Down Syndrome 101
for Educators

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• 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

• 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

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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
- Vision (specs4us.com)
- Thyroid dysfunction
- Leukemia
- Celiac Disease
- Atlanto-Axial Instability

Possible Medical Issues

- Tactile sensitivity
- Higher pain tolerance
- Potty training
- Precocious puberty
- Sleep apnea
- Dual diagnosis of Autism
- Alzheimer’s Disease
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

http://www.down-syndrome.org/reports/301/

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!

What Can You Do?

- Work to identify potential medical issues affecting academic success
- Allow for recovery time and regrouping after illness
- If you see DISTINCT changes in behavior rule out medical issues first
- Teach student how to report medical issues
- Follow any treatment protocols as outlined by physician
- Work with student to wear glasses, hearing aids, take medications and follow dietary or activity restrictions
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 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

- Less is more!
- Ensure you are face to face and have good eye contact when giving instructions
- Ask the student to repeat instructions back to you
- Use simple and familiar vocabulary and short, concise sentences
- Reinforce directions with facial expressions, gestures and signs
- Emphasize key words and reinforce with visual aids as needed
- Authoritative voice with expectation of compliance
- 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

Working Memory Presentation:
http://www.upatdowncountry.com/educational
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 of being afraid of the unknown. They also learn to value diversity and to appreciate that everyone has special gifts and talents.

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
What is Inclusion?

http://www.youtube.com/watch?v=n_qgW9FWegQ

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?

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 or 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 a safe environment
- Teaching student to ask for help as needed
How Down Syndrome Affects Learning

Preferred Teaching Methods

- Consistent vocabulary
- Allow for processing time
- Hands on activities
- Structured, sequenced activities
- Routines followed
- 15-20 repetitions to acquire skills
- Visual learning a strength
- The fewer the cues, the better!

Preferred Teaching Methods

- Avoid learned helplessness
- Allow student to try and fail
- 360 degree approach
- Engage learner at his level
- Reward programs that make sense
- Think like an employer
- Peer mentoring
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"
- Watch a 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.

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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

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Peer Presentation Materials
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 center of attention and dislikes 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 consistent; the child probably has had a lot of practice in testing the limits.

- 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 aids 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

• Follow student’s lead
• Supplement the worksheet with a taped version of the task instructions, which the pupil can play for reinforcement
• Try several different versions of worksheet to discover what works best for the student
• Differentiate clearly between text and illustrations
• Wide border around the edge of the page
• Provide opportunities for collateral success
• Show sample of the finished 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
• 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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