Fostering Independence in Students with Down Syndrome

Presented By,

Amy Allison
Chief Operating Officer

Goals for this presentation

- DREAM BIG!
- Presume competence
- Get out of the way
- Self regulation
- Think like an employer
- Work yourself out of a job

Down Syndrome 101

- Most commonly occurring genetic condition resulting in 1:800 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
- No known cause or cure for Down syndrome-it's a random occurrence 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

Possible Medical Issues

- Heart Defects
- Muscle Hypotonia
- Hearing Loss
- Vision (specs4us.com)
- Thyroid dysfunction
- Celiac Disease

Possible Medical Issues

- Tactile Sensitivity
- High pain tolerance
- Toilet Training Issues
- Stamina
- Sleep apnea
- Dual diagnosis of Autism
What can Educators Do About Medical Issues?

- Communication with parents
- Time in lunchroom/restroom
- Administer meds
- Least challenging subjects end of day
- Rule out medical issues as cause of behavior
- Recovery time from illness

What can Educators Do About Medical Issues?

- How is work compromised when you are not feeling well and can’t explain why?
- Accommodate hearing and vision
- Extra support for potty training/puberty
- Recognize avoidance behavior in lieu of medical issues
- Educate staff on medical issues
- Involve school nurse as needed

Group Exercise

- Discuss medical issues causing behaviors in the classroom
- Discuss strategies for supporting your student moving forward
- How can you communicate with parents regarding medical issues?
- How can you teach students to communicate when they are not feeling well?
- Do you need extra support?
Possible Communication Issues

- Receptive vs. Expressive language
- Hearing
- Short term memory
- Speech articulation
- Processing time
- Echolalia
- Generalization

Communication Strategies

- Demands and Interruptions
  - Necessary vs. Unnecessary Demands
  - Talking too fast and too much information
  - 10 seconds can change a life
  - Visual interruptions
- Fallout of Needless Demands and Interruptions
  - Shut Down-Down syndrome drop
  - Aggressive or Uncooperative Behavior

Communication Strategies

Steps to Successful Communication
Group Exercise:
Communication foul ups!

What strategies does your student use to communicate needs?

- verbalization
- communication device
- picture exchange
- sign language
- Behavior
- Are you allowing processing time?
- How many prompts are you giving?

*Are there any sensory or social issues causing communication difficulties?

How does your student view you?

- My friend?
- My personal assistant?
- My shadow?
- My boss?
- Charlie Brown’s teacher?

Potential Effects of Para Support

- Separation from classmates
- Interference with peers
- Feeling of being stigmatized
- Lack of teacher engagement
- Loss of personal control
- Provocation of behaviors

**Giangreco, Edelman, Lusinelli and MacFarland (1997)**
You’re overthinking it!
- Common behavior for age
- Typical kids do this
- Too much supervision
- Too many prompts/ transitions
- Over verbalizing
- Separate is not equal

You’re under thinking it!
- You have to teach behavior
- Accommodations/ modifications
- Scheduling
- Low expectations
- Judging a book by the cover

Supporting vs. Punishing
- Supporting corrects misbehavior and instills self-discipline
- Punishment stops misbehavior by inflicting pain or penalty.
- Supporting focuses on future correct behavior.
- Punishment focuses on past incorrect behavior.
- Supporting demonstrates attitude of love/concern for the child—they remain calm and relaxed.
- Punishment associated with punisher, not the behavior. (speeding ticket)
Successful supervising adults

• Confident in their actions
• Feel no guilt over the disability
• Look into the future
• Allow student to try and fail
• Natural consequences
• Avoid power struggles
• Are process oriented vs goal oriented

Successful supervising adults

• Are consistent in interactions
  – expectations
  – tone of voice
  – routines
• Are not guided by a clock
• Measure success by level of independence achieved by student
• BELIEVE IN THE STUDENT!!

Help me stay on task

• Predictability
• Tasks uninterrupted
• Transition times for peers
• Prompts for unstructured time
• Reducing verbal demands
• Why is this important to me
• Unnecessary interruptions
• Visual schedules
Help me stay on task

- Watch and wait
- Prompt hierarchy
- Backward chaining
- Ask facilitative questions (what comes next?)
- Use transition objects (headphones to noisy settings)
- Break big tasks down
- Don’t interrupt with praise

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

Range of Supports

<table>
<thead>
<tr>
<th>Type of Support</th>
<th>Definition</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full Physical</td>
<td>Direct and physical assistance</td>
<td>Hand over hand assistance to write name</td>
</tr>
<tr>
<td>Partial Physical</td>
<td>Physical assistance for some part of activity</td>
<td>Connecting zipper and pulling 1 inch</td>
</tr>
<tr>
<td>Modeling</td>
<td>Demonstrate what to do</td>
<td>Para does an art project side by side student</td>
</tr>
<tr>
<td>Direct Oral</td>
<td>Verbal directions only</td>
<td>“Josh, please stand up.”</td>
</tr>
<tr>
<td>Indirect Verbal</td>
<td>Verbal prompt to get student to think about what comes next</td>
<td>“Josh, what should you be doing now that math is over?”</td>
</tr>
<tr>
<td>Gestural</td>
<td>Physical movement to cue (head nod, thumbs up)</td>
<td>Para points to visual schedule on desk</td>
</tr>
<tr>
<td>Natural</td>
<td>No cue change from other students directions</td>
<td>Bell rings and teacher ask students to move to rug</td>
</tr>
</tbody>
</table>

**Adapted from Paraprofessionals Guide to the Inclusive Classroom**
Avoiding Learned Helplessness

• Students with Down syndrome are presumed to need help in areas where they can actually be quite self-sufficient.
• PRESUME COMPETENCE! Provide supports only when the student requests assistance or proves it is needed.
• Are the supports you have in place transferrable to other settings?
  o Community outings
  o Employment situations
  o 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
• 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

Group Exercise: Learned Helplessness

• Discuss behaviors at your table
• Identify strategies that promote independence
• Identify strategies that would cause learned helplessness
Should we change things up?

- 3-6 week trials
- Staffing
  - Too dependent
  - Non-responsive
- Managing behaviors—not teaching
- Lack of rapport
- Anticipating problems
- Peers

How to Fade Support

- When is support truly necessary
  - 10 minutes at recess lineup
  - All day long
- Reduce cues
- Look for more natural supports
- Ensure materials student works on promote independence

Reinforcement Schedule

- Prompt dependency
- Praise dependency
- Reward dependency

**Intermittent reinforcement is the best way to shape behavior**

THINK LIKE AN EMPLOYER!
Mother Hens

- Awesome
- Annoying
- Resentment
- Aggression
- Shutdown
- Enabling

What Works for Students with DS?

- Visual aides with 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

What Works for Students with DS?

- Introduce new concepts in a familiar context.
- Show samples of completed work.
- Provide plenty of visual cues- pictures, diagrams and print.
- Ensure illustrations tie closely with text/task
- Give plenty of opportunities for success
- Use technology! Apps /pads, computers, cell phones [http://a4cwsn.com/]
What Works for Students with DS?

- Tactile or kinesthetic learning
- Understanding why a task is important
- Record instructions so student can play back
- Several versions of the same worksheet
- Provide opportunities for collateral success:
  - Fractions
  - Writing
  - Spelling
- Sample of finished product/ steps to get there

Visual Strategies are KEY!

[Image: tinyurl.com/dsvisuals]

What Works for Students with DS?

- Errorless learning
- Redirect, do not correct
- Teach, don’t test
- Make sure work is challenging
- Engage peers
- Incorporate student’s interests
What Works for Students with DS?

- Adult completes the task for the student.
- Adult provides hand-on hands-on support to enable the student to complete the task.
- Adult provides physical prompts (e.g., re-teaching the task, etc.) to enable the student to complete the task.
- Adult provides verbal/gestures to enable the student to complete the task.
- Adult provides written or symbolic prompts, a list or a picture task card for the student. The student completes the task independently.

Strategies for Disruptive Behaviors

- Teach conflict resolution
- Redirect to appropriate activity.
- Natural consequences
- Reinforce behavior you want
- Be persistent and consistent; student may be testing the limits

Strategies for Disruptive Behaviors

- Warn children before transitions
- Schedule the student’s day for success
- Use role playing, puppets, social stories or video modeling
- If/Then or First/Then scenarios
- Visual task boards/schedules/lists
- Use timers
- Break tasks into smaller manageable steps
IQ or EQ

- Take the emotion out
  Use respond not react method
- Match the student’s pace
  but try to increase stamina
- You know what you are
  supposed to do
- I’m here if you need help
- Be consistent in messaging

Skill vs. Will

Teach skills
- Provide structure
- Visual supports
- Pacing

Teach behavior
- Coping strategies
- Consequences
- Wait it out when possible

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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 thinkcollege.net

• 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 professionals
- IEP Team
- Peers at school
- Internet Resources
- Library (books authored prior to 2005 are likely outdated)

Don’t Limit Me!

Think about what I need to know and be able to do when I leave school.

Hard work pays off!

Thank you for believing in your students with Down syndrome!
Questions???

To learn more about supporting students with Down syndrome:
Down Syndrome Guild of Greater Kansas City
5960 Dearborn Street
Suite 100
Mission, Ks 66202

913.384.4848
amy@kcdsg.org
www.kcdsg.org