Down Syndrome 101
for Educators

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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 if born with Down syndrome today: 55-60 years of age
- Varied mental abilities, physical development, behavior, and accomplishments
- Prenatal testing recommended for EVERY pregnancy
Down Syndrome 101

• Three types of Down syndrome
  – Trisomy 21: extra copy of chromosome 21 in all of the cells
    *The cause of 95 percent of Down syndrome is Trisomy 21. It occurs when a pair of 21st chromosomes separate improperly. Individuals with Trisomy 21 have an extra copy of chromosome 21 – for a total of 47 versus 46 chromosomes – in all of their cells*
  – Mosaic: improper division of chromosome 21
    *Mosaicism occurs when the improper division of chromosome 21 happens after fertilization, so people with mosaicism have 46 chromosomes in some cells and 47 in others. It is the least common form of Down syndrome, accounting for 1 to 2 percent of all cases.*
  – Translocation: additional chromosome 21 is attached to another chromosome. ONLY form that can be inherited
    *Three to four percent of people with Down syndrome have Translocation in which an additional chromosome 21 is attached to another chromosome. This is the only form that can be inherited.*
Possible Medical Issues

- Heart Defects
- Muscle Hypotonia
- Hearing Loss
- Leukemia
- Vision
- Thyroid dysfunction
- Celiac Disease
- Atlanto-Axial Instability
Possible Medical Issues

- Tactile Sensitivity
- High pain tolerance
- Potty Training Issues
- Stamina
- Sleep apnea
- Dual diagnosis of Autism
Medical Issues

• Apraxia- neurological disorder affecting the ability to control fine and gross motor movement and gestures

• Apraxia can range from mild to severe.

• People with Apraxia often cannot perform controlled, purposeful movement, despite having the physical strength and intellectual thought and desire to do so.
  – Zipping up jacket, opening back pack, carrying lunch tray
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

• Currently being reviewed and updated

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

Kansas City is home to **FOUR** Down Syndrome Clinics:

**Children’s Mercy Down Syndrome Clinic for Children**
2401 Gilham Road
Kansas City, MO

Open every Wednesday for appointments
Call 816-234-3771 to schedule appointments

**Children’s Mercy Down Syndrome Clinic for Adolescents**
2401 Gilham Road
Kansas City, MO

Open three days each month for appointments
Call 816-234-3771 to schedule appointments

**KU Adult Down Syndrome Clinic**
3901 Rainbow Boulevard
Kansas City, KS

Open one day per month for appointments
Call 913-588-1915 to schedule appointments

**KU Down Syndrome Dementia Clinic**
3901 Rainbow Boulevard
Kansas City, KS

Open two days per month for appointments
Call 913-588-6820 to schedule appointments
Communication Issues

• Receptive language vs. Expressive language

• Hearing

• Attention span

• Short term memory

• Speech articulation

• Processing time
Communication Issues

- Reliving a moment
- Recalling information
- Echolalia
- Behavior is a form of communication
- Generalization
Communication Issues

• Dyspraxia of speech- a partial loss of the ability to perform skilled, coordinated verbalization

• It is caused by a neurological difference that has not yet been pinpointed.

• Treatment is via intensive speech therapy concentrating on oral-motor skills
  • Bubble blowing, horn blowing, sucking through straws
  • Books by Libby Kumin www.woodbinehouse.net
  • Talk Tools Products http://www.talktools.net/
Communication Strategies

• Demands and Interruptions
  • Necessary vs. Unnecessary Demands
  • Talking too fast and too much information
  • 10 seconds can change a life
  • Visual interruptions

• Fallouts of Needless Demands and Interruptions
  • Shut Down-Down syndrome drop
  • Aggressive or Uncooperative Behavior
Communication Strategies

• Ask the student to repeat instructions back to you

• Ensure you are face to face and have good eye contact when giving instructions

• 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 the student to speak in more than one word utterances

• Develop language through drama and role-play

• Use a home-school log to help relay information
Memory Issues

Because of their poor working memory, students with Down syndrome have greater difficulty than their peers with:

- Processing and retaining spoken words
- Understanding and responding to spoken language
- Following verbal instructions
- Learning abstract or unfamiliar vocabulary
- Remembering rules or routines
- Developing organizational skills
- Remembering sequences or lists
Social Issues

- The Dreaded “R” Word
- At-risk population for bullying/abuse
- Research indicates 70-80% of people with developmental disabilities will be abused either verbally, physically or sexually in their lifetime
- Issues with self-reporting
- People First Language
- Extra curricular activities
Why Inclusive Education?

Inclusive education benefits not only the student with Down syndrome, but also leads to greater understanding and less prejudice in the community at large.

Students in inclusive schools learn to become more tolerant and patient and to support each other, rather than competing or being afraid of the unknown. They also learn to value diversity and to appreciate that everyone has special gifts and talents.

Aims of Inclusion

- The acquisition of new skills
- Development of age appropriate behavior
- The development of independence in learning and behavior
- The development of friendships with “typical” peers

STUDENT
Successful Inclusion Requires

- A belief that all children can learn
- A positive attitude throughout the whole school
- A flexible approach to the use of support staff
- Ownership of the student’s learning by the classroom teacher
- Good communication between home and school
- Disability awareness education for students and educators
- Teaching independence not learned helplessness
Avoiding Learned Helplessness

• Students with Down syndrome are often presumed to need help in areas where they can actually be quite self sufficient.

• It is best to presume competence and provide supports only when the student 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

• Are you training your student to be a productive member of society?

• Are you setting the student up to fail later in life by rescuing him/her now?
Avoiding Learned Helplessness

Promotes Learned Helplessness

• Protecting student from taking risks
• Rescuing student from anticipated outcomes
• Overlooking errors
• Constant prompts
• Speaking for your student
• Giving inflated grades
• Permitting bad behavior
• Making excuses
• Interceding before they ask for help
• Inconsistency in discipline/expectations

Promotes Independence

• Setting clear limits on what is safe
• Discussing issues and creating solutions
• Giving clear directions/expect follow through
• Student encouraged to speak for self
• Teaching at a challenging level using learning strengths
• Using rubric scoring honestly
• Coaching student on errors
• Consistency in discipline/expectations
• Holding student accountable for actions
• Allowing student to fail in safe environment
• Teaching student to ask for help as needed
How Down Syndrome Affects Learning
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 learned helplessness
• Allow student to try and fail
• Use consistent language between home and school
• Avoid multi-tiered rewards programs
• Think like an employer
• Peer role modeling
The Power of Peer Presentations

- Helps other students understand what it is like to live with Down syndrome
- Provides students with strategies for supporting their friend with Down syndrome
- Opens the door for an important conversation
- Teaches diversity and tolerance
- Facilitates friendships
The Power of Peer Presentations

• 15-20 minute classroom or grade level presentation tailored around a specific student to address any issues related to their disability that others in the class may need help to understand.

• Ask parents if child should be included or out of the room during the presentation.

• Should be done across the grade level.

• The following should be present for the presentation, if possible:
  – All educators who are on the IEP team
  – Administrative staff (if pertinent)
  – School Counselor
  – School Nurse
  – Parents of student (if not presenting)
The Power of Peer Presentations

- Icebreaker(s)
  - Age-Appropriate books
  - The “Superstar List”
  - “Segregation Simulation”

- NDSS Dreams video or read an age appropriate book

- Down syndrome 101
  - What is Down syndrome?
  - Hypotonia
  - Speech
  - Hearing

- Opening the Doors to Friendships
  - Peer modeling
  - How to be a friend

- Q & A

- Send child home with give-aways (personalized book marks, pencils, candy)
The Power of Peer Presentations

• **GOAL #1**
  To increase the students’ personal awareness and knowledge about similarities and differences between people, and to raise their personal awareness about disabilities.

• **GOAL #2**
  To share language and give them knowledge about Down Syndrome.

• **GOAL #3**
  To ask for the students’ help in supporting and teaching their classmate with Down Syndrome and any other people who may have differences or special needs.
The Power of Peer Presentations

- Letter to classroom parents
- Myths/Truths About Down Syndrome
- Personalized Bookmarks
- Other fun items like pencils, candy, or school supplies if they are available
Dear Parent,

Some of you already know our daughter, Hannah. For those of you who do not, Hannah has Down Syndrome. She is excited to be in 2nd grade with your child. She is a cheerful student who loves school and to learn with her classmates.

Our expectations for Hannah are high, much like those you have for your child. We hope she will learn to the best of her ability, make lasting friendships, follow school rules, and be a contributing member of the classroom.

Your child’s role modeling and positive interactions with Hannah will help her to be successful in these areas.

Today, your child was part of a brief presentation which highlighted and explained some challenges Hannah and others with Down Syndrome face along with some truths about Down Syndrome.

In addition, it hopefully gave some insight into her similarities to other children. We hope this helped answer some of the questions your child may have.

We hope you will contact us if your family has any questions. Children with Down Syndrome have unlimited potential when given opportunity and support.

Sincerely,

Joy and Jane Luthi

Peer Presentation Materials

Myths & Truths About Down Syndrome

Myth: Down syndrome is a rare genetic disorder.
Truth: Down syndrome is the most common occurring genetic condition. One in every 800 births is a child with Down syndrome. There are currently 530,000 people in the U.S. with Down syndrome, with 5,800 to 6,000 births per year.

Myth: Most children with Down syndrome are born to older parents.
Truth: Eighty percent of children born with Down syndrome are born to women younger than age 35 due to higher fertility rates. However, research has shown a link between the incidence of Down syndrome and maternal age.

Myth: Down syndrome is hereditary and runs in families.
Truth: Most cases of Down syndrome are sporadic chance events. In general, Down syndrome does not run in families and a sibling or more does not have a higher chance of contracting a child with Down syndrome.

Myth: People with Down syndrome have severe cognitive delays.
Truth: Most people with Down syndrome have cognitive delays that are mild to moderate. IQ is not an adequate measure of the functional status of people with Down syndrome. People with Down syndrome have great potential if given opportunity.

Myth: The life expectancy of people with Down syndrome is 30.
Truth: Thanks to advances in medical and clinical treatment and opportunities to live as many as 40 percent of adults with Down syndrome reach age 55, and many live longer.

Myth: Behavioral problems and depression are just part of having Down syndrome.
Truth: Mental or mood health problems are untreated due to the assumption that it is typical of having this genetic condition. Complete examination by appropriate care providers should always be pursued.

Myth: Children with Down syndrome are placed in segregated special education programs.
Truth: Children with Down syndrome are included in regular academic classrooms across the country. Students may be integrated into specific courses or fully included in the regular classroom for all subjects.

Myth: Adults with Down syndrome may be unable to work.
Truth: Businesses seek young adults with Down syndrome for a variety of positions. They are employed by banks, corporations, mobile homes, hotels, and restaurants. They work in the music and entertainment industry. People with Down syndrome bring to their jobs enthusiasm, reliability and initiative.

Hannah

My name is Hannah and I am 7 years old. I enjoy doing a lot of the same things as other kids my age.

I jump on my trampoline. I can jump 30 jumps. I play kickball and run, I play board games like Candy Land and my favorite game is Uno. I love to play "Hide and Seek". I read books and sing songs like "Jama Love Me."

I have two brothers and two sisters. I love to spend time with my family. I ride the 3 wheeler with my brother, Aaron and run races with my brother, Michael. I go swimming with my sister, Marni and talk with my sister, Andrea, on the phone. I cook with my mom and play on the trampoline with my dad.

I am a lot like everyone else my age. One difference is that I have Down Syndrome. I can do everything everyone else can except sometimes it takes me a little longer to do it which is why I may sometimes need extra help or more time to do it.

My friends are very important to me. My friends help me learn. Thank you for being my friend.

Questions About Down Syndrome (DS) That Kids May Ask

Why does Hannah have Down syndrome?

Hannah was born with DS. Our bodies are made up of cells and every cell has 46 chromosomes. People with DS have an extra chromosome.

Can I catch Down syndrome?

No. If you weren’t born with DS you will never get it. You can’t catch DS from Hannah.

Is there a cure for Down syndrome?

No. There’s no medicine to make DS go away. Hannah will have it for the rest of her life.

Why does Hannah seem so tired in class?

All the muscles in Hannah’s body are very soft and flexible. She has to work extra hard to do the things you can do easily. This extra work makes her tired.

What should I do if I can’t understand what Hannah is saying?

Ask Hannah to say repeat what she said, have her show you what she is talking about or ask your teacher to help you understand each other.

Why does Hannah leave the classroom with adults?

Hannah works with some adults to get extra practice with her speech, math and handwriting. Some days she may have a helper here with her in class to explain what is being taught and help her understand everything.

Why does Hannah sometimes scratch or hit others?

Hannah has feelings just like you. Sometimes when she is upset she can’t find the right words to tell someone how she is feeling. She might be feeling sad, afraid, or hurting. This seems to be when this happens. Giving her personal space seems to help Hannah.

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The Role of the Support Professionals

• Encourage cooperative learning and involvement of peers as good role models

• Act as a bridge between student and the curriculum

• Provide feedback to the classroom teacher on the student’s response to the curriculum

• 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.

• Some students with Down syndrome may appear to misbehave when they are, in reality, just confused or uncertain about what they are supposed to do.

• Students may have failed to understand instructions given to the whole class.

• Student may have forgotten what they have been told (short term memory issues).

• Student may find it hard to learn new rules and routines and still do things in the old way.
Behavior is a Form of Communication

• Rule out any medical reasons for behavior

• Compromised concentration or memory skills compared to peers.

• Immature play and social skills.

• Immature behavior may have been ignored or reinforced in the past.

• Is your student treated like his/her peers?

• The first response to a request may be NO!
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 dislike being ignored.
- Resents having an adult by their side all the time
- Resents adult helping other students
- 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?
- Misbehave because they are angry, frustrated or hurt.
What is Your Student 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.

- Refusal to cooperate with teacher or assistant to gain control.

- Give opportunities to choose activities.

- Students may feel under pressure and need a break.

- Students may resent being regularly withdrawn from class and separated from their friends.

- The student’s immaturity may lead to behaviors more appropriate to a younger child.
What is Your Student Telling You?

• Wants to do the same work as everyone else but an adult insists they do something different.

• Tries to do the same as others, but find they can’t cope without help.

• Presumes the work they are being given is too difficult or sees it as uninteresting.

• Are you over supporting?

• Confused by different adults giving conflicting messages.

• Self stimming and sensory issues
Strategies for Disruptive Behaviors

• Give choices in activities.

• Give the child the opportunity to resolve a conflict with another child before intervening.

• When intervening - problem solve with the child, do not just stop the behavior.

• Give an alternate suggestion on what to do with the impulse. Redirect to another more appropriate activity.

• When possible allow the child to experience the natural consequence of his/her behavior.

• Repeat rules and limits frequently; keep to a few basic rules.

• Reinforce behavior you want to continue.

• Be persistent; the child probably has had a lot of practice in testing the limits.
Strategies for Disruptive Behaviors

- Warn children before transitions are made.
- Arrange the learning environment for positive interaction.
- Intervene before “robust” play becomes rough play.
- Encourage and assist children to verbally come up with their own solutions.
- Schedule the student’s day for success.
- Try not to let the student become overly tired.
- Some students respond to role-playing, using puppets or social stories to work out solutions to conflict situations.
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!

• Decrease opportunities for distractions.

• Verbal redirection first. Physical redirection only when necessary.
Curriculum Adaptations

• Modifications to the curriculum call for creative thinking and imagination on the part of the IEP team.

• Using common sense, being flexible and locating additional resources will be an effective approach.

• Differentiating materials will provide more access for ALL students in a classroom.

• As a para it is not your responsibility to adapt the curriculum. HOWEVER, you can make suggestions to the general and special education teachers based on your interactions with the student.
Curriculum Adaptations

- Rely heavily on visual aides rather than auditory instructions.
- Modify worksheets
  - Fewer items and/or more visuals
  - More border around edge of page
  - Highlighted text that is important
  - Large print
  - Meaningful context to learner
- Use of manipulatives
- Multiple choice tests vs. spontaneous answers
- Writing utensils
- Books on tape
Curriculum Adaptations

• Use meaningful material within or close to the pupil’s experience.

• Introduce new concepts in a familiar context.

• Show samples of completed work.

• Provide plenty of visual cues- pictures, diagrams and print.

• Ensure illustrations tie in closely with text and task.

• Give plenty of opportunities for success.

• Use technology! Ipads, computers, cell phones, Nintendo DS
Curriculum Adaptations

• Use student feedback to decide whether or not the worksheet fulfills your educational aims and objectives.

• Supplement the worksheet with a taped version of the task instructions, which the pupil can play for reinforcement.

  If possible try out several different versions of the same worksheet to discover what works best for the student.

• Differentiate clearly between text and illustrations.

• Leave a wide border all round the edge of the page.

• Provide opportunities for collateral success.

• Show a sample of the finished product you want and the steps to get to the product.
Adaptations That Work

**Size**
Adapt the number of items that the learner is expected to learn or complete.

*For example:* Reduce the number of social studies terms a learner must learn at any one time. Worksheet is two sided with big print and five questions on each side instead of one sided with all ten items in small print.

**Time**
Adapt the time allotted and allowed for learning, task completion, or testing.

*For example:* Individualize a timeline for completing a task; pace learning differently (increase or decrease) for some learners.

**Level of Support**
Increase the amount of personal assistance with a specific learner.

*For example:* Assign peer buddies, teaching assistants, peer tutors, or cross-age tutors.
Adaptations That Work

**Input**
Adapt the way instruction is delivered to the learner.

*For example:* Use different visual aids; plan more concrete examples; provide hands-on activities; place students in cooperative groups.

**Difficulty**
Adapt the skill level, problem type, or the rules on how the learner may approach the work.

*For example:* Allow the use of a calculator to figure math problems; simplify task directions; change rules to accommodate learner needs.

**Output**
Adapt how the learner can respond to instruction.

*For example:* Instead of answering questions in writing, allow a verbal response; use a communication book for some students; allow students to show knowledge with hands-on material. Multiple choice spelling tests. Shaving cream spelling.
Adaptations That Work

Participation
Adapt the extent to which a learner is actively involved in the task.

*For example:* In geography, have a student hold the globe, while others point out locations.

Alternate Goals
Adapt the goals or outcome expectations while using the same materials.

*For example:* In social studies, expect one student to be able to locate just the states while others learn to locate capitals as well.

Substitute Curriculum
Provide different instruction and materials to meet a learner’s individual goals.

*For example:* During a language test one student is learning computer skills in the computer lab.
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 Students With Down Syndrome?

- Post secondary opportunities
- Real jobs for real people
- Relationships and marriages
- Actively participating in their communities

People with Down syndrome have unlimited potential when given opportunities and support!
What Does the Future Hold for Students With Down Syndrome?

- Living independently or in semi-supported environments
- 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
Where Can You Find Help?

- Case Manager for the student
- Down Syndrome Specialist in your district
- Student’s parents
- Other para professionals
- IEP Team
- Peers at school
- Internet Resources
- Library (books authored prior to 2000 are likely outdated)
- Down Syndrome Guild of Greater KC
THANK YOU FOR ALL YOU DO!
Resource Materials

• Down’s Syndrome Association Education Support Packet
  http://downs-syndrome.org.uk/

• Down Syndrome Guild of Greater Kansas City

• Down’s Ed International http://www.downsed.org/

• Prep Program   http://www.prepprog.org/

• Down Syndrome Association of Central Texas Educator Packet
Questions???

To learn more about supporting students with Down syndrome:

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