



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

**Therapro Saturday Seminar Series
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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**



"I know nothing about the subject,
but I'm happy to give you my expert opinion."

A great deal of
information. . .
And many
perspectives -

I hope you will
share examples
as we go!



Meaningful
Inclusion
for Students with Down Syndrome

A Resource Guide for Elementary Educators



by the Massachusetts Down Syndrome Congress
Education Task Force

**What do you know
about individuals
with Down
syndrome?
Working with
students with DS?**

**What do you want
to know about
individuals with
Down syndrome?
Working with
students with DS?**

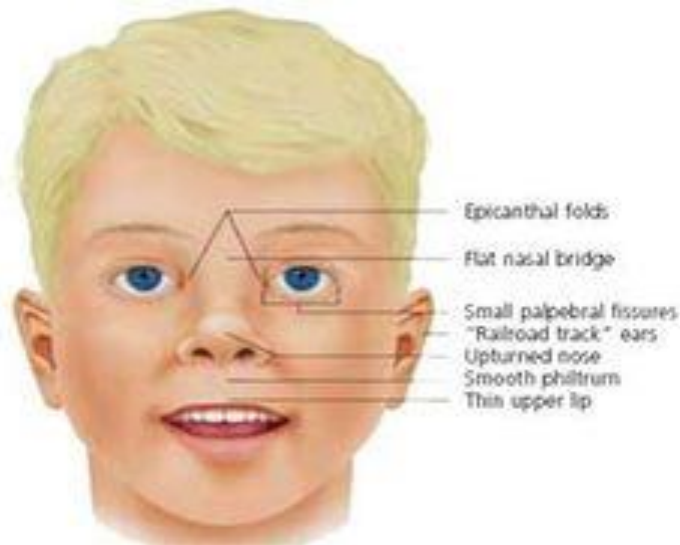
THE BASICS ON DOWN SYNDROME (P.2)

- 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



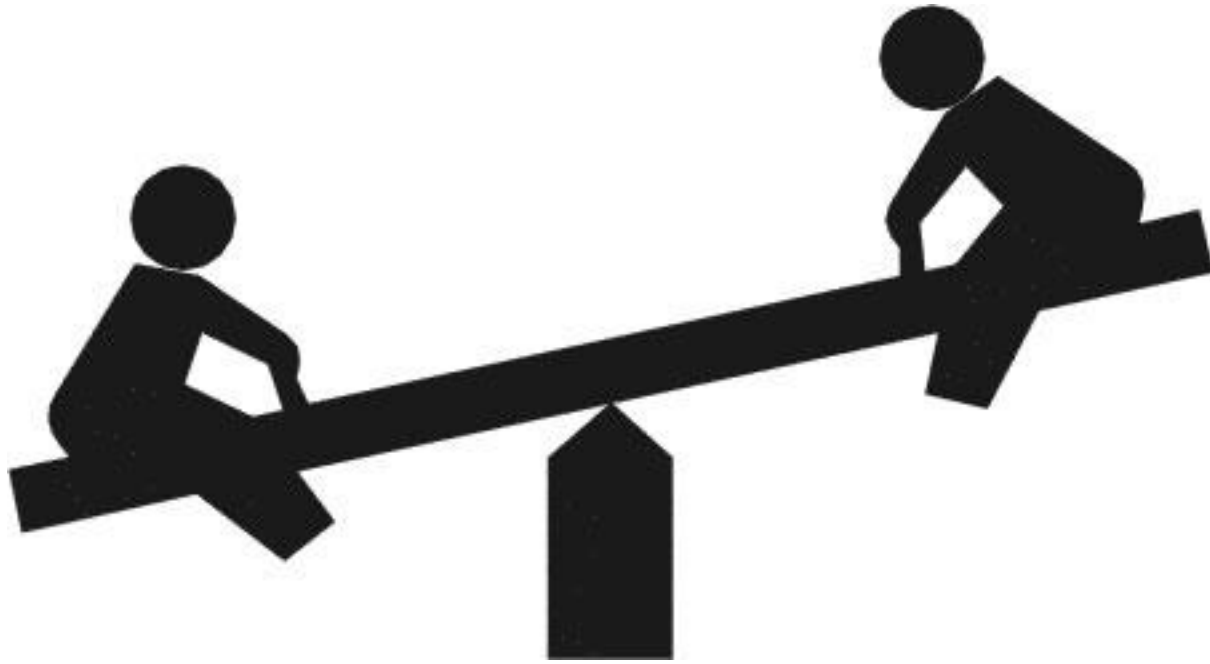
- Greater prevalence of Autism Spectrum Disorders (ASD) in individuals with Down syndrome – estimates up to 18%
- Life expectancy for people with Down syndrome has increased dramatically in recent decades – from 25 years in 1983 to 60 today.

- 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 *EXCPRESSIVE 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

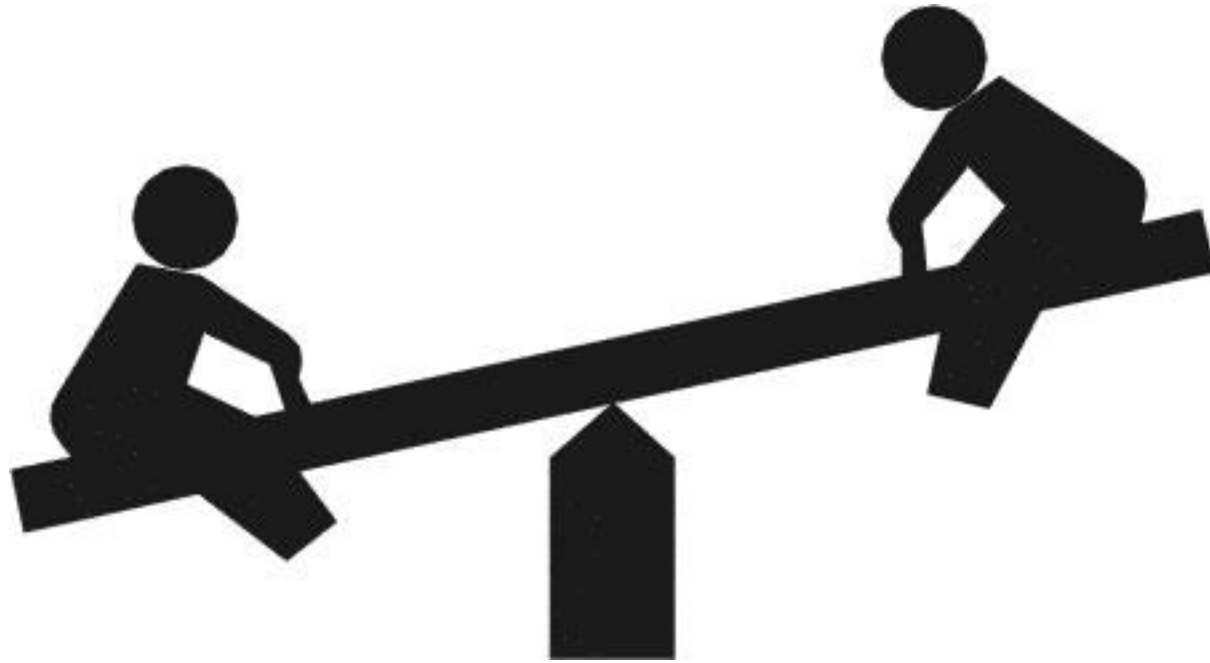
BEHAVIOR PROFILE ASSOCIATED WITH STUDENTS WITH DS (CONT.)

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.**

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!

Put a \checkmark in the box each time you raise your hand.



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A solid orange circle is located in the bottom right corner of the grid area.

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

	Identify Behavior	Evaluate Behavior	Reinforce Behavior
Self-Monitoring/ Recording	yes	no	no
Self-Evaluation	yes	yes <i>(quality)</i>	no
Self-Reinforcement	yes	yes	yes <i>(act on behavior)</i>

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




























Lunch

Goal: I will have good table manners.



1.		Sit down quietly.	
2.		Wait for everyone to get their food.	
3.		Use a napkin.	
4.		Talk with a soft voice.	
5.		Stay in my seat until I am finished.	

My Schedule & Check-In

	just right voice 	in my space <input type="checkbox"/>	yes 	no 
	just right voice 	in my space <input type="checkbox"/>	yes 	no 
	just right voice 	in my space <input type="checkbox"/>	yes 	no 
	just right voice 	in my space <input type="checkbox"/>	yes 	no 
	just right voice 	in my space <input type="checkbox"/>	yes 	no 
	just right voice 	in my space <input type="checkbox"/>	yes 	no 
	just right voice 	in my space <input type="checkbox"/>	yes 	no 
	just right voice 	in my space <input type="checkbox"/>	yes 	no 
	just right voice 	in my space <input type="checkbox"/>	yes 	no 

When I sit down in my seat I have to have good posture!

*Thank you Jen Roberts,
Walpole Public Schools*

1. Are my feet on the ground? _____

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



YES!!!



NO!!!

CLASSROOM SELF-EVALUATION SCALE

Name: _____
Class: _____

Date: _____
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
when the teacher was talking. | 4 | 3 | 2 | 1 |
| 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

Number of Periods				
6				
5				
4				
3				
2				
1				
Week of 10/31/16	Monday	Tuesday	Wednesday	Thursday



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

VISUAL SUPPORTS: RESEARCH

- 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)
 - Decreasing yelling and other distracting noises (Agosta, et al, 2004)
 - Disruptive, tantrum, off-task behavior (Clarke et al, 1999)
 - Off-task and prompt dependent behavior (Hall et al, 1995)

We are making a leap. . . not really a large one.

- **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 . . .



BOTTOM LINE RATIONALE. . .

“ 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*

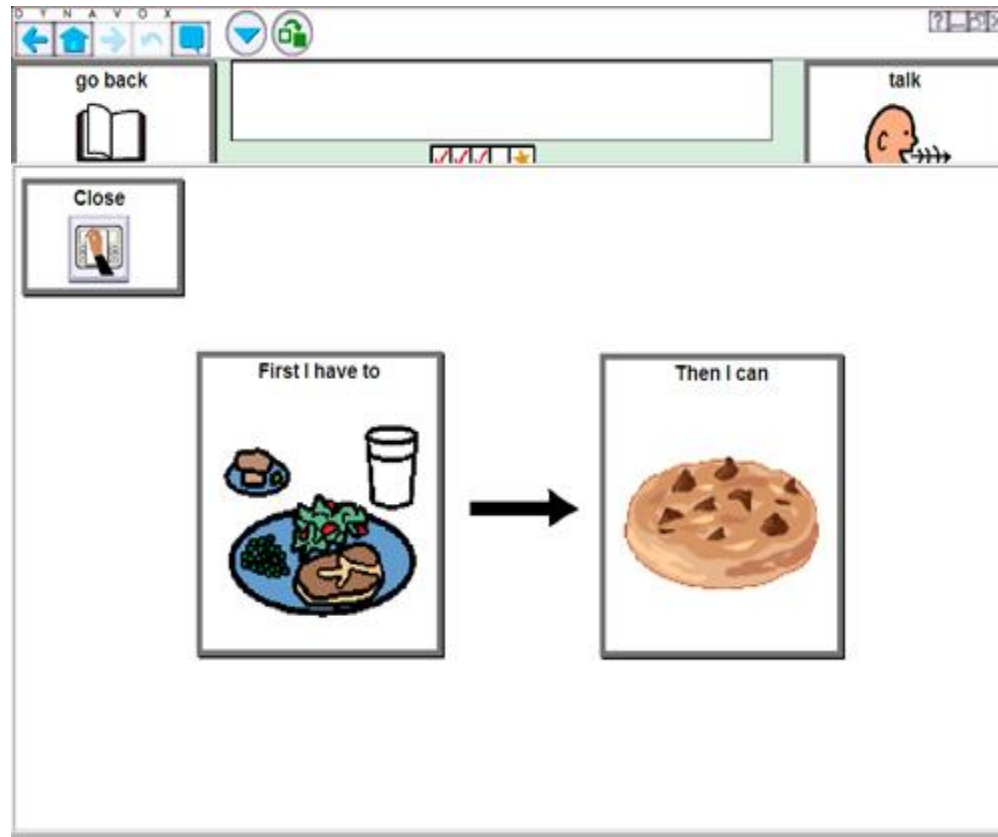
- Visual schedules/timetables
- Choice boards
- Calendars
- Classroom rules
- Social stories
- Traditional tools for organization



PREVENTION: FIRST-THEN CHARTS

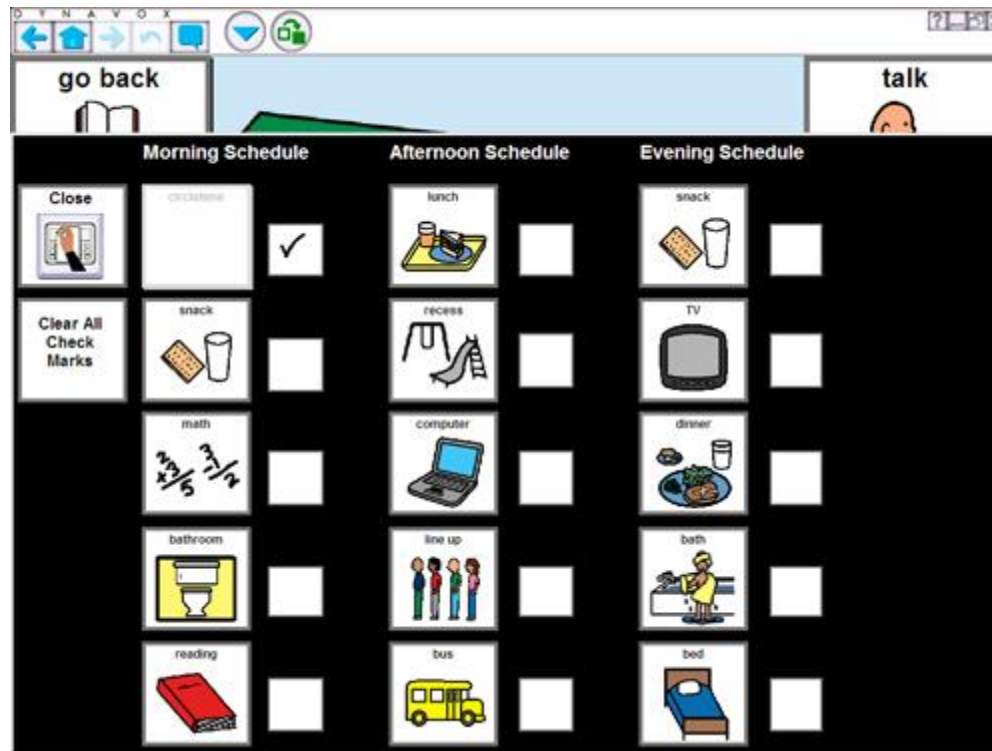
<http://itunes.apple.com/us/app/first-then-visual-schedule/id355527801?mt=8>

Identifies sequence of a task (e.g., first eat dinner – then get a cookie)



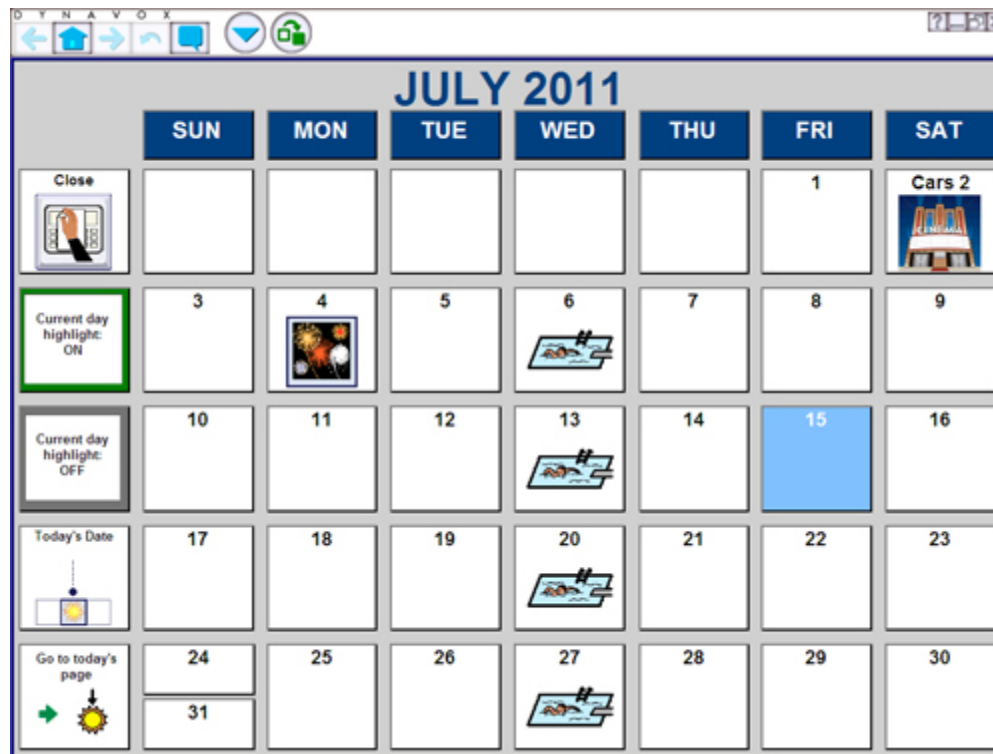
PREVENTION: CHECK LISTS

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

The screenshot displays the DynaVox Xpress Design Software interface. At the top, the title bar reads "DynaVox Xpress Design Software" and the menu bar includes "Undo", "Redo", "Modify", "Design Mode", "XpressDesktopEditor", "Tools", and "Help".

The main workspace contains two contingency maps for a user named "Johnny":

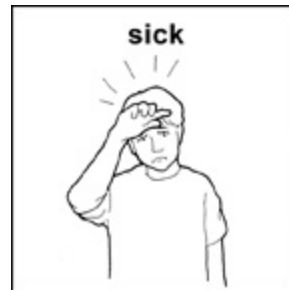
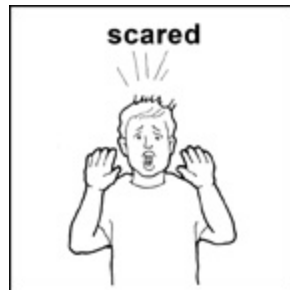
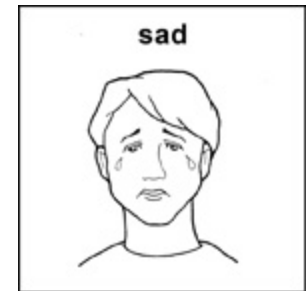
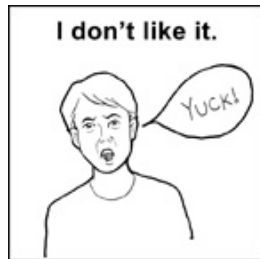
- Top Map:** An arrow pointing up-right is followed by a box labeled "sit at the table" with an illustration of a person sitting. This is followed by a plus sign (+), a box labeled "read book" with an illustration of a person reading, an equals sign (=), and a box labeled "DVD" with an illustration of a DVD player and disc.
- Bottom Map:** An arrow pointing down-right is followed by a box labeled "stand up" with an illustration of a person standing up from a chair. This is followed by a plus sign (+), a box labeled "crying" with an illustration of a crying face, an equals sign (=), and a box labeled "DVD" with a red prohibition sign over the DVD player and disc illustration.

On the right side of the interface, there are four vertical panels:

- Quickfires:** A red lightning bolt icon.
- Word Lists:** A checklist icon with a red checkmark.
- Core Words:** Three overlapping circles containing the words "we", "and", and "the".
- Home Page:** A red house icon.

At the bottom center, a status bar shows the date and time: "7/22/2011 8:00 AM".

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*

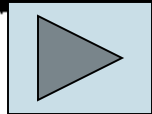
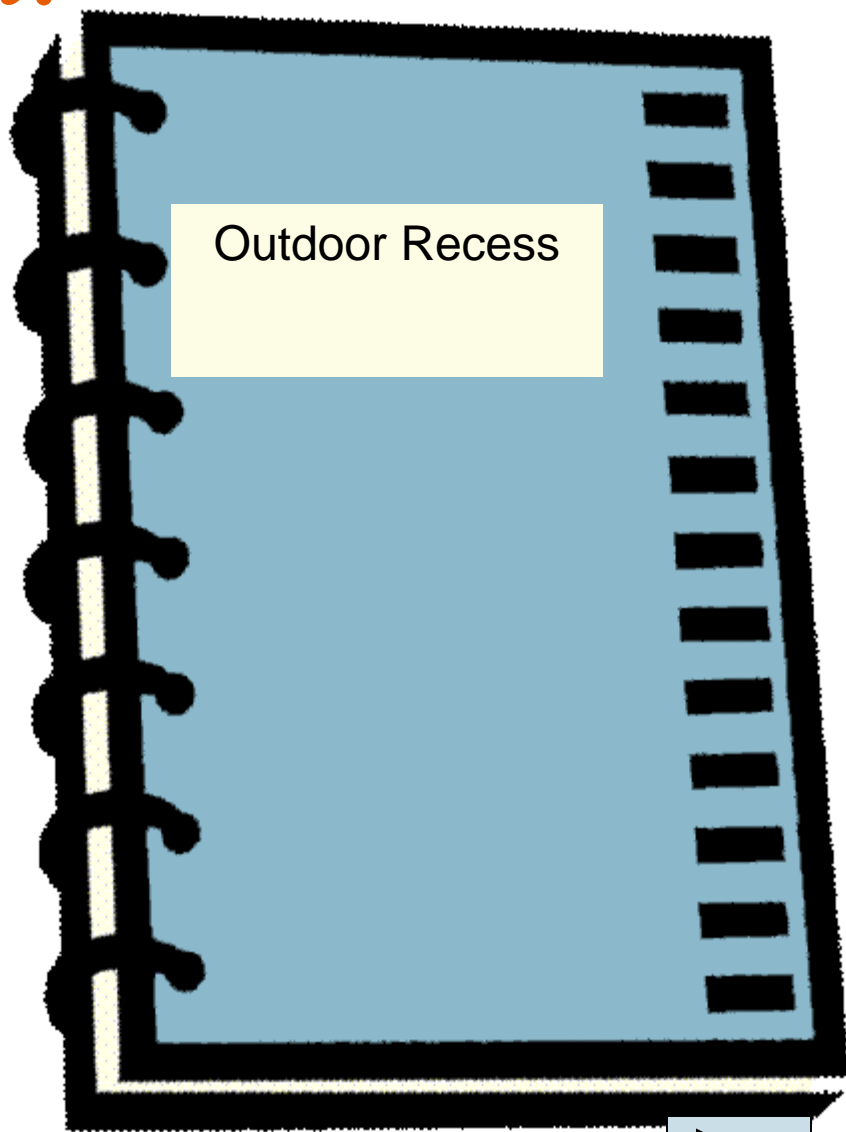
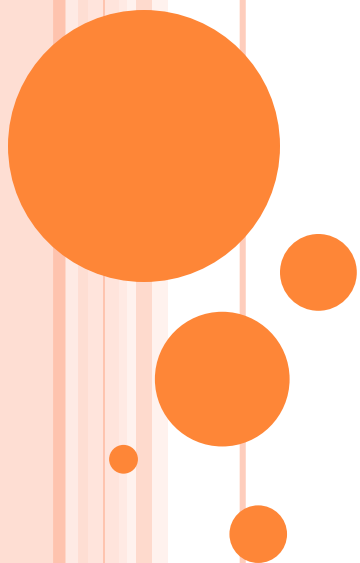
SEE PAGE 6 - HUME, K. & SMITH, S. (2009)

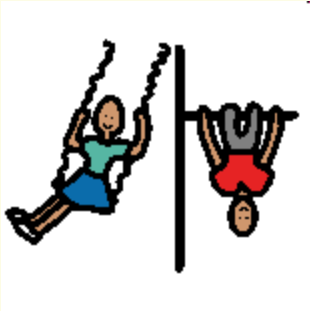
- *Step 1: Developing Visual Supports for Individual Learners*
- Determine **what** information should be presented visually for the student (e.g., expected behavior in specific situation)
- Assess student's comprehension skills to select a **form of representation**
 - objects
 - photographs
 - drawing 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)

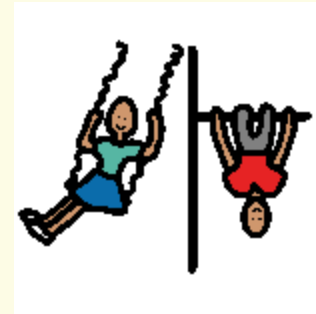
- ***Step 3: Implementing Visual Supports for Individual Learners***
 - A. Build on knowledge of optimal teaching methods for target student
 - B. Teach the student how to use the visual support by:**
 - Showing the student the visual support;
 - Standing behind the student when prompting the use of 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.



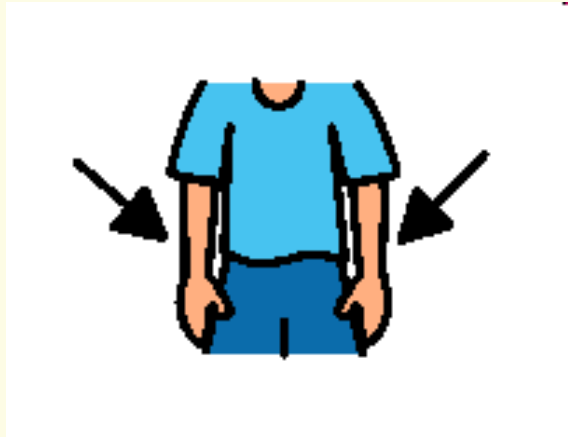
Sometimes we have
another recess in the
afternoon.



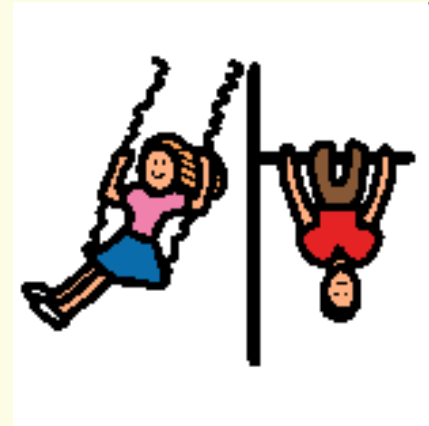
Sometimes recess is outside.



We can play on the playset or we can play soccer or basketball.

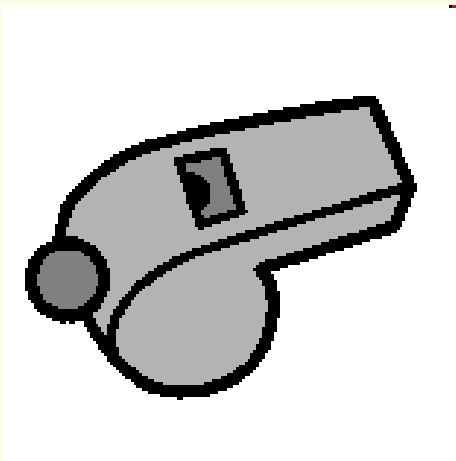


Everyone should keep their hands to themselves and play safely.

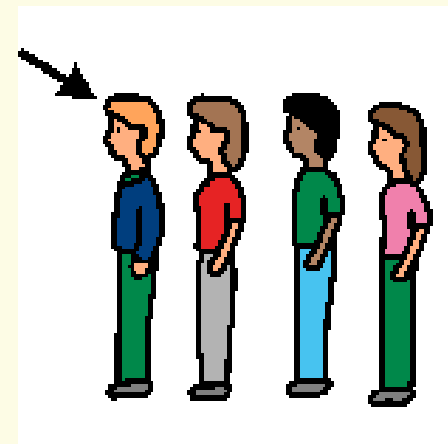


I will keep my hands to myself and play safely.



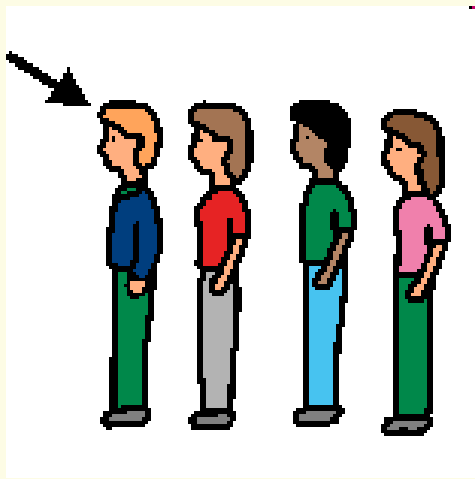


When the whistle blows,
everyone should line up to
go inside.

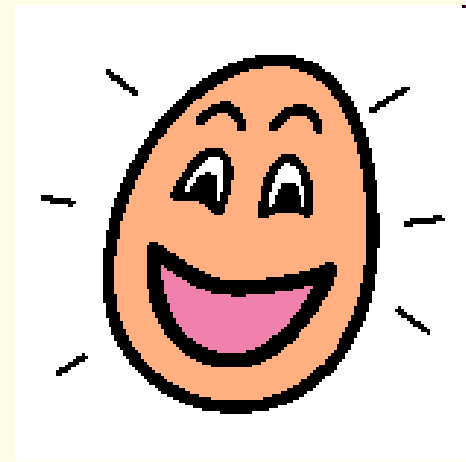


I will line up when I hear
the whistle blow.





I will stay in line and walk
with my class back to our
classroom.



When everyone plays safely,
recess can be fun!

A graphic of a book cover with a light blue background and a yellow border. The text 'The End' is centered in a large, black, sans-serif font. At the bottom left, the author's name 'By: Stephanie Dyer' is written in a smaller, black, sans-serif font.

The End

By: Stephanie Dyer

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/>
- [12th MDSC Annual Educators Forum, Tuesday, November 15, 2016, College of the Holy Cross, Worcester, MA](http://www.mdsc.org/events/EducatorsForum.cfm)
<http://www.mdsc.org/events/EducatorsForum.cfm>
- 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

Time and Activity	Objectives from IEP												
	Pants down/up	Use toilet	Pullover top	Say "hi"	Reject task	Request "more"	Make requests	Choose Item	Palmar grasp	Pincer grasp	Sidesit	Stand and kneel	Two-hand carry
8:30 A.M. Arrival			X	X	I		help coat						bag
Bathroom	X	X			I		help wash						
Jobs					I								materials
Free play					I	three times	Ernie, paint	four times (toys)			X	four times	toys
9:00 A.M. Opening				X	I		G	G	marker	X			
9:30 A.M. story					I		G	G			X	one time	
9:50 A.M. Gross motor					I	G	G				G	two times	G
10:10 A.M. Bathroom	X	X					help wash						
10:20 A.M. Fine Motor					I	G	paint	one time	marker	X			G
10:45 A.M. Snack			X	X	I		cookie cracker cheese	one time	cup	after wearing splint			materials
11:15 A.M. Bathroom	X	X	X		I		help wash		tooth-brush > brush				
Clean up							Ernie		lotion		X	one time	
11:30 A.M. Departure			G				help coat						G
Specials			G	G	G		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!

