

Down Syndrome 101 for Service Providers



Presented By,



Amy Allison
Executive Director

Down Syndrome 101

- Most commonly occurring genetic condition resulting in 1:691 births
- Down Syndrome is prevalent in all races, socioeconomic classes and shows no gender bias
- There are over 250,000 individuals are living with Down syndrome in the United States
- Currently no known cause or cure for Down syndrome-it's a result of an error in cell division when a baby is forming in the womb



Down Syndrome 101

- 80 percent of babies with Down syndrome are born to women under the age of 35
- Average life span
- Spectrum of Down syndrome
- People with Down syndrome are achieving things we never thought possible



Down Syndrome 101

- Down syndrome diagnosis
- Family dynamics
- Early Intervention
- People first language
- Research
- Accurate information (<10 years)
- Support organizations



Possible Medical Issues

- Heart Defects
- Muscle Hypotonia
- Gastrointestinal issues
- Respiratory Issues
- Hearing Loss
- Vision issues
- Thyroid dysfunction



Possible Medical Issues

- Tactile Sensitivity
- High pain tolerance
- Sleep apnea
- Dual diagnosis of Autism
- Leukemia
- Precocious Puberty



Possible Medical Issues

- Atlanto-Axial Instability
- Celiac Disease
- Menopause
- Alzheimer's Disease
- Geriatric aging process



Down Syndrome and Alzheimer's Disease

· 25% or more of individuals with Down syndrome over age 35 show clinical signs and symptoms of Alzheimer's type dementia. This is 3-5 times greater than the general population.

· Onset of Alzheimer's in individuals with DS may begin as early as 30 as compared to 50 in the general population.

· While all people with Down syndrome will exhibit the plaques associated with Alzheimer's not every person with Down syndrome will have Alzheimer's Disease.



Down Syndrome and Alzheimer's Disease

Persons with Down syndrome who are diagnosed with Alzheimer's may progress through the disease more quickly than their typical peers.

· Symptoms: Loss of memory, change or decline in daily living skills, new onset of seizures, changes in coordination or gait, loss of continence or general cognitive decline.

· Diagnosis: Based on clinical history after ruling out other conditions History should show slow steady decrease in cognitive functioning.



Down Syndrome and Alzheimer's Disease

· Baseline Testing: 30 years to provide baseline reading and periodically thereafter. Order further tests if deterioration occurs.

· There is currently no cure for Alzheimer's but medication interventions can slow the degenerative process.

· Research: Current research shows that certain genes on Chromosome 21 may predispose individuals with Down syndrome to Alzheimer's disease. Brain tissue donation or mouse models will be necessary to further this research.

· Researchers believe Alzheimer's medications will help improve cognition for people with Down syndrome.



Down Syndrome Healthcare Guidelines

• Created by medical professionals who are passionate about people with Down syndrome

• Identifies various screening tests and standardized tests which physicians should utilize when working with patients who have Down syndrome

• Categorized by age range

• American Association of Pediatrics Guidelines released July 2011

• With appropriate health care and preventive medicine, people with Down syndrome have doubled their lifespan in the past few decades!



Down Syndrome Clinics in Missouri

Down Syndrome Center
St. Louis Children's Hospital
2nd Floor
800.678.5437 or 314.454.6093
Stlouischildrens.org/dsc
downsyndromecenter@kids.wustl.edu



Albert Pujols Wellness Center
Mr. & Mrs. Theodore Desloge, Jr.
Outpatient Center
121 St. Luke's Center Dr, Ste 503
Chesterfield, MO 63017
314.576.2300
www.stlukes-stl.com



Down Syndrome Clinics in Missouri

Children's Mercy Down Syndrome Clinic
2401 Gilham Road
Kansas City, MO 64108
816-960-2864



KU Medical Center
Adult Down Syndrome Clinic
3901 Rainbow Boulevard
Kansas City, MO
913-588-1915
mpeterso@kumc.edu

KU Medical Center
DS & Dementia Clinic
3901 Rainbow Boulevard
Kansas City, MO
Heather Anderson
handerson3@kumc.edu



Communication Issues

- Receptive language vs. Expressive language
- Hearing
- Attention span
- Short term memory
- Speech articulation



Communication Issues

- Processing time
- Recalling information
- Echolalia
- Generalizing skills
- Behavior is a form of communication



Communication Strategies

- Demands and Interruptions
 - Necessary vs. Unnecessary Demands
 - Talking too fast
 - Too much information
 - Fewer cues
 - 10 seconds can change a life
 - Visual interruptions
- Fallouts of Needless Demands and Interruptions
 - NO!
 - Shut Down
 - Down syndrome drop
 - Aggressive or Uncooperative Behavior



Communication Strategies

- Ensure you are face to face and have good eye contact when giving instructions
- Ask the person to repeat instructions back to you
- Use simple and familiar language and short and concise sentences
- Reinforce directions with facial expressions, gestures and signs
- Emphasize key words and reinforce with visual aids as needed
- Avoid closed questions and encourage person to speak more than one word utterances
- Good communication between all staff/family/guardian



Avoiding Learned Helplessness

- People with Down syndrome can actually be self sufficient.
- Presume competence and provide supports only when the person requests assistance or proves it is needed.
- Are the supports you have in place transferrable to other settings?
 - Community outings
 - Employment situations
 - Post secondary education
- How can this person be more independent?
- Prompt, praise and reward dependency



Avoiding Learned Helplessness

<p>Promotes Learned Helplessness</p> <ul style="list-style-type: none">• Protecting person from taking risks• Rescuing person from anticipated outcomes• Overlooking errors• Constant prompts• Speaking for the person• Permitting bad behavior• Making excuses• Interceding before they ask for help• Inconsistency in expectations	<p>Promotes Independence</p> <ul style="list-style-type: none">• Setting clear limits on what is safe• Discussing issues and creating solutions• Giving clear directions/expect follow through• Encouraged to speak for self• Consistency in expectations• Holding person accountable for actions• Allowing person to fail in safe environment• Teaching person to ask for help as needed
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Preferred Teaching Methods

- Hands on activities
- Structured, sequenced activities
- Routine oriented
- 15-20 repetitions to acquire skill
- Visual learning
- The fewer the cues, the better!



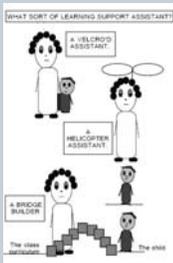
Preferred Teaching Methods

- Avoid constant rewards
- Find what motivates the person and engage them in activities around that
- Age appropriate materials/activities
- Shadowing vs. supervising
- Don't over compensate and deter "Mother Hens"
- Life long learning



The Role of the Support Professionals

- Encourage independence
- Act as a bridge between person and the community
- Provide feedback to the person and/or team on how to achieve goals
- Encourage development of age appropriate behavior
- Set high expectations and refuse to accept inappropriate behavior



Behavior is a Form of Communication

- Annoyed when other people don't take the time to understand what they are trying to say.
- Confused or uncertain about what they are supposed to do.
- Failed to understand instructions given.
- Forgot what they have been told (memory issues)
- Not given enough processing time



Behavior is a Form of Communication

- Examine what part you may play in the behavior
- Environmental changes
- Wants to be the center of attention and dislikes being ignored.
- Resents being told what to do all the time
- Used to getting special treatment and object if it is withdrawn.
- Attention seeking behavior has worked in the past so why not use it again?



What is Your Consumer Telling You?

- Subjected to a high level of structure and supervision. As a result they may feel the need to exert some control over their lives.
- Rule out medical issues
- Feels under pressure and needs a break.
- Too many transitions, directions
- Who is in charge?



Strategies for Disruptive Behaviors

- Predictability
- Schedule the day for success
- Emergency response plan in place
- Natural consequences
- Praise intermittently
- Find the "Guru" the consumer responds to and model his/her engagement



Strategies for Disruptive Behaviors

- If/Then scenarios to give clarity to tasks required.
- Visual task boards/ schedules.
- Timers to help with awareness of time (this non-preferred activity WILL END at some point!)
- Break tasks into smaller manageable steps.
- Consistency is the key!
- Verbal or visual redirection first.
- Physical redirection only when necessary.



We've Come A LONG Way

Over the last thirty years, research has increased our knowledge about the capabilities of people with Down syndrome. At the same time, significant advances in health care, early intervention and family support have vastly improved the quality of life for people with Down syndrome and their families.



What Does the Future Hold for People With Down Syndrome?

- Post secondary opportunities
- Relationships and marriages
- Actively participating in their communities
- Living independently or in semi-supported environments
- Real jobs for real people



What Does the Future Hold for Students With Down Syndrome?

- Amazing medical advances
- A potential cure for cancer found in people with Down syndrome?
- Research which will result in therapies or medications which could enhance cognition
- People with Down syndrome have unlimited potential when given opportunities and support!



Where Can You Find Help?

- Down Syndrome Guild of KC
www.kcdsg.org
- Down Syndrome Association of Greater St. Louis
www.dsagsl.org
- Down Syndrome Group of the Ozarks
ozarksdsg.org
- Up at Down Country
upatdowncountry.com

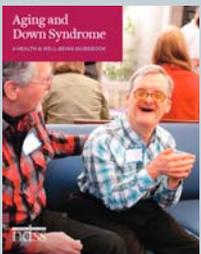


Resources

This guidebook is to provide guidance, education and support to families and caregivers of older adults with Down syndrome, and to prepare them for medical issues commonly encountered in adulthood.

Topics covered include:

- Common Medical Conditions
- Emotional and Psychiatric Well-Being
- An Introduction to Alzheimer's Disease
- A Caregiver's Guide to Alzheimer's Disease
- Planning for Old Age
- Resources for Further Information



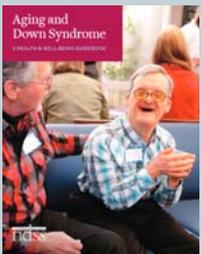
<http://www.ndss.org/About-NDSS/Newsroom/Recent-News/Aging-and-Down-Syndrome-A-Health-Well-Being-Guidebook/>



Aging and Down Syndrome Webinar

One hour overview of the aging process covered by a physician.

Health, social, behavioral and familial issues covered in depth.



http://www.youtube.com/watch?v=3yQc_7cjTDA



THANK YOU FOR ALL YOU DO!



Questions???

To learn more about supporting students with Down syndrome:

Down Syndrome Guild of Greater Kansas City
5960 Dearborn Street
Mission, KS 66202
www.kcdsg.org

Phone: 913-384-4848
Fax: 913-384-4949
Email: info@kcdsg.org