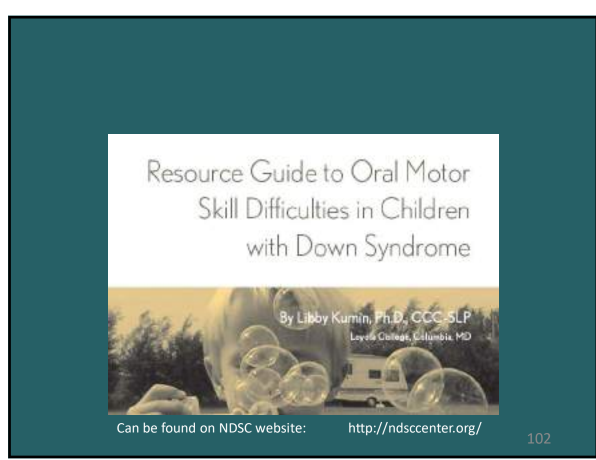

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What Happens When I'm Gone?

Special Needs Planning for North Carolina Parents

Paul Yokabitus
Cary Estate Planning
919-659-8433
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 <u>means-tested</u> 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 (**<u>NOT</u>** 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”

15

Planning Tools

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

16

ABLE Accounts (529A)

17

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."

19

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

24

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

28

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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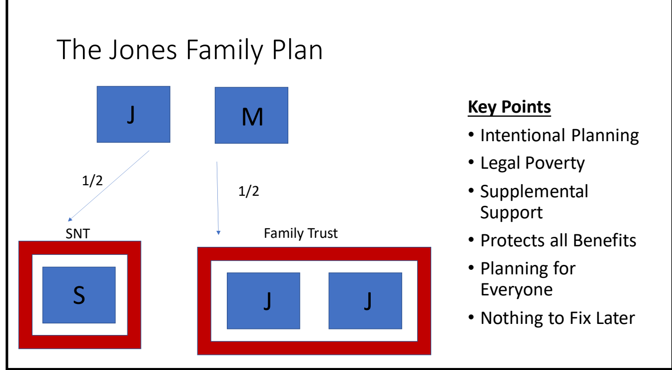
Planning for the Jones Family

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

31

The Jones Family Plan



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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

33

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

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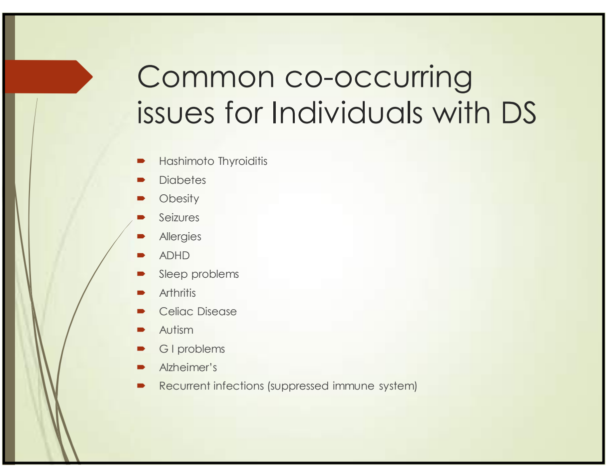

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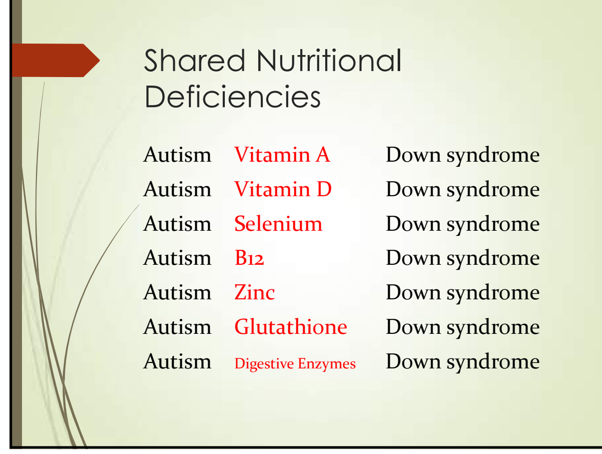

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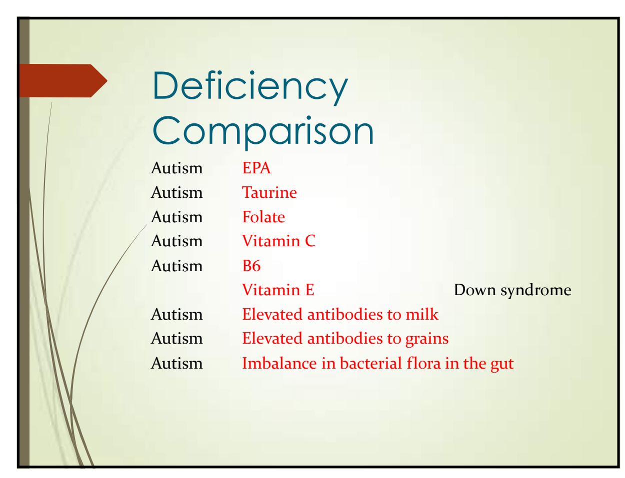

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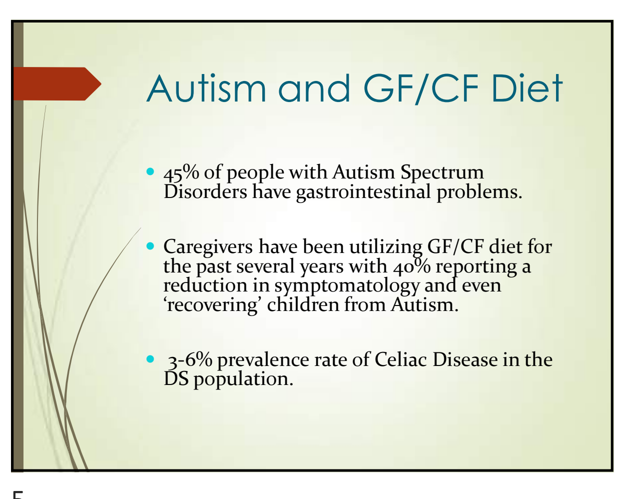

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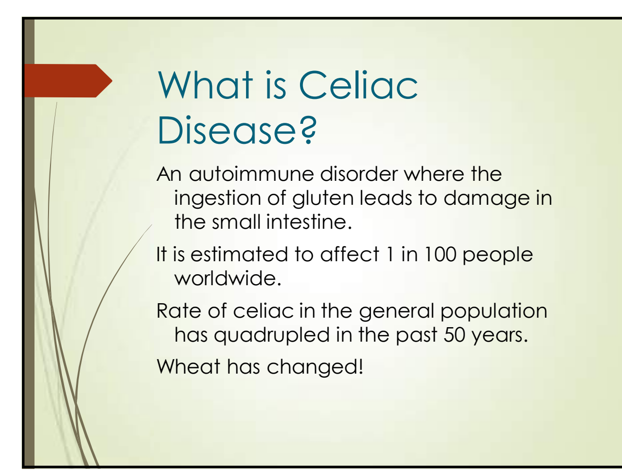

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Leaky Gut/ Intestinal Permeability

- 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)

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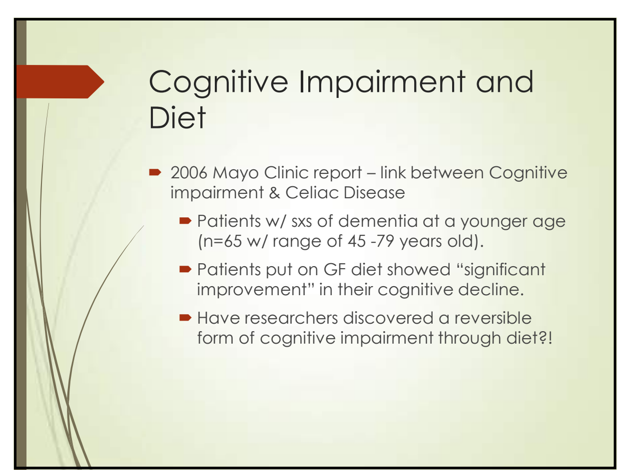

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Inflammation

- 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.

12

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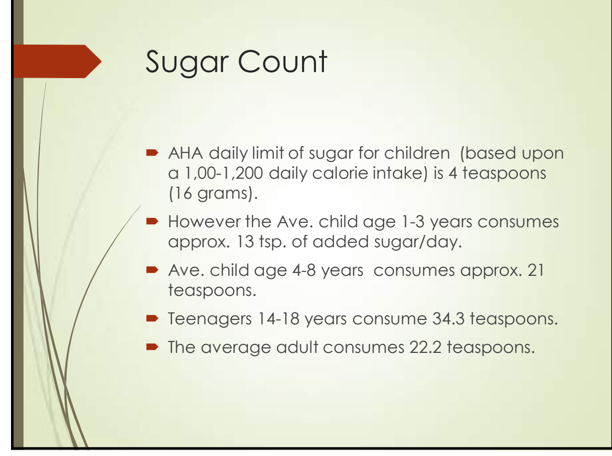

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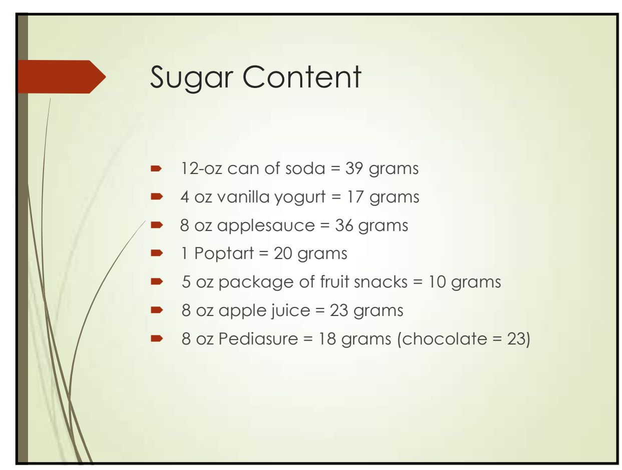

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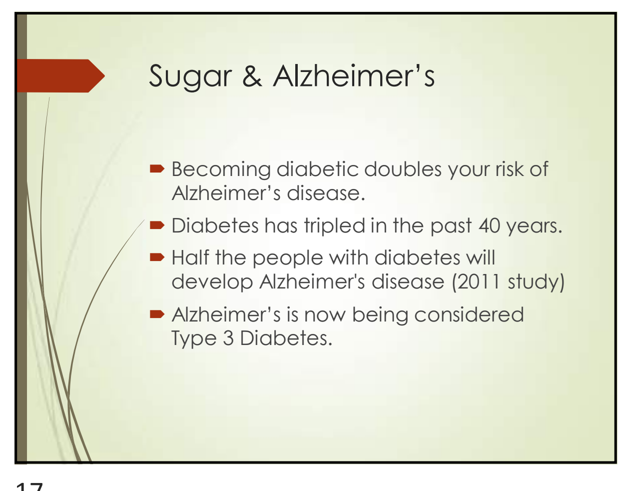

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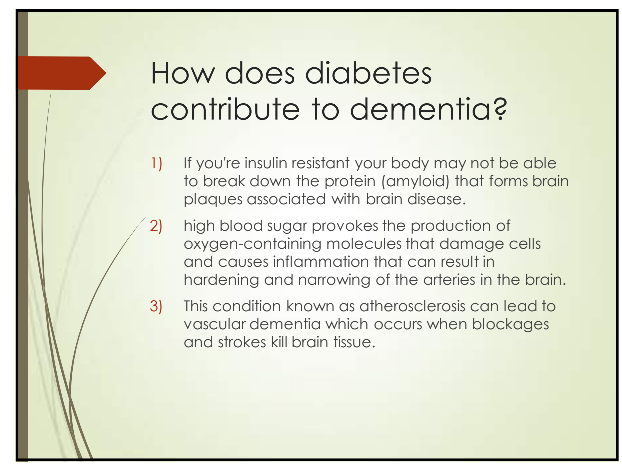

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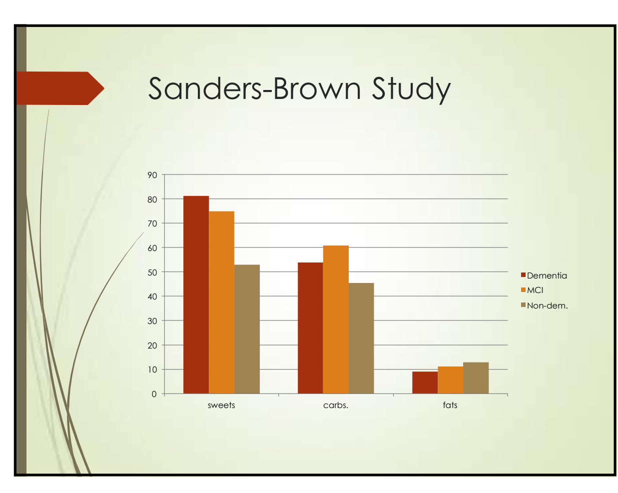

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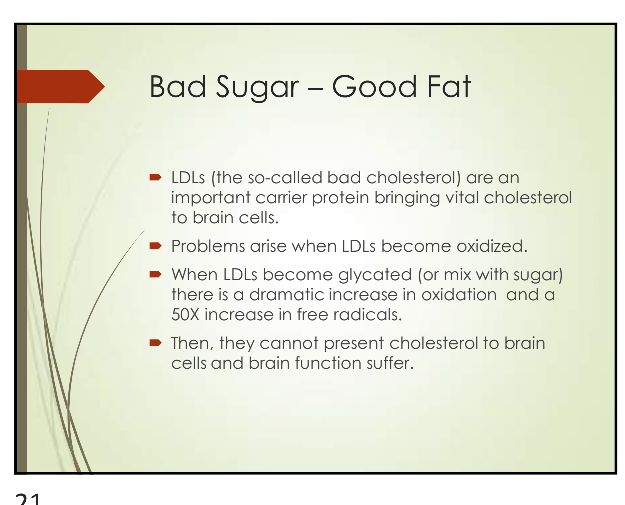

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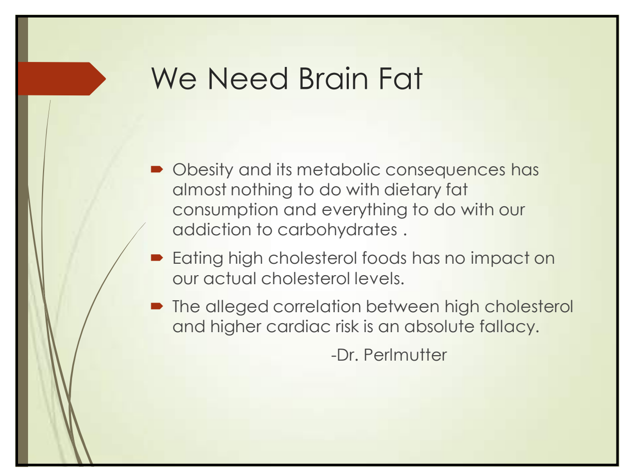

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Fat Brain

- 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 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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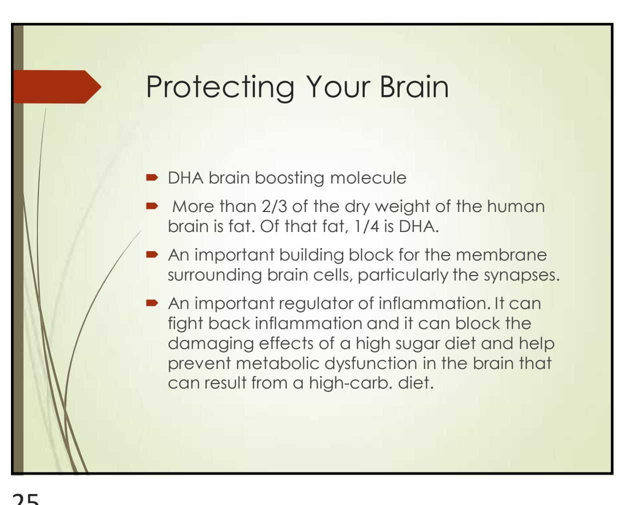

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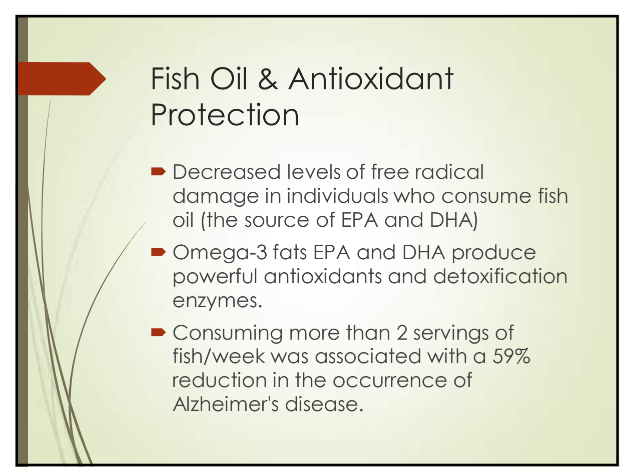

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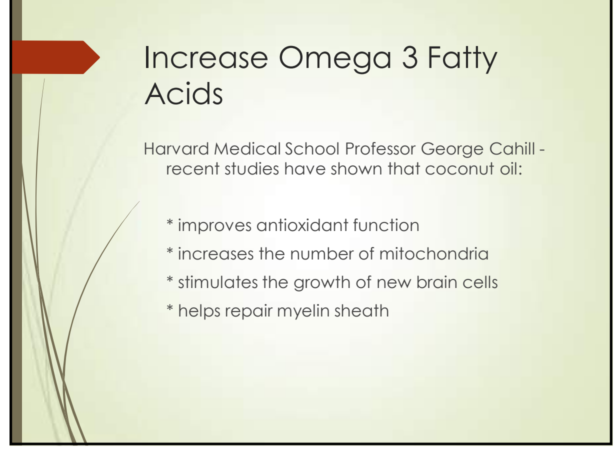

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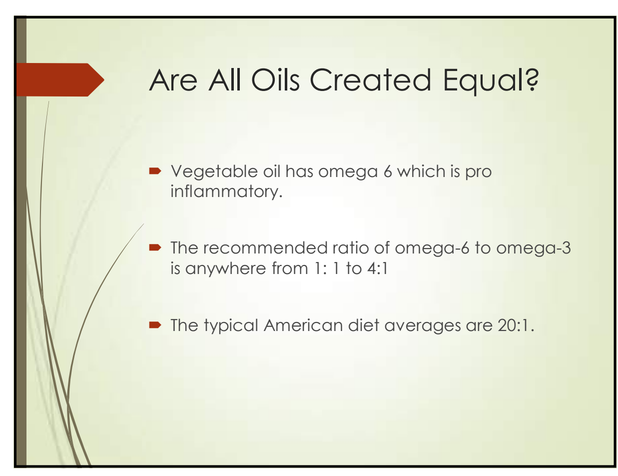

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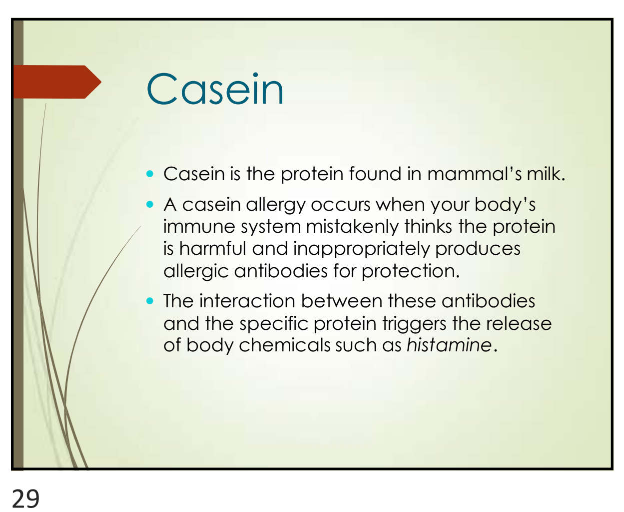

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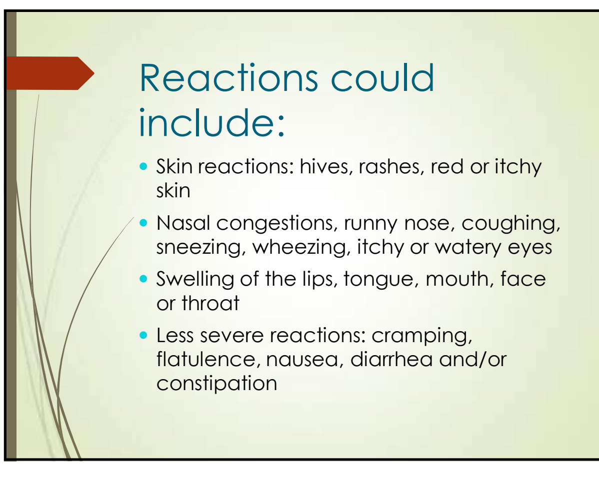

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Dairy Sensitivity

- 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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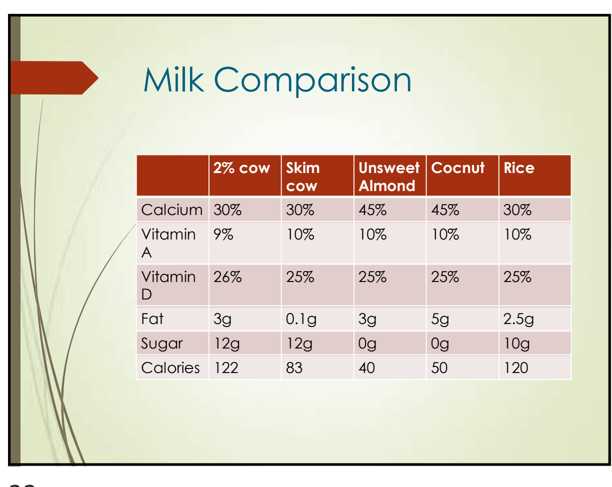

	2% cow	Skim cow	Unsweet Almond	Cocnut	Rice
Calcium	30%	30%	45%	45%	30%
Vitamin A	9%	10%	10%	10%	10%
Vitamin D	26%	25%	25%	25%	25%
Fat	3g	0.1g	3g	5g	2.5g
Sugar	12g	12g	0g	0g	10g
Calories	122	83	40	50	120

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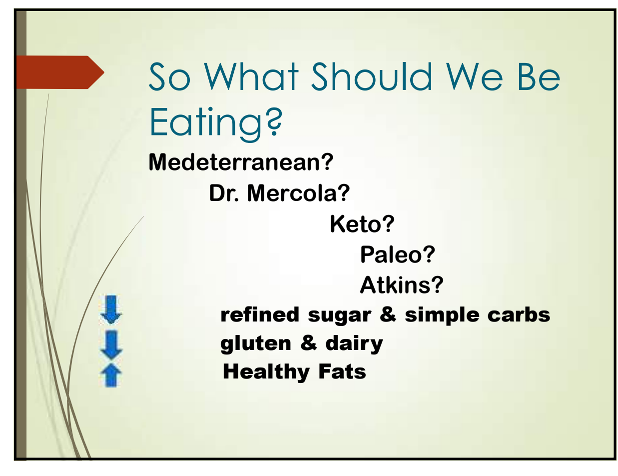

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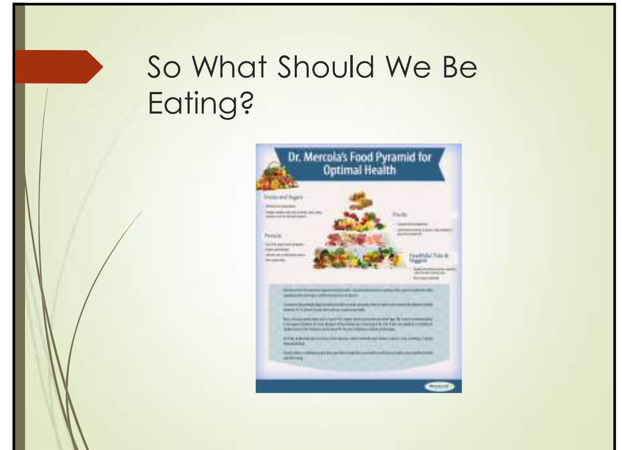

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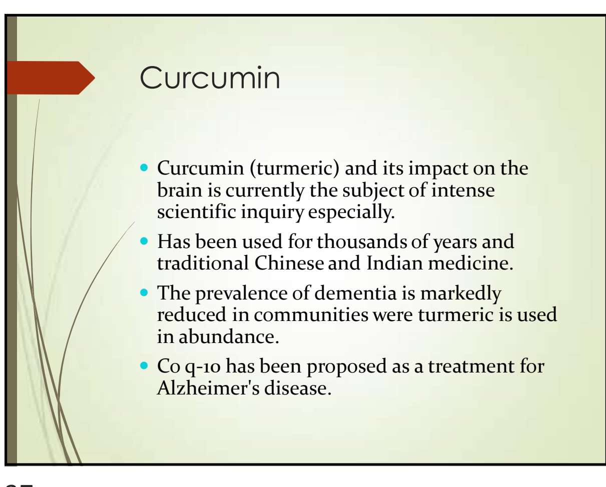

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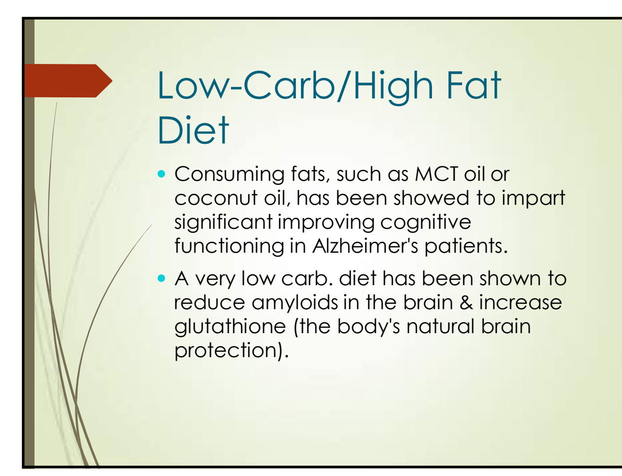

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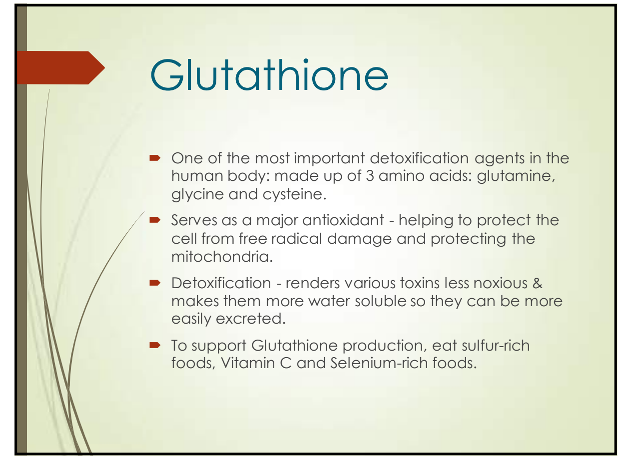

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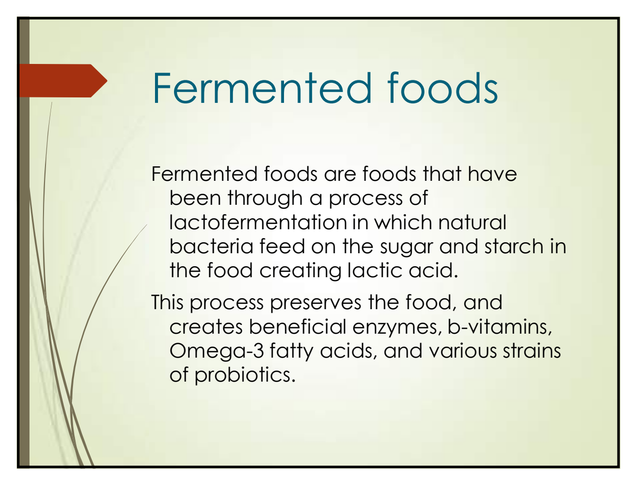

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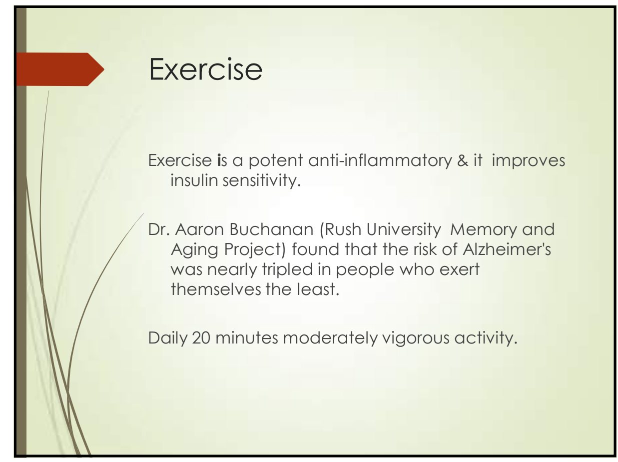

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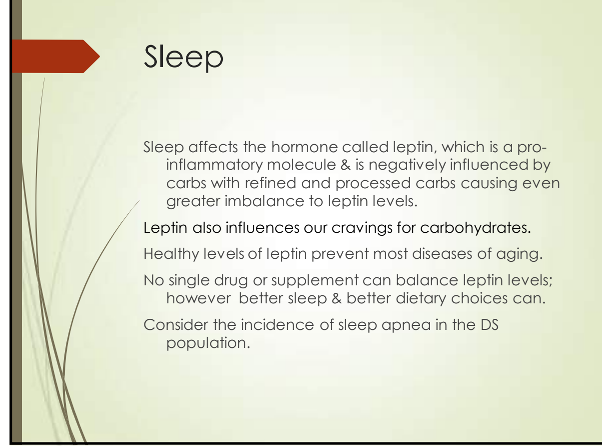

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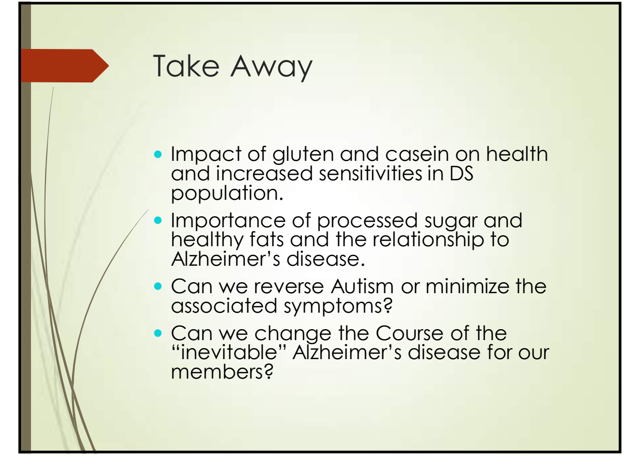

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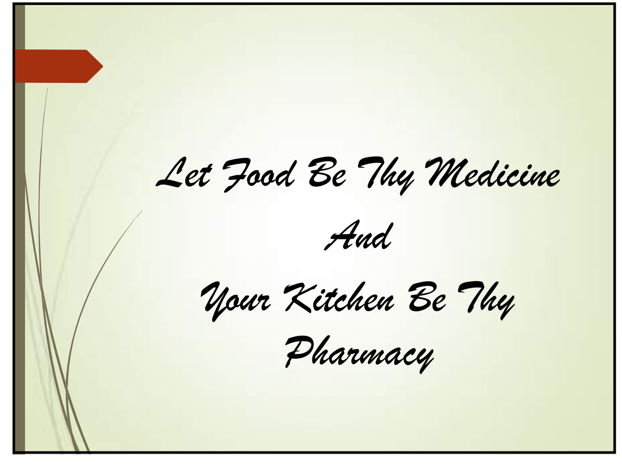

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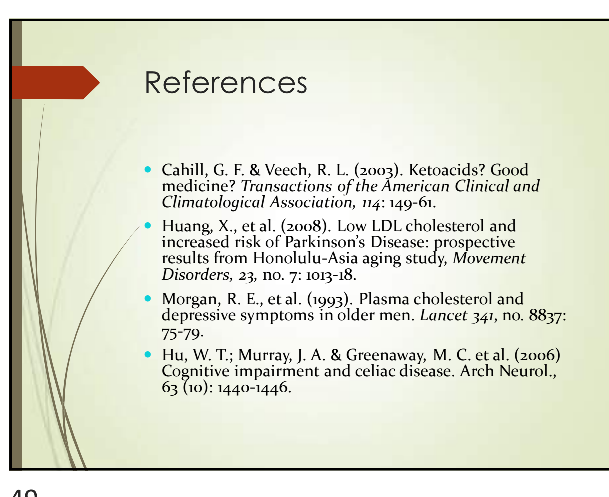

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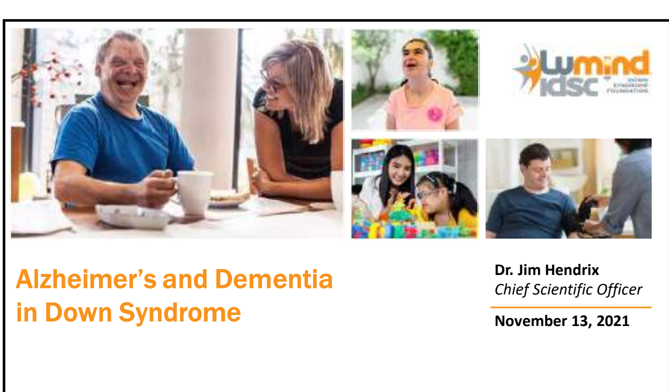

Alzheimer's and Dementia in Down Syndrome

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.

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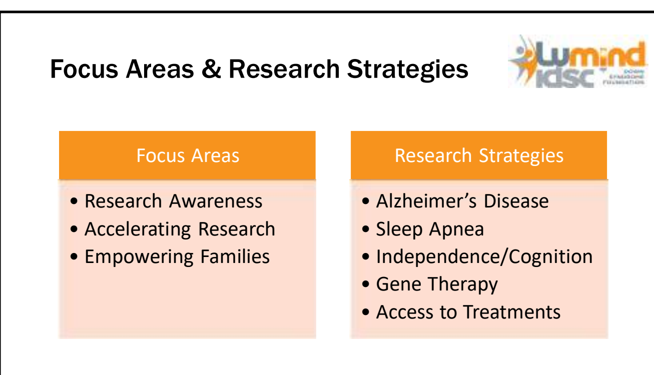

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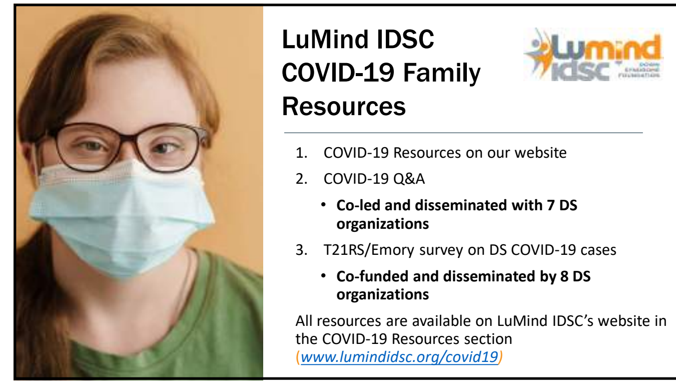

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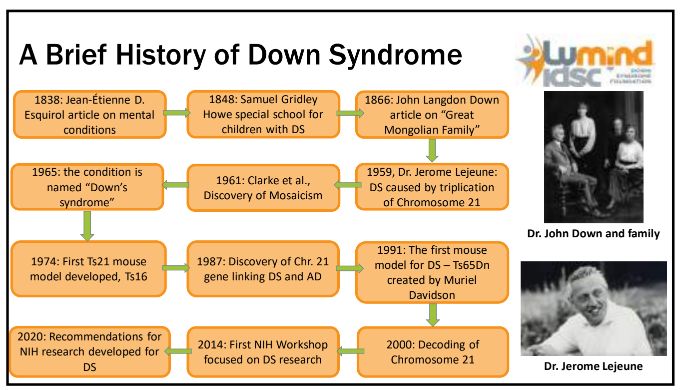

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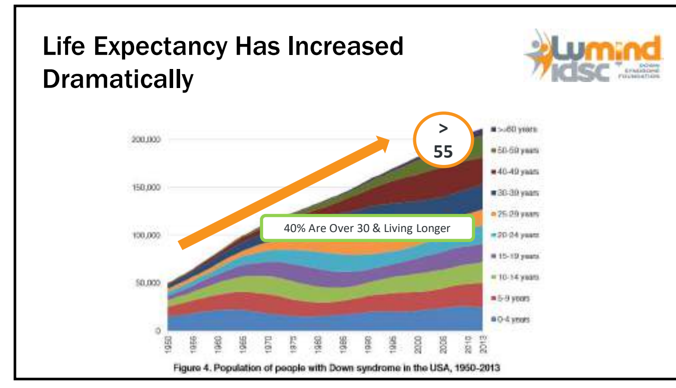

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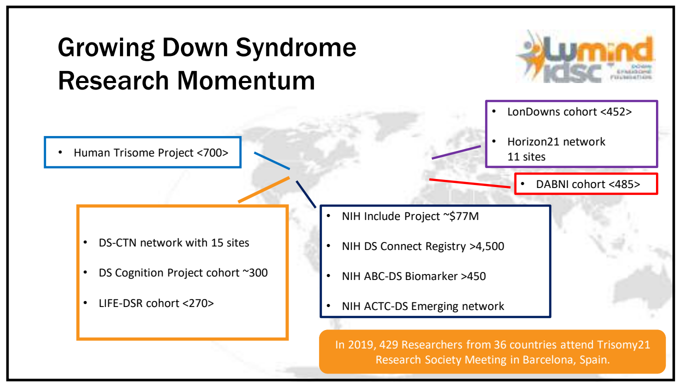

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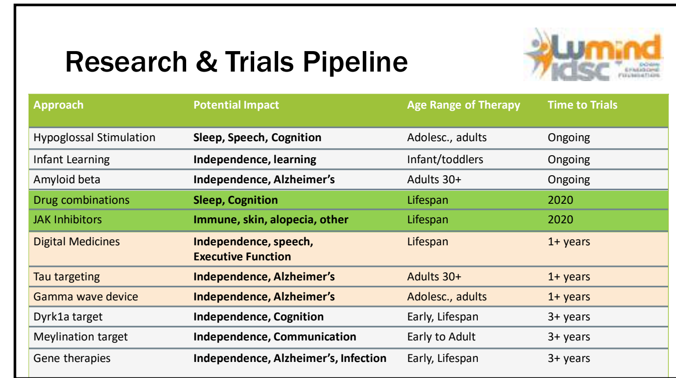

Approach	Potential Impact	Age Range of Therapy	Time to Trials
Hypoglossal Stimulation	**Sleep, Speech, Cognition**	Adolesc., adults	Ongoing
Infant Learning	**Independence, learning**	Infant/toddlers	Ongoing
Amyloid beta	**Independence, Alzheimer's**	Adults 30+	Ongoing
Drug combinations	**Sleep, Cognition**	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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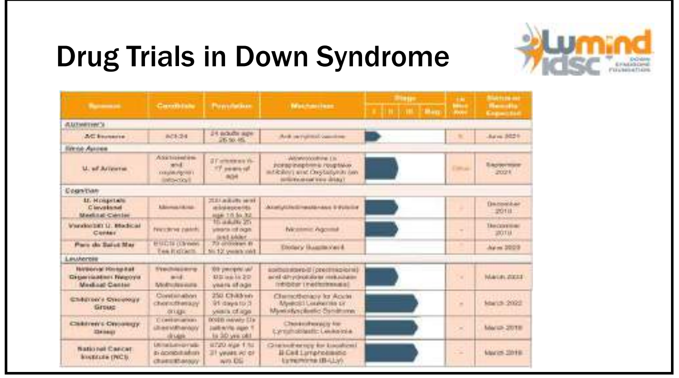

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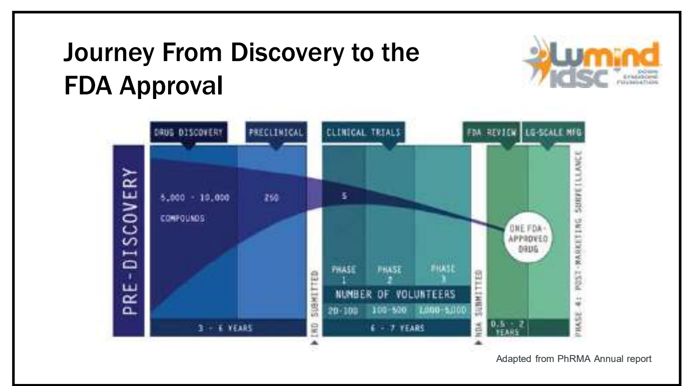

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What Are Clinical Trials?

- **Clinical research** that is 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?

- 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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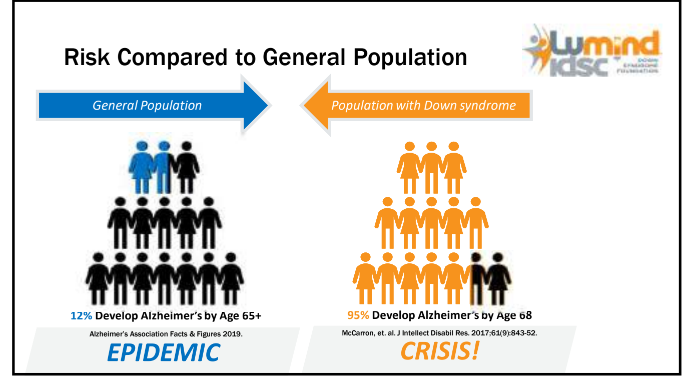

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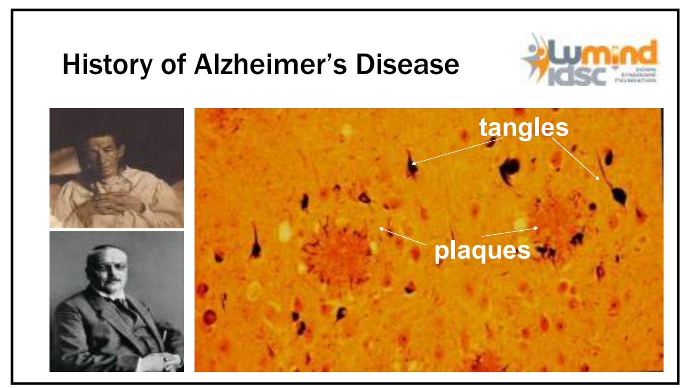

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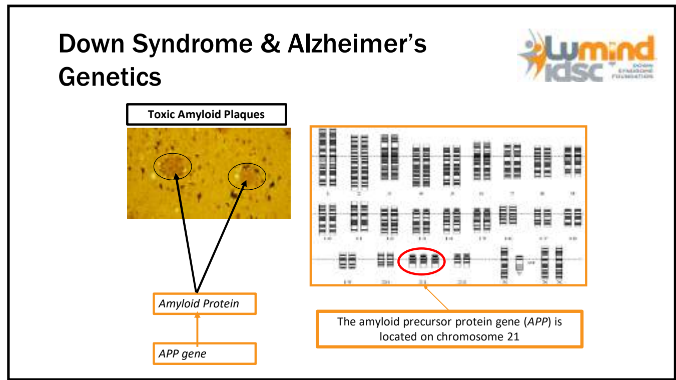

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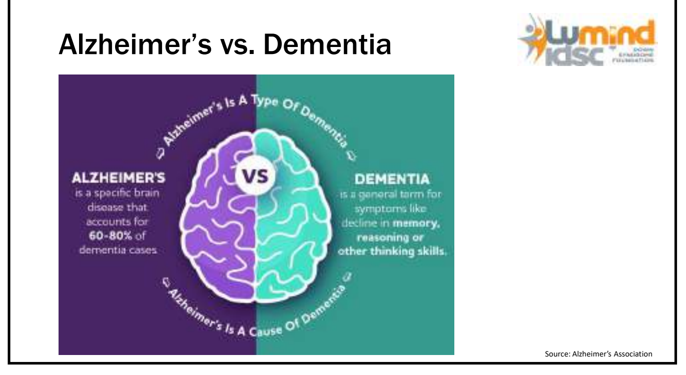

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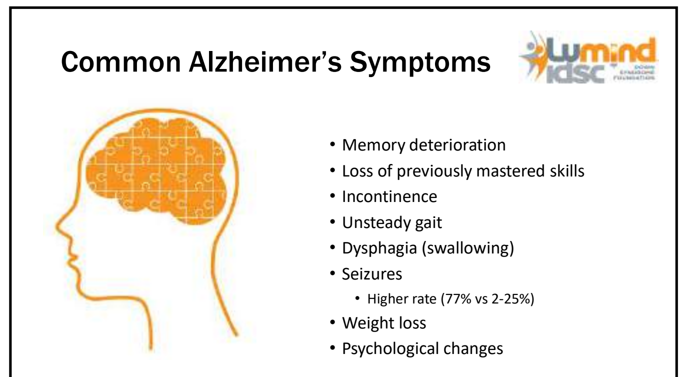

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Progression Over Time

- 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)

25

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

26

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)

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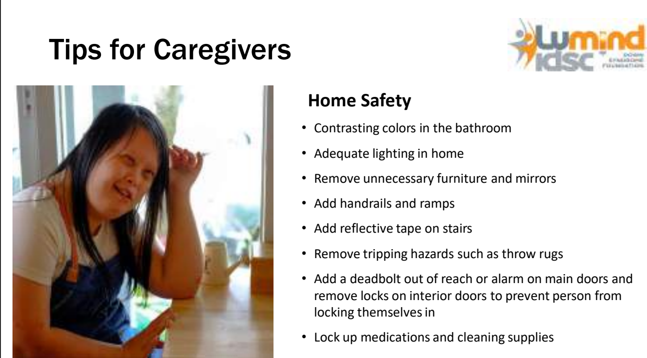

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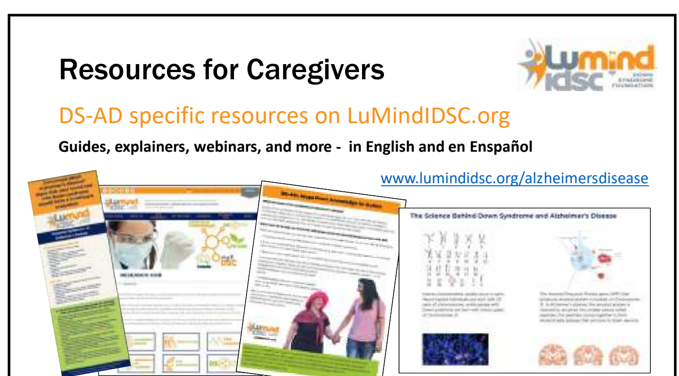

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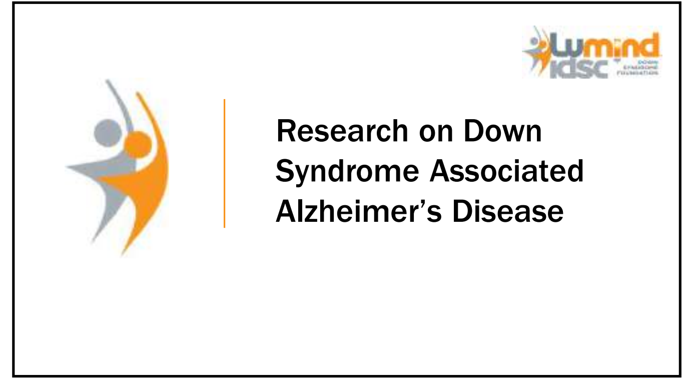

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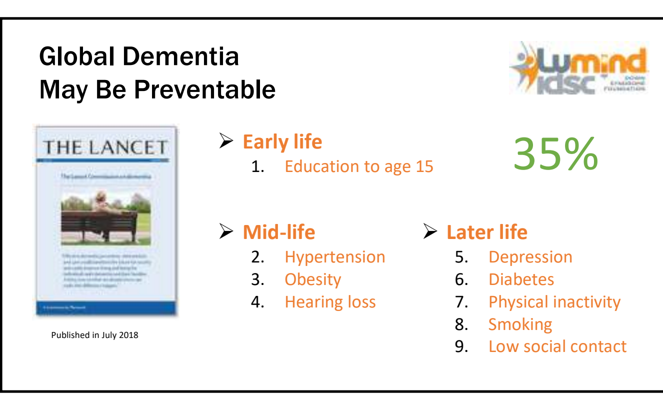

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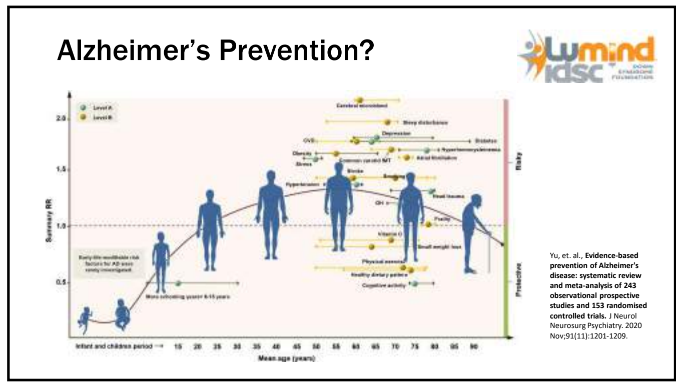

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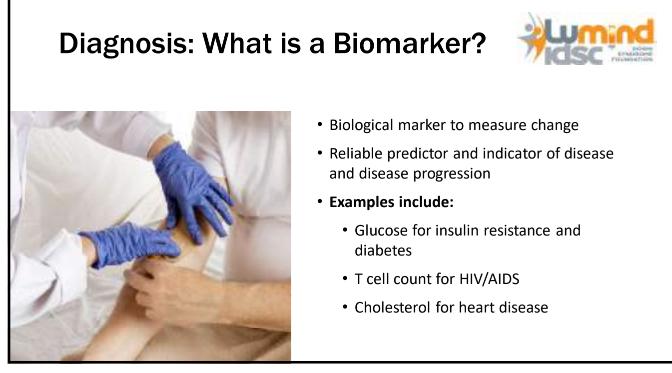

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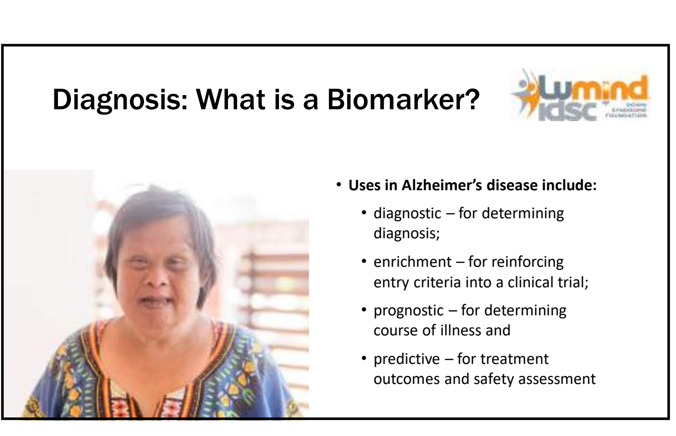

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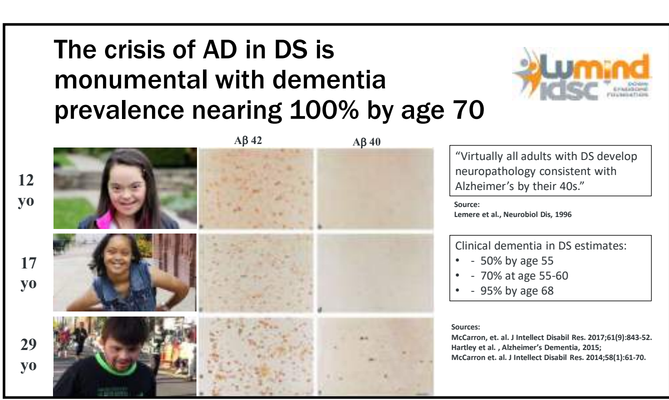

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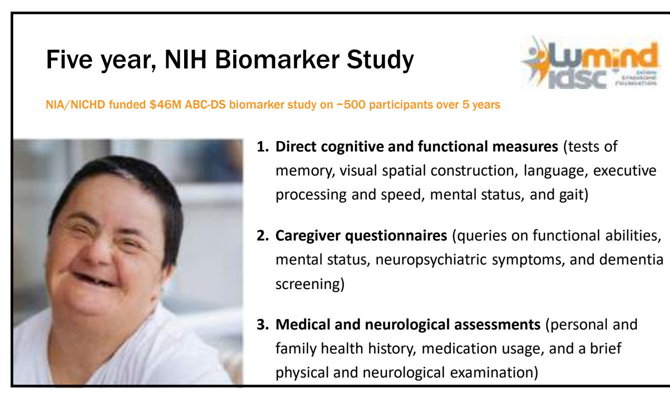

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Five year, NIH Biomarker Study

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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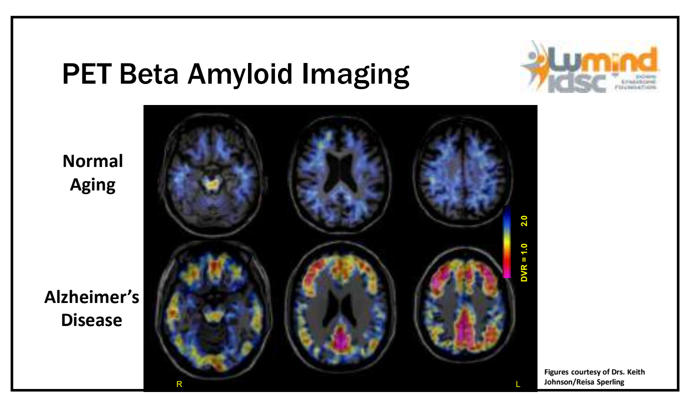

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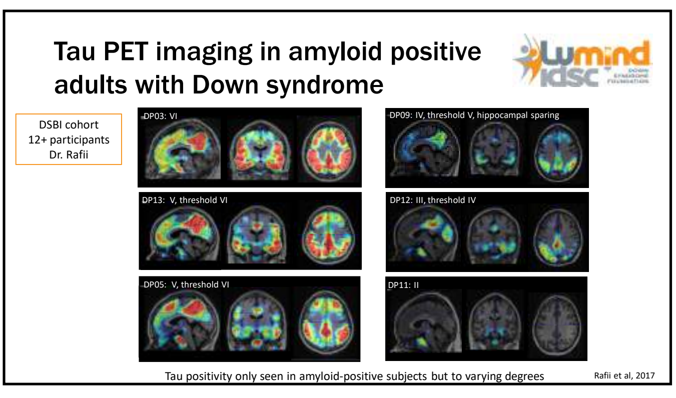

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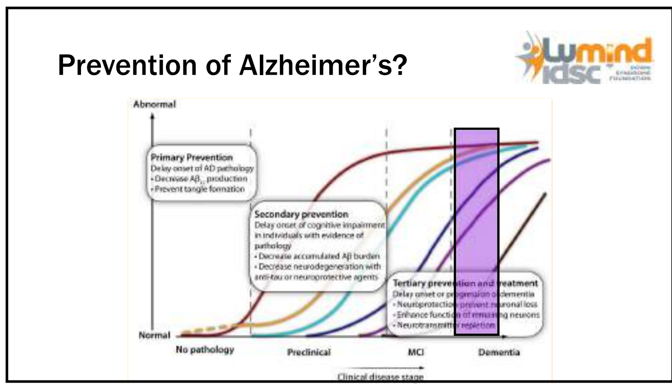

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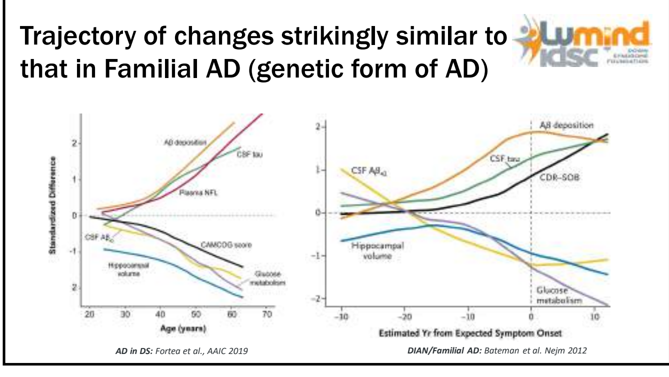

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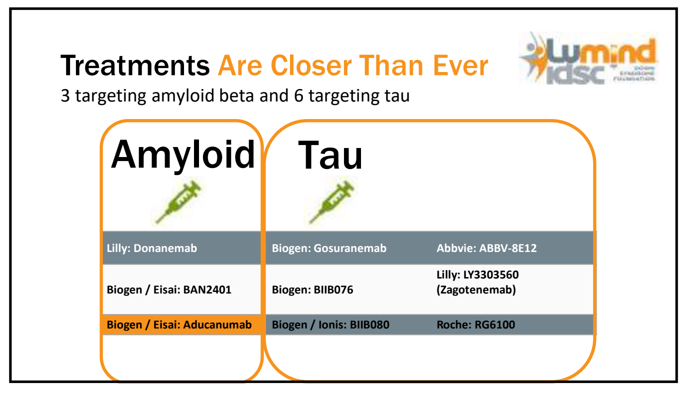

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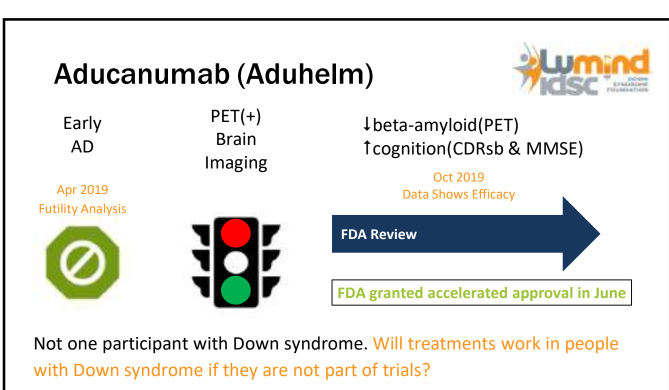

Not one participant with Down syndrome. Will treatments work in people with Down syndrome if they are not part of trials?

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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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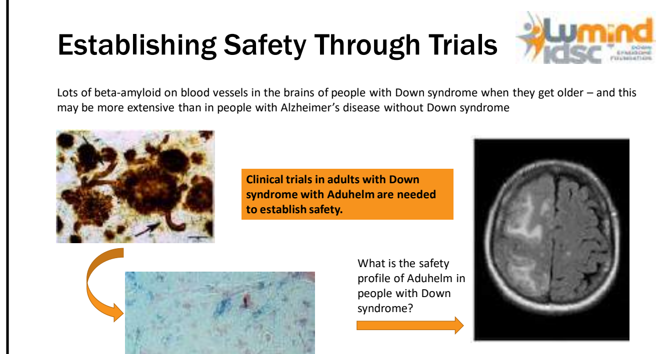

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Immunotherapy for AD

- **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*

Stakeholders:

Key Academic Partners,

National Institutes of Health (NIH)

Pharma / Biotech Companies

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, *Siemers Integration*

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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

LiFE DSR

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

DS CTN

Down Syndrome Clinical Trial Network

LuMind IDSC Research Consortium

LuMind IDSC Research Consortium

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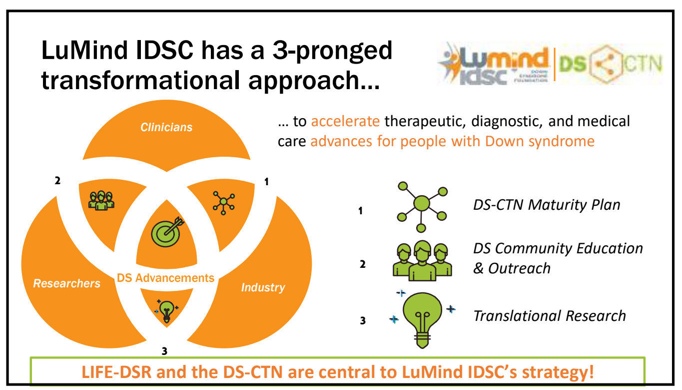

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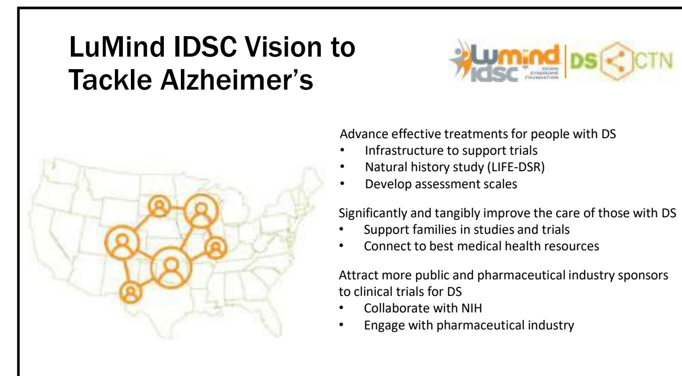

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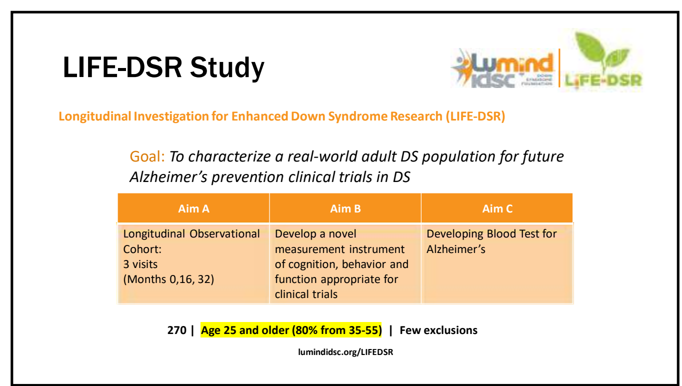

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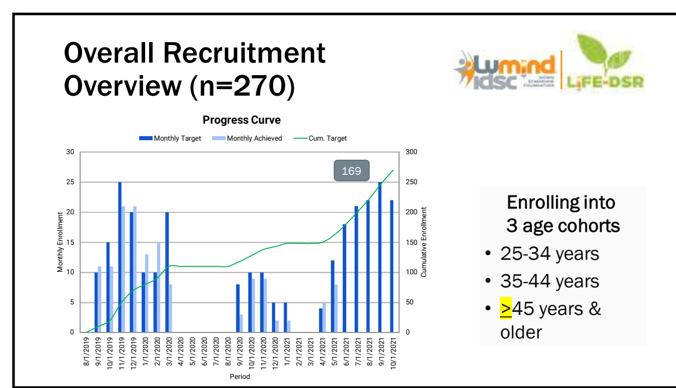

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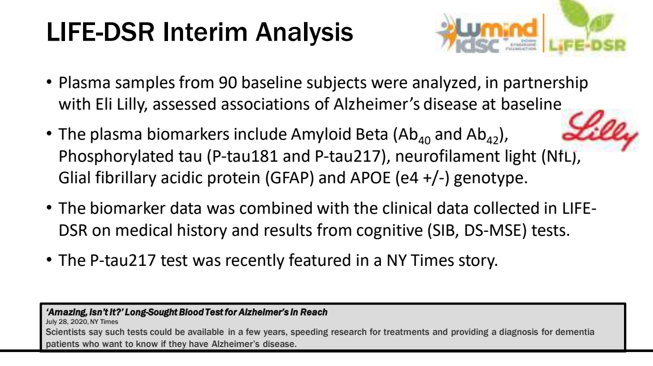

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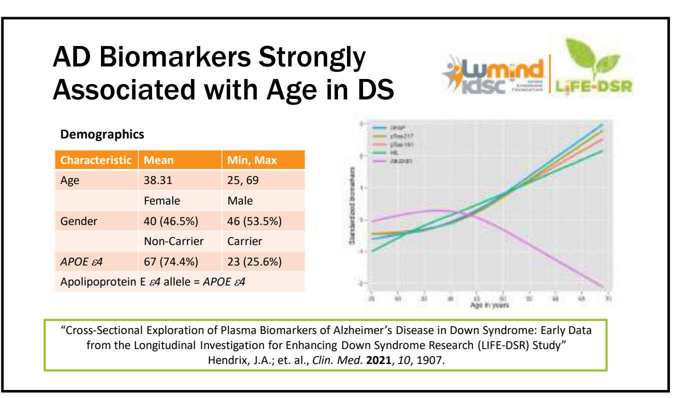

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LuMind IDSC Research Consortium

- **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
  1. Tau PET imaging *30 participants at 2-time points*
  2. CSF Biomarkers with PBMC (Peripheral Blood Mononuclear Cell) isolation *30 participants at 2-time points*
  3. Goal Attainment Scale (GAS) feasibility study *45 caregivers at baseline, 12 wks. and 6 mos*
  4. Strydom Composite Assessment *60 participants at 2-time points*

MERCK

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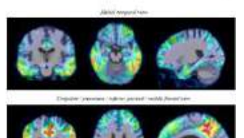
LuMind IDSC Research Consortium: Tau PET Imaging

- 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



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

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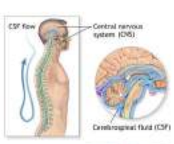
LuMind IDSC Research Consortium: Cerebrospinal Fluid (CSF) Collection



- 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

2. 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 being 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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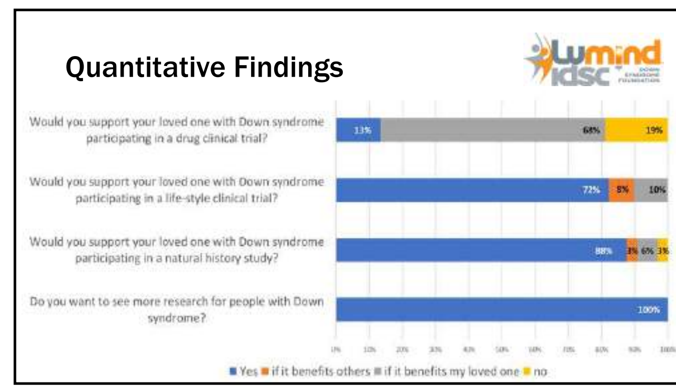

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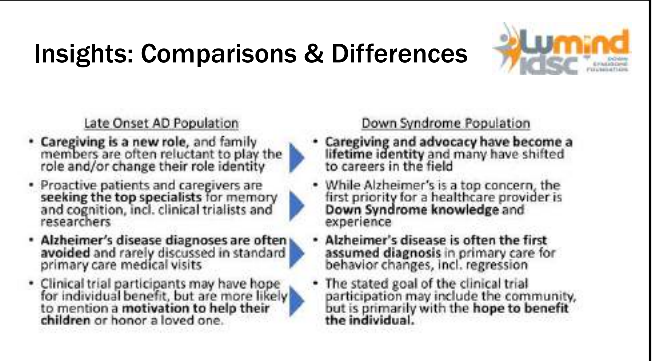

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Recommendations for DS-AD Trials

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.

Fight for Inclusion

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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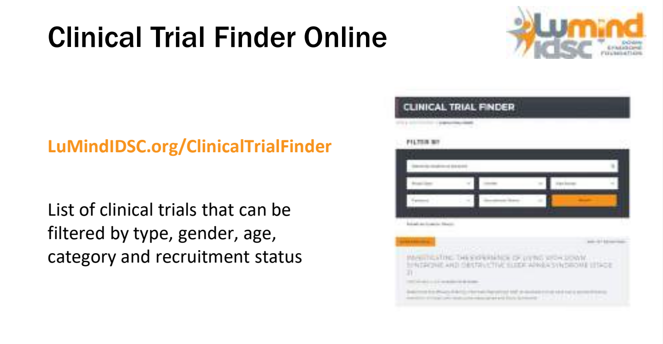

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4 Ways You Can Rally Around Research!

1. **Get educated on research –** learn about the current status of Down syndrome research and stay updated **(lumindidsc.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 **(lumindidsc.org/research)**
4. **Give to research –** your time, a donation, a fundraiser **(lumindidsc.org/donate)**

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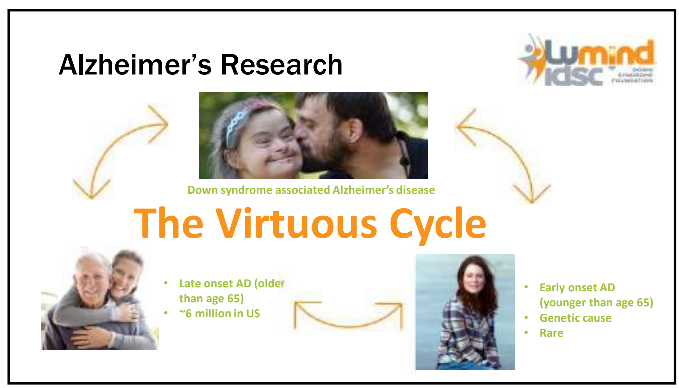

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1

What We are Covering Today

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

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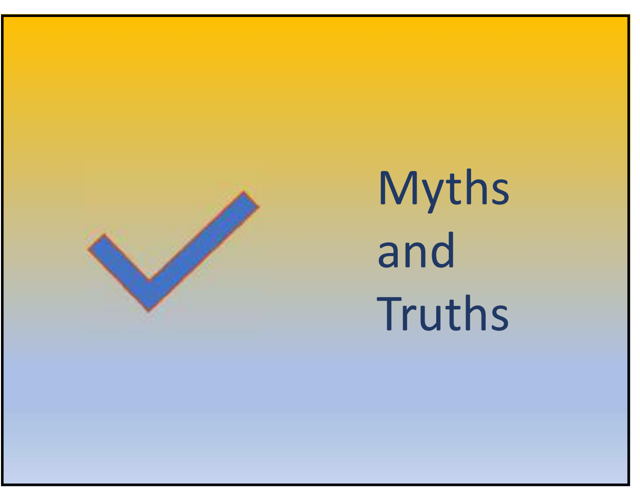

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Truths

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

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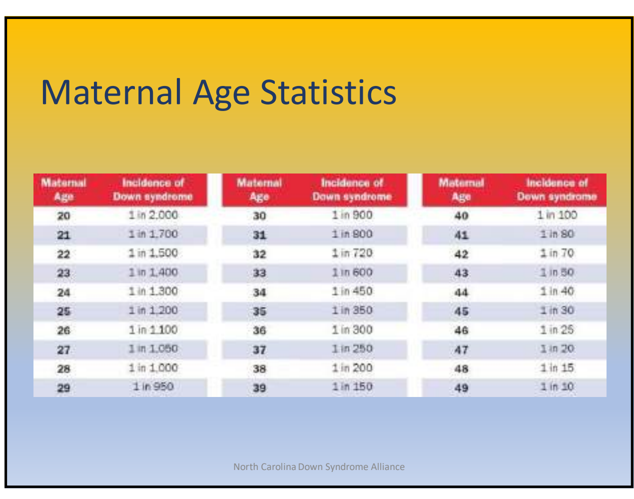

Maternal Age	Incidence of Down syndrome	Maternal Age	Incidence of Down syndrome	Maternal Age	Incidence of Down syndrome
20	1 in 2,000	30	1 in 900	40	1 in 100
21	1 in 1,700	31	1 in 800	41	1 in 80
22	1 in 1,500	32	1 in 720	42	1 in 70
23	1 in 1,400	33	1 in 600	43	1 in 50
24	1 in 1,300	34	1 in 450	44	1 in 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

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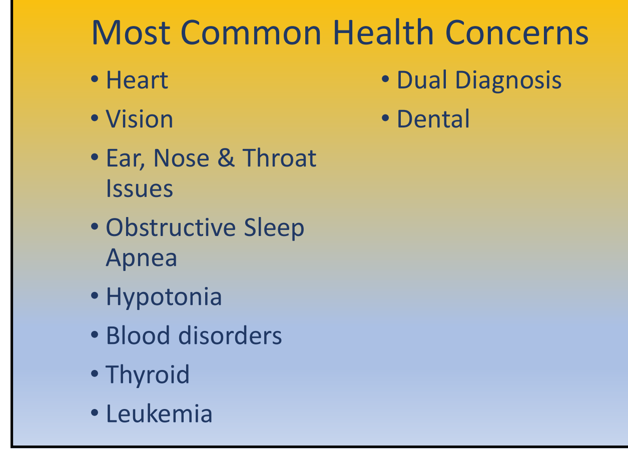

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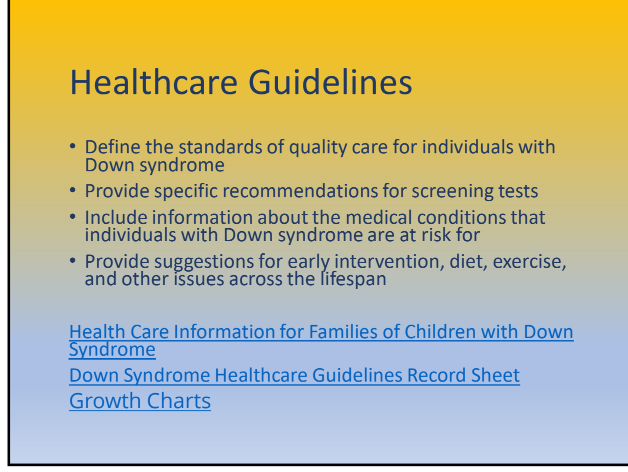

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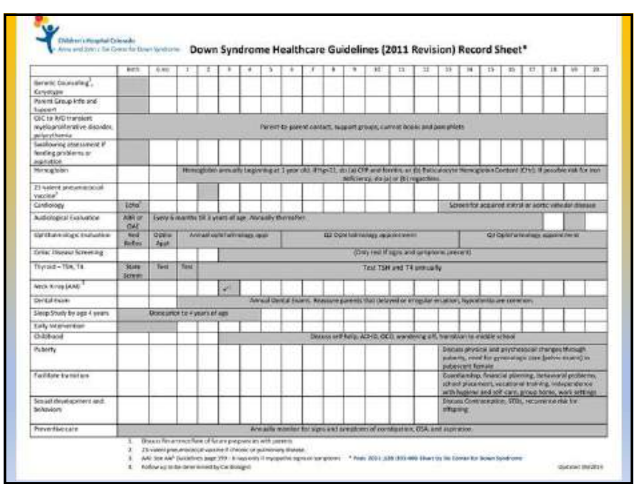
Down Syndrome Healthcare Guidelines (2011 Revision) Record Sheet*

10

Birth To 3
Early Intervention

- Children's Developmental Services Agency (CDSA)
- Individualized Family Service Plan (IFSP)
- What do they do?
- LEARN MORE at www.beearly.nc.gov

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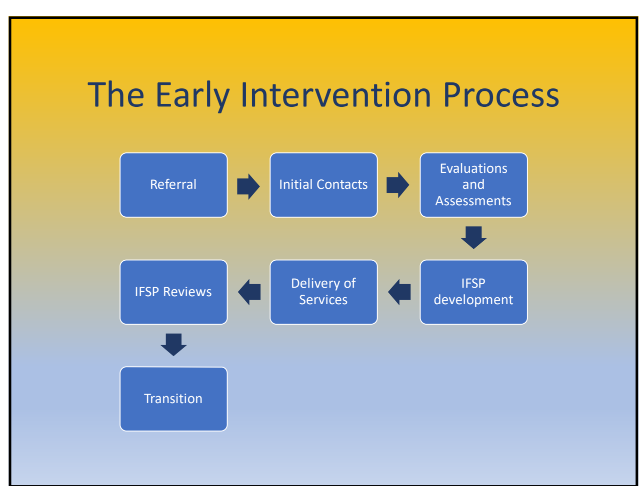

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Acronyms

- 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

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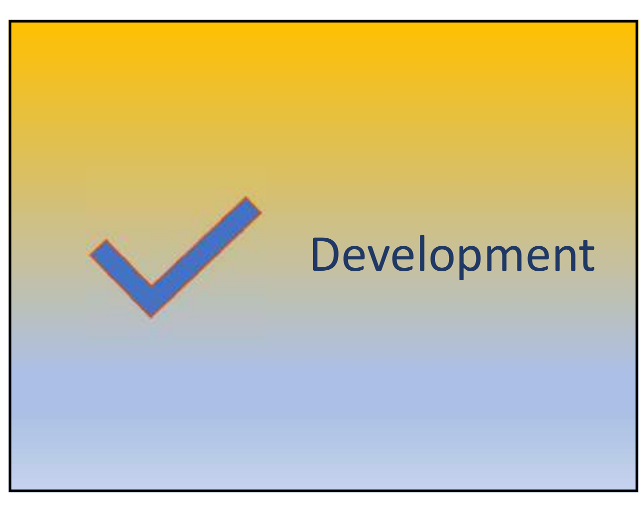

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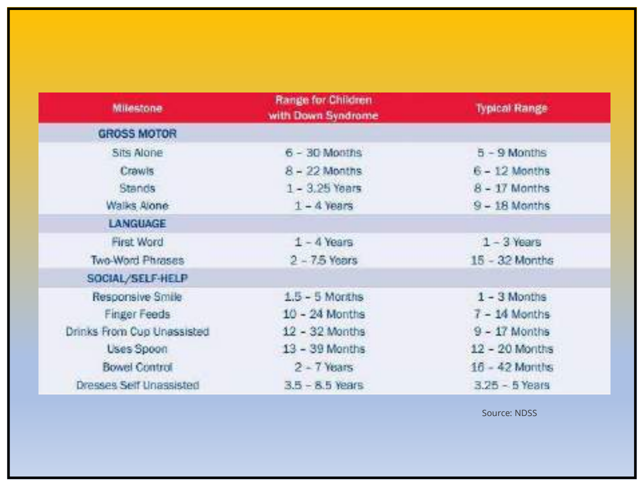

Milestone	Range for Children with Down Syndrome	Typical Range
GROSS MOTOR		
Sits Alone	6 – 30 Months	5 – 9 Months
Crawls	8 – 22 Months	6 – 12 Months
Stands	1 – 3.25 Years	8 – 17 Months
Walks Alone	1 – 4 Years	9 – 18 Months
LANGUAGE		
First Word	1 – 4 Years	1 – 3 Years
Two-Word Phrases	2 – 7.5 Years	15 – 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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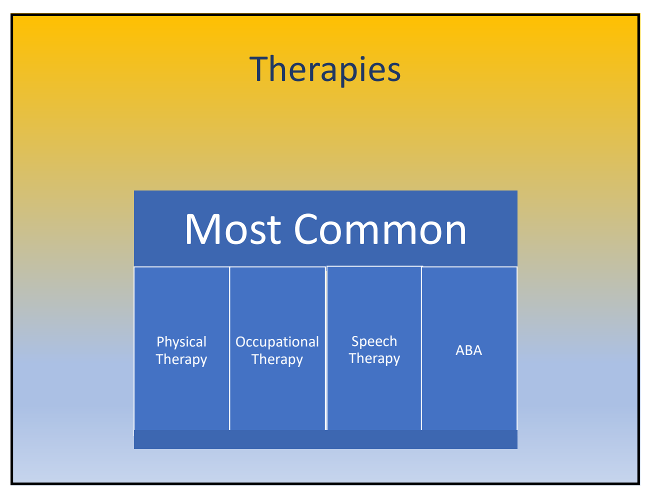

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Other Therapies

- 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

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Positive Behavior Support

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

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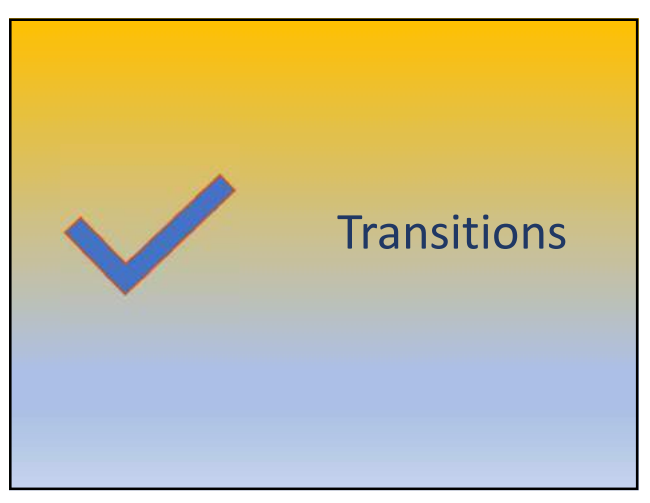

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What is a Vision Statement and Why is it SO Important?

A Vision Statement is your child's road map. It clearly defines your expectations, ambitions, and goals.

Your Vision Statement is the destination. Your IEP is your road map.

How do you know which map to get, if you don't know where you're going?

26

What is a Vision Statement and Why is it SO Important?

Your Child's Vision Statement should include:

What are your future plans and long-term goals for your child?

What do you want your child to be able to do when he/she leaves the public school system?

What steps do you need to take to help your child meet these goals?

The vision statement is a visual picture that describes your child in the future.

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One Parent's Perspective on Why the Vision Statement is Important

"It doesn't matter how fast you can go, it doesn't matter how much passion you have, and it doesn't matter how much energy you put into something. If you don't have a vision and clarity on the destination you want to reach, you'll simply never get there."

"Long range planning does not deal with future decisions, but with the future of present decisions."
— Peter F. Drucker

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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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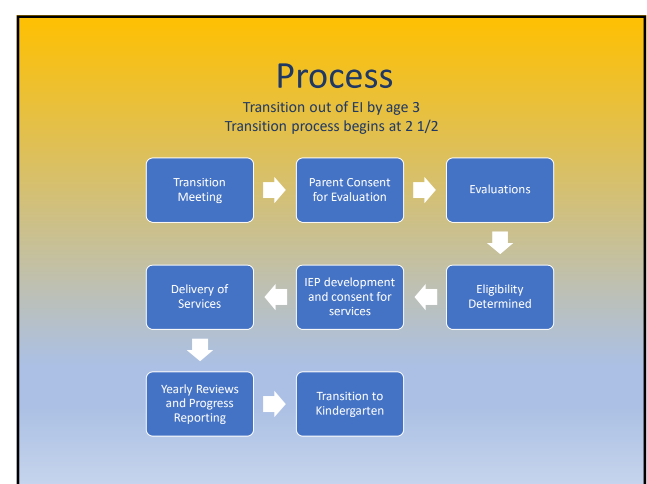
Process

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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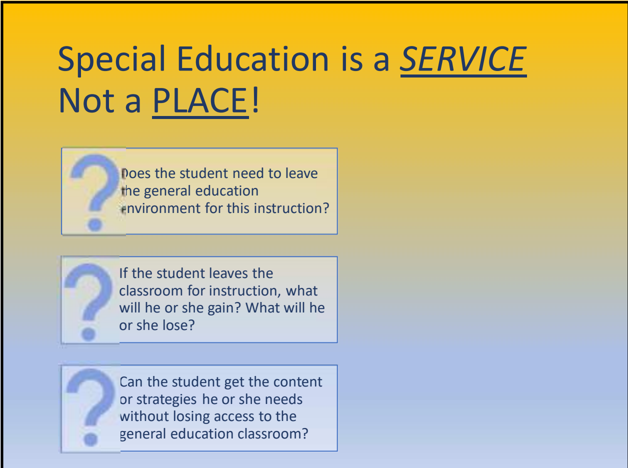

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- Medicaid
- NC Health Choice (Previously CHIP)
- Care Coordination for Children (CC4C)
- CAP/C Waiver
- Innovations Waiver
- SSI
- SSDI

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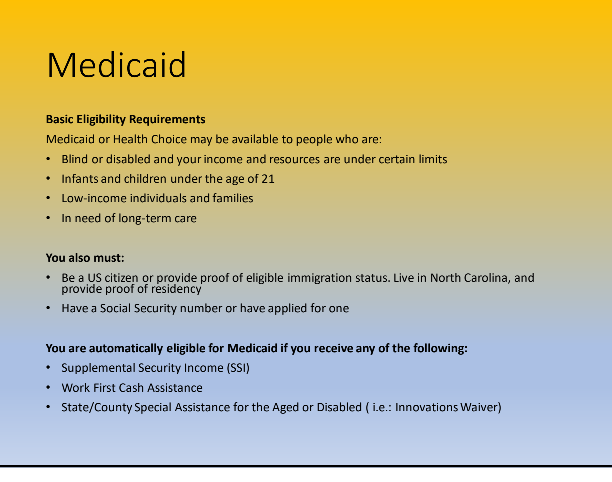

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Monthly Income Limits: Medicaid for Infants & Children		
Family Size	Age 0-5	Age 6-18
1	$2,233	$1,415
2	$3,017	$1,911
3	$3,801	$2,408
4	$4,585	$2,904
5	$5,369	$3,401

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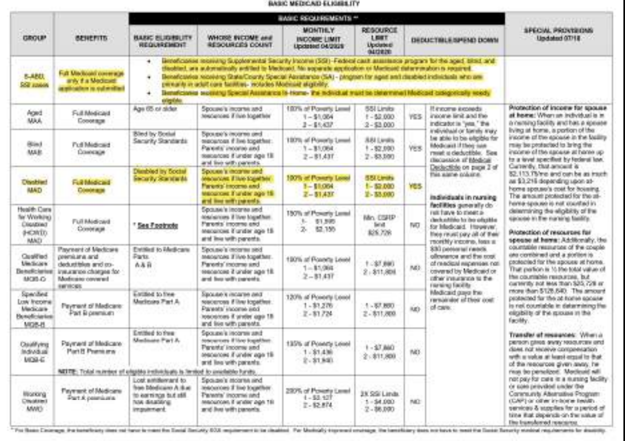

BASIC MEDICAID ELIGIBILITY

GROUP	BENEFITS	BASIC REQUIREMENTS ** — BASIC ELIGIBILITY REQUIREMENT	WHOSE INCOME and RESOURCES COUNT	MONTHLY INCOME LIMIT Updated 04/2020	RESOURCE LIMIT Updated 04/2020	DEDUCTIBLE/SPEND DOWN		SPECIAL PROVISIONS Updated 07/18
S-ABD SSI cases	Full Medicaid coverage only if a Medicaid application is submitted	• Beneficiaries receiving Supplemental Security Income (SSI) - Federal cash assistance program for the aged, blind, and disabled, are automatically entitled to Medicaid. No separate application or Medicaid determination is required. • Beneficiaries receiving State/County Special Assistance (SA) - program for aged and disabled individuals who are primarily in adult care facilities - includes Medicaid eligibility. • Beneficiaries receiving Special Assistance In-Home - the individual must be determined Medicaid categorically needy eligible.						
Aged MAA	Full Medicaid Coverage	Age 65 or older	Spouse's income and resources if live together	100% of Poverty Level 1 – $1,064 2 – $1,437	SSI Limits 1 - $2,000 2 - $3,000	YES	If income exceeds income limit and the indicator is "yes," the individual or family may be able to be eligible for Medicaid if they can meet a deductible. See discussion of Medical Deductible on page 2 of this same column. Individuals in nursing facilities generally do not have to meet a deductible to be eligible for Medicaid. However, they must pay all of their monthly income, less a $30 personal needs allowance and the cost of medical expenses not covered by Medicaid or other insurance to the nursing facility. Medicaid pays the remainder of their cost of care.	Protection of income for spouse at home: When an individual is in a nursing facility and has a spouse living at home, a portion of the income of the spouse in the facility may be protected to bring the income of the spouse at home up to a level specified by federal law. Currently, that amount is $2,113.75/mo and can be as much as $3,216 depending upon at-home spouse's cost for housing. The amount protected for the at-home spouse is not counted in determining the eligibility of the spouse in the nursing facility. Protection of resources for spouse at home: Additionally, the countable resources of the couple are combined and a portion is protected for the spouse at home. That portion is ½ the total value of the countable resources, but currently not less than $25,728 or more than $128,640. The amount protected for the at-home spouse is not countable in determining the eligibility of the spouse in the facility. Transfer of resources: When a person gives away resources and does not receive compensation with a value at least equal to that of the resources given away, he may be penalized. Medicaid will not pay for care in a nursing facility or care provided under the Community Alternative Program (CAP) or other in-home health services & supplies for a period of time that depends on the value of the transferred resources.
Blind MAB	Full Medicaid Coverage	Blind by Social Security Standards	Spouse's income and resources if live together. Parents' income and resources if under age 18 and live with parents.	100% of Poverty Level 1 – $1,064 2 – $1,437	SSI Limits 1 - $2,000 2 - $3,000	YES		
Disabled MAD	Full Medicaid Coverage	Disabled by Social Security Standards	Spouse's income and resources if live together. Parents' income and resources if under age 18 and live with parents.	100% of Poverty Level 1 – $1,064 2 – $1,437	SSI Limits 1 - $2,000 2 - $3,000	YES		
Health Care for Working Disabled (HCWD) MAD	Full Medicaid Coverage	* See Footnote	Spouse's income and resources if live together. Parents' income and resources if under age 18 and live with parents.	150% of Poverty Level 1- $1,595 2- $2,155	Min. CSRP limit $25,728	NO		
Qualified Medicare Beneficiaries MQB-Q	Payment of Medicare premiums and deductibles and co-insurance charges for Medicare covered services	Entitled to Medicare Parts A & B	Spouse's income and resources if live together. Parents' income and resources if under age 18 and live with parents.	100% of Poverty Level 1 – $1,064 2 – $1,437	1 - $7,860 2 - $11,800	NO		
Specified Low Income Medicare Beneficiaries MQB-B	Payment of Medicare Part B premium	Entitled to free Medicare Part A	Spouse's income and resources if live together. Parents' income and resources if under age 18 and live with parents.	120% of Poverty Level 1 - $1,276 2 - $1,724	1 - $7,860 2 - $11,800	NO		
Qualifying Individual MQB-E	Payment of Medicare Part B Premiums	Entitled to free Medicare Part A	Spouse's income and resources if live together. Parents' income and resources if under age 18 and live with parents.	135% of Poverty Level 1 - $1,436 2 - $1,940	1 - $7,860 2 - $11,800	NO		
	NOTE: Total number of eligible individuals is limited to available funds.							
Working Disabled MWD	Payment of Medicare Part A premiums	Lost entitlement to free Medicare A due to earnings but still has disabling impairment.	Spouse's income and resources if live together. Parents' income and resources if under age 18 and live with parents.	200% of Poverty Level 1 - $2,127 2 - $2,874	2X SSI Limits 1 - $4,000 2 - $6,000	NO		

* [illegible]

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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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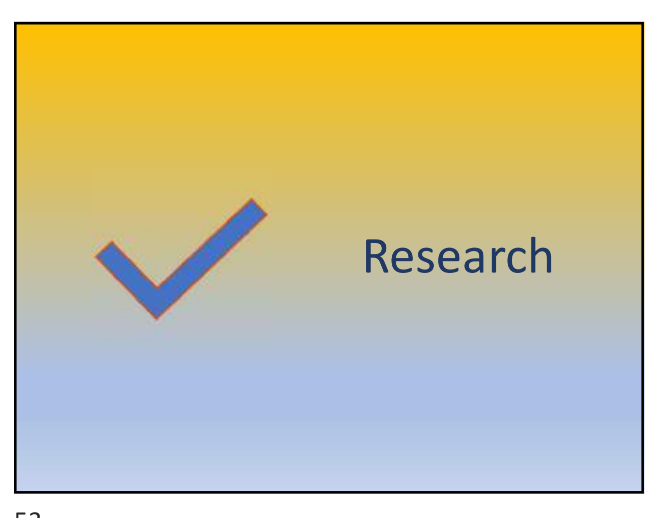

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- DS Connect
- GLOBAL Down Syndrome Foundation
- Local Universities
- Down Syndrome Educational International
- Why Get Involved?
- How to get involved

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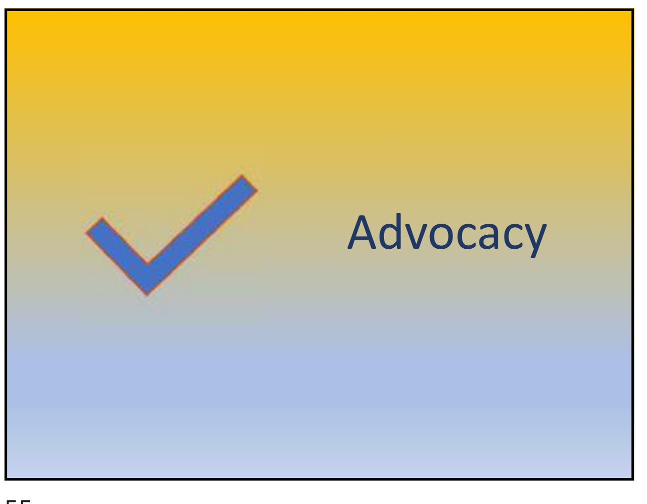

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Your Voice Matters

- What is advocacy?
- Why is advocacy important?
- How do I become an advocate?
- Include your child
  - Nothing about me without me!
- How do I get involved in advocacy for my child and people with Down syndrome?

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

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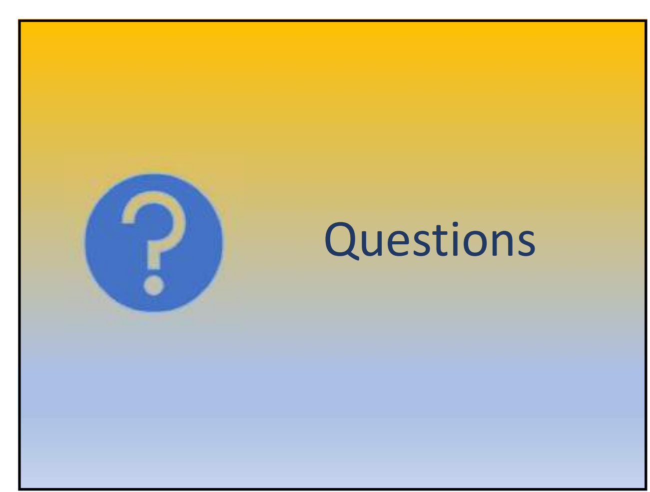

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