Providing Optimal Services and Supports for Students with Down syndrome in Educational Settings

Therapro Saturday Seminar Series
November 5, 2016

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LEARNING OBJECTIVES

At the conclusion of this session, participants will be able to:

- Articulate the common learning characteristics and associated physical and health care needs of students with Down syndrome.
- Describe learning strategies (e.g., use of visual supports, self-management) effective for students with Down syndrome.
- Identify organizational strategies and tools to facilitate the integration of therapy services into educational programs of students with Down syndrome.
AGENDA

1. Overview and Introductions
2. Basic Overview of Down syndrome (DS) and associated medical conditions
3. Learning Characteristics of Students with Down syndrome
4. Key Strategies - focus on facilitating independence
   • Visual Supports
   • Self-Management
5. Facilitating the integration of therapy services educational settings
6. Wrap-up
A great deal of information. . . And many perspectives -

I hope you will share examples as we go!

“I know nothing about the subject, but I’m happy to give you my expert opinion.”
Meaningful Inclusion for Students with Down Syndrome
A Resource Guide for Elementary Educators

by the Massachusetts Down Syndrome Congress Education Task Force
<table>
<thead>
<tr>
<th>What do you know about individuals with Down syndrome? Working with students with DS?</th>
<th>What do you want to know about individuals with Down syndrome? Working with students with DS?</th>
</tr>
</thead>
<tbody>
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</table>
Down Syndrome is the most commonly occurring chromosomal condition – one in every 733 babies in the US

Approximately 400,000 individuals with DS in US

Estimated decrease of 30% due to abortion

Approximately 67% of fetuses thought to have DS are believed to be aborted in the US.

80% of children with DS are born to women <35

Cause and prevention of DS are unknown

DS occurs in people of all races, nations, religions, and economic levels.
**Types of Down Syndrome (Trisomy 21)**

- **Nondisjunction** (95%) – error in cell division that results in an embryo with 3 copies of chromosome 21 instead of the usual 2 copies.

- **Mosaicism (mosaic Down syndrome)** (1%) – nondisjunction of chromosome 21 takes place in one (but not all) of the initial cell divisions after fertilization. This results in a mixture of two types of cells – some with 46 chromosomes (23 pairs) and some with 47.

- **Translocation** (4%) – an additional full or partial copy of chromosome 21 breaks off during cell division and attaches to another chromosome – usually #14.
Individuals with all types of Down syndrome have an extra, critical portion of chromosome 21 present in all or some of their cells -> this changes their development and causes the characteristics associated with Down syndrome.
HEALTH AND MEDICAL ISSUES

- **Congenital heart disease** – 30 to 60% of children with DS
- **Vision** – 30-50% of children with DS have eye abnormalities
- **Hearing** – The majority of children with DS have some hearing loss – attributed to frequent middle ear infections, structurally short and narrow ear canals which cause difficulty with drainage.
- **Thyroid** – 15% of children with DS are treated for thyroid disorders
- **Leukemia** – many times more likely to develop either acute lymphocytic leukemia (ALL) or acute myeloid leukemia (AML) than are other children, with an overall risk of about 2% to 3%.
Atlantoaxial instability - Excessive mobility of atlas (C1) and the axis (C2), may lead to subluxation of the cervical spine.
Higher rate of infections due to compromised immune system and decrease in number of T cells.

Dry mouth caused by mouth breathing associated with upper respiratory infections.

Periodontal disease accelerated by increased number of infections.
Infants with Down syndrome may be of average size, but typically they grow slowly and remain shorter than other children of similar age.

In general, developmental milestones, such as sitting and crawling, occur at about twice the age of children without impairment.

Sleep apnea. Because of soft tissue and skeletal alterations that lead to the obstruction of their airways, children with Down syndrome are at greater risk of obstructive sleep apnea.

Obesity. People with Down syndrome have a greater tendency to be obese than does the general population.
Greater prevalence of Autism Spectrum Disorders (ASD) in individuals with Down syndrome – estimates up to 18%

Life expectancy for people with Down syndrome has increased dramatically in recent decades – from 25 years in 1983 to 60 today.
Any other health or medical conditions associated with Down syndrome?
Learning Profile – Typical Characteristics of Child with DS
Behavioral Phenotype Information

- Higher probability but not all children... Great variability

Looking at child as an individual
Learning Profile (Page 3)

- Stronger **RECEPTIVE language than EXPRESSIVE language**
- Many students have articulation difficulties
- Strong **visual/spacial processing** and memory
- May need additional time for **auditory processing**
- Hearing loss may exacerbate challenges
- Difficulty with short term and working memory
- Strong imitative skills
- Difficulty **generalizing** skills and knowledge
- Abstract concepts more difficult to learn
**Strategies/Recommendations**

- Use visual supports for expressive language (augmentative communication)
- Provide multiple opportunities for child to communicate in small groups
- Listen carefully; reinforce all communication efforts
- Ensure face-to-face communication and eye contact
- Use short clear statements; if repetition needed, use same wording
- Provide ample time for processing language
Strategies/Recommendations (cont.)

- Use peer support rather than adult support when possible
- Auditory input should be supported by visuals (e.g., write on board, diagrams, pictures)
- Provide visual supports to facilitate information retrieval (e.g., list of key words)
- Seat child near good role models
- Ask child to repeat directions
- Build in opportunities for child to generalize as new skills are taught
BEHAVIOR PROFILE ASSOCIATED WITH STUDENTS WITH DS

Common Behavioral Strengths
- Interested in peers and adults
- An interest in friendship
- Amiability and generosity
- A measured and methodical working pace
- Pronounced strength for learning through visuals of all kinds, music, drama, and imitation
- A sense of humor
- Capacity for social learning
BEHAVIOR PROFILE ASSOCIATED WITH STUDENTS WITH DS (CONT.)

Common Learned Behaviors

- Giving up on tasks too soon
- Learned helplessness . . . Prompt dependent
- Choosing to socialize instead of attempting a difficult task
- Avoiding a difficult task with attention seeking, distractions, problems, or personal interests
- Self-talk
- Quitting due to reduced stamina – “flop and drop”
- Imitating other children’s inappropriate behavior
STRATEGIES TO SUPPORT PRODUCTIVE BEHAVIOR

- Familiar routines – and preparation for any change in routine
- Support for any transitions – verbal, visual
- Visual supports – MORE LATER
- Specific positive verbal feedback
- Guided opportunities for social interaction and play
- Sufficient WAIT TIME for auditory processing – repeat simple directions using the same words
- Opportunities for CHOICE
- High behavioral and curricular expectations
Behavioral Phenotype Information

- Higher probability but not all children... Great variability

Looking at child as an individual
We are More Alike than Different
✓ Self-management
✓ Use of visual supports
**Positive Behavior Support (PBS)**

Positive Behavior Intervention and Support (PBIS)

PBS is assessment based. Interventions are directly linked to environmental influences and hypotheses concerning function of the problem behavior.

--Bambara & Knoster, 1998

Communicative Functions

- Getting attention
- Escape or avoidance
- Getting something tangible

Sensory Functions

- Self-regulation
- Play or entertainment
OVERVIEW OF PBS

- PBS is a broad range of systemic and individual strategies for achieving important social and learning outcomes while preventing problem behaviors.

- PBS is a package of strategies, not just one intervention, that focuses on:
  - teaching new skills,
  - changing conditions & environments, and
  - preventing problem behavior from occurring.

Center on Positive Behavior Interventions & Supports, 2001
Basic Principles of PBS

- Always change the ecology before planning to change the student

- Behavior intervention is about teaching and learning -- not about control

- Behavior intervention is about empowering the student, not gaining power over the student
**Key Components/Model of Positive Behavior Support**

- **PREVENT:** Prevention strategies prevent problem behavior before it occurs (proactive rather than reactive).

- **TEACH:** Teach the student skills/behaviors that will serve the same function in a more acceptable way.

- **RESPOND/REINFORCE:** How will you reinforce targeted behavior being taught? How will you respond to the problem behavior if it occurs [and not reinforce inappropriate behavior]?
**SELF-MANAGEMENT STRATEGIES**

- Are a natural link between PBS and Visual Strategies!

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</table>

Put a √ in the box each time you raise your hand.
 Reasons For Using Self-Management Procedures

✓ Golden Rule – Most of us would not want someone else imposing behavior change goals and strategies on us

✓ They are EFFECTIVE

✓ Self-regulation procedures such as self-monitoring have shown positive effects on changing behavior (Menzies, Lane & Lee, 2009; Polsgrove & Smith, 2004).

✓ One of the least intrusive and least restrictive behavior management strategies (Kerr & Nelson, 2010).
REASONS FOR USING SELF-MANAGEMENT PROCEDURES (cont.)

- Person implementing the intervention can become an environmental cue – inadvertently resulting in the performance or lack of performance of a behavior. (*Learned helplessness*)

- Human supports are not always available in the environment where the target behavior is occurring or should occur. → Ultimately we want student to behave without outside intervention.
TYPES OF SELF-MANAGEMENT (PAGE 5)

Least to most complex:

1. Self-Monitoring/Recording
2. Self-Evaluation
3. Self-Reinforcement
## Select Self-Management Procedure

<table>
<thead>
<tr>
<th>Behavior Type</th>
<th>Identify Behavior</th>
<th>Evaluate Behavior</th>
<th>Reinforce Behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Monitoring/Recording</td>
<td>yes</td>
<td>no</td>
<td>no</td>
</tr>
<tr>
<td>Self-Evaluation</td>
<td>yes</td>
<td>yes (quality)</td>
<td>no</td>
</tr>
<tr>
<td>Self-Reinforcement</td>
<td>yes</td>
<td>yes</td>
<td>yes (act on behavior)</td>
</tr>
</tbody>
</table>
But my student is “too low”. . .

Remember that these are skills that need to be taught.

Few children get on a bike and ride without direct instruction.
Example of Self-Monitoring/ Self-Recording

Goal: I will have good table manners.

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Sit down quietly.</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>Wait for everyone to get their food.</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>Use a napkin.</td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>Talk with a soft voice.</td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>Stay in my seat until I am finished.</td>
<td></td>
</tr>
<tr>
<td>Time</td>
<td>Activity</td>
<td>Location</td>
</tr>
<tr>
<td>------</td>
<td>----------</td>
<td>----------</td>
</tr>
<tr>
<td>08:00</td>
<td>Morning 1</td>
<td>Home</td>
</tr>
<tr>
<td>09:00</td>
<td>Morning 2</td>
<td>School</td>
</tr>
<tr>
<td>12:00</td>
<td>Lunch</td>
<td>Restaurant</td>
</tr>
<tr>
<td>14:00</td>
<td>Afternoon 1</td>
<td>Home</td>
</tr>
<tr>
<td>16:00</td>
<td>Afternoon 2</td>
<td>School</td>
</tr>
<tr>
<td>18:00</td>
<td>Evening 1</td>
<td>Home</td>
</tr>
<tr>
<td>20:00</td>
<td>Evening 2</td>
<td>Home</td>
</tr>
</tbody>
</table>

Note: Check-in times are not included in the schedule.
When I sit down in my seat I have to have good posture!

1. Are my feet on the ground? __________

1. Am I sitting up with a straight back? ________

Thank you Jen Roberts, Walpole Public Schools

YES!!!

NO!!!
CLASSROOM SELF-EVALUATION SCALE

Name: _______________________
Date: _____________________
Class: ______________________
Teacher: __________________

Circle one of the Four Choices
4 = Always  3 = Most of the Time
2 = Some of the Time  1 = Did Not Do

1. Worked without disturbing others. 4 3 2 1
2. Participated in class. 4 3 2 1
3. Listened and paid attention 4 3 2 1
   when the teacher was talking.
4. Asked for help when I needed it. 4 3 2 1
5. Followed teacher directions. 4 3 2 1
6. Completed class assignment. 4 3 2 1
7. Turned in completed assignment. 4 3 2 1

TOTAL Score ___________

28 – 24 Super
23 – 20 Good
19 – 14 Fair
13 – 0 Make a Plan
EXAMPLE of a Self-Graphing Form – *Katie’s Perfect Posture Chart*

**INSTRUCTIONS** – Fill in the number of boxes for each period that you circled YES for Perfect Posture.

<table>
<thead>
<tr>
<th>Number of Periods</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Week of 10/31/16
Other ideas for use of Self Management?
What are Visual Supports?

Visual supports are those things that we can see that can improve communication, interaction, understanding and behavior.

Everyday examples:
- Calendars/Schedules
- Traffic lights
- Icons on rest rooms
- Reminder sticky notes
- ?
EXAMPLES OF VISUAL SUPPORTS

- Natural cues found in the environment
- Body language (e.g., Facial expressions, body stance)
**Visual Supports: Research**

- Most research has focused on individuals with Autism Spectrum Disorders (ASD)
- Visual Supports recognized as an evidence-based practice by the National Professional Development Center on ASD

[Evidence Based Practices ASD](#)
Research has shown success using visual supports for:

- Facilitating transitions (Dettmer et al, 2000)
- Increasing engagement and decreasing self-injury (O’Reilly et al 2005)
- Disruptive, tantrum, off-task behavior (Clarke et al, 1999)
- Off-task and prompt dependent behavior (Hall et al, 1995)
Based on profile of individuals with DS as strong visual learners . . .

Building on research done with students with ASD. . .

Based on personal and anecdotal experience in the field . . .

We are making a leap. . . not really a large one.
“When we present information verbally, the words are available for a brief moment.

When we present information visually, it can be there for as long as the individual needs it.”

National Professional Development Center on ASD
VISUAL SUPPORTS help to...

- Organize the environment
- Teach skills
- Provide information
- Communicate what is happening/changing
- Explain rules, behavior expectations

Prevent  
Teach  
Overlap  
Respond
VISUAL SUPPORTS: PREVENT

- Visual schedules/timetables
- Choice boards
- Calendars
- Classroom rules
- Social stories
- Traditional tools for organization
**PREVENTION: FIRST-THEN CHARTS**


Identifies sequence of a task (e.g., first eat dinner – then get a cookie)
**Prevention: Check lists**

Can help children focus and provides a sense of accomplishment
**PREVENTION:** **CALENDARS**

Help with organization and present concept of time in a concrete way
**Teach: Contingency Maps**

Depicts (behavior we do and don’t want to see)

- **Antecedent** (triggers for problem behavior)
- **Problem behavior** (stated in observable & measurable terms)
- **Consequences** that will follow if it occurs.
- A functionally-related (desired) alternative behavior and
- **consequences** that will follow if it occurs.
Teach: Contingency Maps
Teach: Visual Strategies for Emotions and Self-Management
**PREVENTION AND RESPOND:**

**CHOICE BOARDS**

Give student a sense of control - may select order of activities, select reinforcement, etc.
**Steps for Implementing Visual Supports**

*See Page 6 - Hume, K. & Smith, S. (2009)*

- **Step 1: Developing Visual Supports for Individual Learners**
  - Determine what information should be presented visually for the student (e.g., expected behavior in specific situations)

- Assess student’s comprehension skills to select a form of representation
  - objects
  - photographs
  - drawing or picture symbol
  - words
  - phrases or sentences
  - combination of the above
Step 2: Organizing Visual Supports for Individual Learners (i.e., location(s) for easy access, pair with materials, communication with relevant staff)

Step 3: Implementing Visual Supports for Individual Learners

A. Build on knowledge of optimal teaching methods for target student

B. Teach the student how to use the visual support by:
   - Showing the student the visual support;
   - Standing behind the student when prompting the use of the visual support (to ensure learner is looking at visual information, not at staff member);
   - Using only relevant language while teaching use of visual support;
   - Assisting the student in participating in activity/event with visual support (e.g., remaining in place in line while waiting for turn); and
   - Fading prompts as quickly as possible.

C. Use data collection system to record how learners use visual supports
Prevent and Teach:
Social Stories
After lunch we go to recess.

Sometimes we have another recess in the afternoon.
Sometimes recess is outside.

We can play on the playset or we can play soccer or basketball.
Everyone should keep their hands to themselves and play safely.

I will keep my hands to myself and play safely.
When the whistle blows, everyone should line up to go inside.

I will line up when I hear the whistle blow.
I will stay in line and walk with my class back to our classroom.

When everyone plays safely, recess can be fun!
Experience with using Social Stories with Children with Down Syndrome?
VIDEO MODELING

http://www.youtube.com/watch?v=JeKkHCWnxQQ&feature=player_detailpage
OTHER RESOURCES  (PAGE 6)

- 3-21 Foundation - ADVANCING INNOVATIONS IN EDUCATION & COGNITION FOR PEOPLE WITH DOWN SYNDROME - http://321foundation.org/education/learning-program-boston/


- Federation for Children with Special Needs (FCSN) Saturday March 4, 2017 annual Visions of Community conference for families of children with special needs and professionals who serve them.
A Green Light to Driving - one of ten videos part of the NDSS My Great Story Video Project

http://www.ndss.org
Tools to facilitate integration of therapy into Educational Programs

<table>
<thead>
<tr>
<th>Time and Activity</th>
<th>Pants down/up</th>
<th>Use toilet</th>
<th>Dullover top</th>
<th>Say <em>h</em></th>
<th>Reject task</th>
<th>Request &quot;more&quot;</th>
<th>Make requests</th>
<th>Choose Item</th>
<th>Palmar grasp</th>
<th>Diner grasp</th>
<th>Sidesit</th>
<th>Stand and feel</th>
<th>Two-hand carry</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:30 A.M. Arrival</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>I</td>
<td>help coat</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>bag</td>
</tr>
<tr>
<td>Bathroom</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>I</td>
<td>help wash</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jobs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>I</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Free play</td>
<td></td>
<td></td>
<td></td>
<td>I</td>
<td>three times</td>
<td>Ernie point</td>
<td>four times</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>materials</td>
</tr>
<tr>
<td>9:00 A.M. Opening</td>
<td>X</td>
<td></td>
<td></td>
<td>I</td>
<td></td>
<td>G</td>
<td>G</td>
<td>marker</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>four times toys</td>
</tr>
<tr>
<td>9:30 A.M. Story</td>
<td></td>
<td></td>
<td></td>
<td>G</td>
<td>G</td>
<td>X</td>
<td>G</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>one time</td>
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<tr>
<td>9:50 A.M. Gross motor</td>
<td></td>
<td></td>
<td></td>
<td>G</td>
<td>G</td>
<td>G</td>
<td>G</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>two times G</td>
</tr>
<tr>
<td>10:10 A.M. Bathroom</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>I</td>
<td>G</td>
<td>help wash</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>10:20 A.M. Fine Motor</td>
<td></td>
<td></td>
<td></td>
<td>I</td>
<td>G</td>
<td>paint</td>
<td>one time</td>
<td>marker</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>G</td>
</tr>
<tr>
<td>10:45 A.M. Snack</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>I</td>
<td>cookie</td>
<td>broken</td>
<td>one time</td>
<td>cup</td>
<td>after wearing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11:15 A.M. Bathroom</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>I</td>
<td>help wash</td>
<td>toothbrush</td>
<td>X</td>
<td>lotion</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clean up</td>
<td></td>
<td></td>
<td></td>
<td>I</td>
<td></td>
<td>Ernie</td>
<td>help coat</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11:30 A.M. Departure</td>
<td></td>
<td></td>
<td></td>
<td>G</td>
<td>G</td>
<td>G</td>
<td>G</td>
<td>G</td>
<td>G</td>
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<td></td>
<td></td>
<td>G</td>
</tr>
</tbody>
</table>
| Specials         | G            | G          | G            | G       | G           |               |               |             |             |            |        |                | X

Figure 7.2. Activities-skills matrix for Kristen. (X, provide instruction; I, as incidents arise; G, generalization opportunity.)
Have fun!