



# Sensory Processing and Cornelia de Lange Syndrome

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# What is Sensory Processing? Why is It Important?

Individuals diagnosed with Cornelia de Lange Syndrome (CdLS) often experience difficulties with sensory processing. Providing occupational and physical therapy consultations at the CdLS Foundation's National Conferences has given us the opportunity to meet with and support individuals with CdLS and their families. During these meetings we have observed sensory-based behaviors in many of the children we have seen with CdLS. This realm of "Sensory" can be overwhelming to both parents and professionals, including unfamiliar terminology, unusual interventions, and sometimes differing interpretations of how sensory disorders manifest into behaviors. Though not all difficult behaviors are due to a Sensory Processing Disorder (SPD), some are. A clear understanding of Sensory Processing Disorder is needed to make the delineation between sensory-based and non-sensory-based behaviors and, ultimately, provide the appropriate interventions.

This Power Point presentation is a basic overview of "Sensory Processing Disorders." It can be used as an educational starter or a refresher course for parents, caretakers, teachers, paraprofessionals, and even therapists—in other words, just about anyone involved with a child who is exhibiting sensory-related behaviors. In it you will find definitions of Sensory Processing Disorder (SPD) and associated terminology, assessment tools that occupational and physical therapists may use to evaluate sensory concerns, the Behavioral Response Continuum (according to Dunn's *Sensory Profile*), a review of therapeutic strategies and interventions, and general sensory supports for home and the classroom.



# What is Sensory Processing? Why is It Important? *Con't.*

As therapists, we believe accurate evaluation and treatment of sensory issues is imperative for a child to reach his or her optimal level of functional independence. In assessing possible sensory issues, we therapists rely heavily on input and follow through from many of those involved in caring for the child. Parents, professionals, and paraprofessionals who have a core understanding of sensory issues are best equipped to work together as a team and help a child with sensory issues to get the appropriate therapy and programming that they need.



\* Note: Sensory Processing Disorder (SPD) is not a diagnosis acknowledged by the general medical community; SPD is still not included in the most recent version of the DSM.



## What is Sensory Processing and Why Is It Important?

- Generally speaking, sensory processing is how the brain takes in and manages input from all the senses.
- - Besides dealing with incoming information from the five traditional senses of touch, sound, sight, taste, and smell, sensory processing theory also deals with two other powerful senses:
  - 1) Vestibular (located in the inner ear and contributes to balance, movement, and the awareness of where the head and body are in space), and
  - 2) Proprioceptive (located in the joint/muscle receptors and provides awareness of where our body parts are in space).



## What Is Sensory Processing and Why Is It Important? (continued)

- Through the sensory systems, people continually take in and recognize, or process, sensory information from their environment and bodies.
- Their nervous systems sort through this information and determine if, or how, they should respond.
- Usually the nervous system either filters out unimportant sensory input, or provides enough internal “regulation” to maintain focus and attention in spite of these external influences.

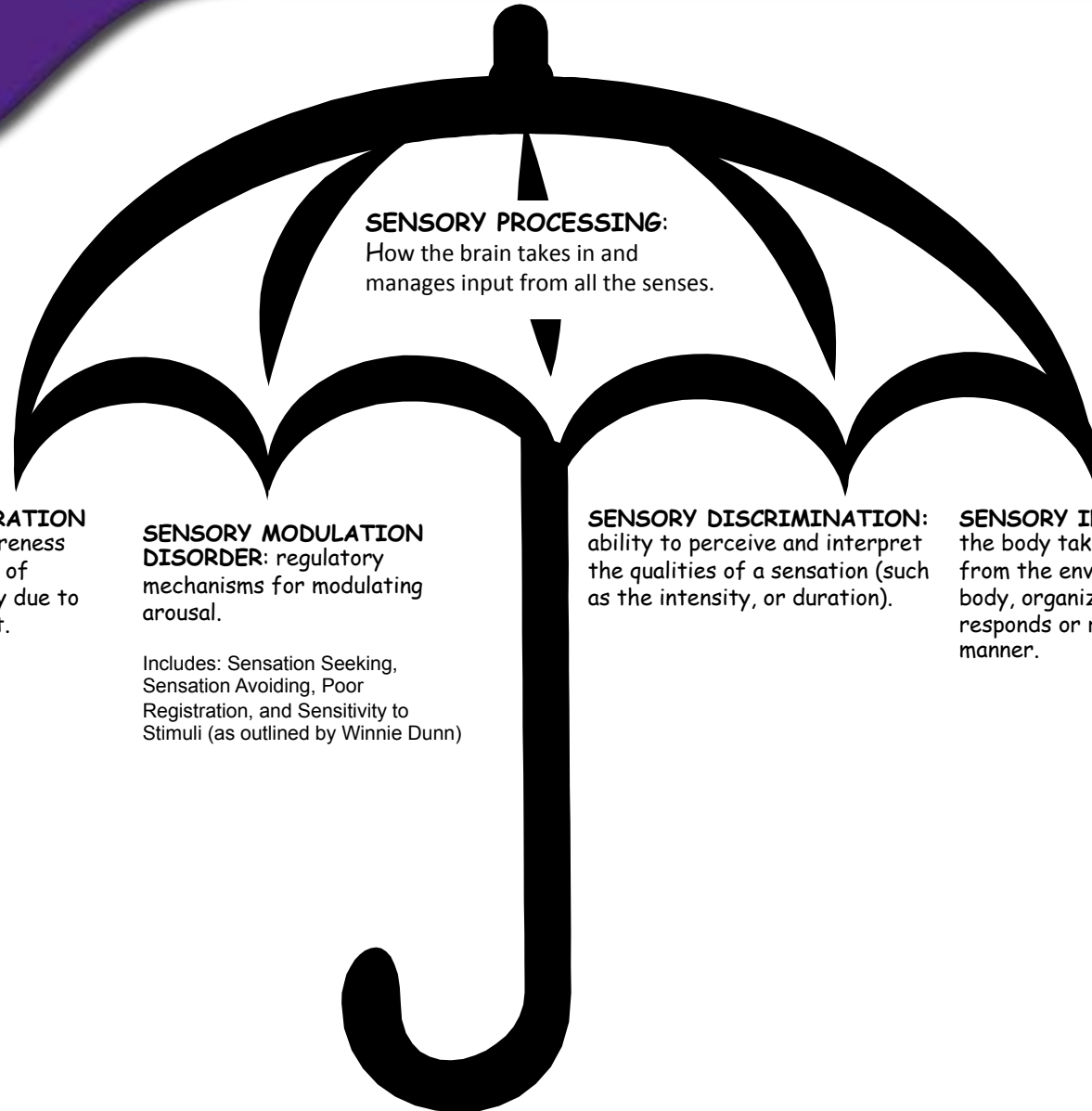


# What Is Sensory Processing and Why Is It Important? (continued)

- Four subcategories comprise the umbrella term “Sensory Processing.” These are:
  - Sensory Registration - The awareness or lack of awareness of sensory input; usually due to a neurological deficit.
  - Sensory Discrimination - The ability to perceive and interpret the qualities of a sensation, such as intensity and duration; often related to body awareness or lack thereof. Includes visual and auditory processing, or how the brain *interprets* sensory information.
  - Sensory Integration - How the body takes in sensory input from the environment and one’s own body, organizes it, and then responds or reacts in an effective manner. Deficits in this area are often related to difficulty with bilateral coordination, crossing the midline of the body, and motor planning.
  - Sensory Modulation - How the brain interprets sensory information as dangerous or not. Includes hypo-responsiveness and hyper-responsiveness (sensory seeking and sensory avoiding), as well as the consistency of one’s arousal state. This area is often related to unusual or unwanted behavioral patterns that can be a child’s response to how much he/she registers sensory input.



# Sensory Umbrella



**SENSORY PROCESSING:**  
How the brain takes in and manages input from all the senses.

**SENSORY REGISTRATION DEFICITS:** The awareness or lack of awareness of sensory input; usually due to a neurological deficit.

**SENSORY MODULATION DISORDER:** regulatory mechanisms for modulating arousal.

Includes: Sensation Seeking, Sensation Avoiding, Poor Registration, and Sensitivity to Stimuli (as outlined by Winnie Dunn)

**SENSORY DISCRIMINATION:** ability to perceive and interpret the qualities of a sensation (such as the intensity, or duration).

**SENSORY INTEGRATION:** How the body takes in sensory input from the environment and one's own body, organizes it, and then responds or reacts in an effective manner.



# Results of Sensory Dysfunction

- Sensory processing problems can cause difficulty with behavior, attending, movement, perception, and coordination.
- The four types of sensory dysfunction are:
  - Sensitivity to Stimuli: Unable to filter out extraneous sensory stimulation, and so are more sensitive to it.
  - Sensation Avoiding: Avoid sensory stimulation and withdraw or become distracted by it.
  - Sensation Seeking: Unable to maintain a steady-state of arousal for participation in class, causing them to seek out sensation or be unaware of it.
  - Poor Registration: Unaware of how their body interacts with the environment.





# Sensory Modulation

- This subcategory of SPD is most often the area assessed when a child exhibits unusual or atypical, non-productive behavioral patterns.
- Sensory Modulation involves adjusting to the environment and maintaining an appropriate arousal level for what is required of oneself at the moment.
- It involves regulating and organizing the amount and type of responses to tactile and gravitational sensations in adaptive ways.



# Gravitational Modulation

- Children over-sensitive or insecure about their movement abilities will not let their feet leave the ground, avoid playground equipment, go down steps one at a time, and dislike being picked up.
- Children under-sensitive may crave movement by jumping, hanging upside down, swinging, and climbing.
- Gravitational modulation involves the working together of two sensory systems: vestibular (movement in space) and proprioception (pressure to joints and muscles).



## Tactile Modulation

- Children who are tactile defensive are alert to avoid things they perceive as dangers. They may avoid touching, messy play, some fabric textures and clothing seams/tags, and certain foods.
- Children who are under responsive to touch may get hurt easily due to not being aware enough of their environment. They may bump into people, crave touching, ask for hugs, or stuff food in their mouths.



## The Sensory Profile

- Children with significant sensory problems may be seen by Occupational Therapy for diagnostic testing.
- During testing, caregivers are given a rating scale to classify the child's particular sensory pattern. One such scale is the *Sensory Profile (SP)* by Winnie Dunn.
- The SP is a standardized classification system that describes a child's behavioral response as acting in accordance with or acting to counteract their sensory thresholds.
- Dunn's model proposes thinking of sensory processing based on a child's neurological thresholds and behavioral response patterns.



# Sensory Thresholds

- Low Threshold:
  - Nervous system responds frequently to stimuli because it takes very little sensory input to reach the threshold and activate the sensory system.
- High Threshold:
  - Nervous system does not respond to stimuli often because it takes a lot of input to reach the threshold (system is often dormant or unresponsive).
- Children are most functional when they can achieve a balance so they can be alert to selected stimuli, while screening out other stimuli.



# Behavioral Responses

- Behavioral responses to sensory stimuli can be described as acting in accordance with or counteracting the threshold.
- Acting in accordance with threshold:
  - Is when the child responds more passively to stimuli.
- Acting to counteract the threshold:
  - Is when the child actively opposes the threshold.



## Categories

- Based on the mix of sensory thresholds and behavioral responses, Dunn separates children into one of four categories:
  - Poor Registration
  - Sensitivity to Stimuli
  - Sensation Seeking
  - Sensation Avoiding



## Children with Poor Registration

- Have high neurological thresholds with tendency to act in accordance with those thresholds.
- Appear uninterested, have low energy levels, often seem tired, and have a flat affect.
- Appear apathetic and are not interested in perceiving the sensation to generate responses.
- May have inadequate neural activation to support sustained performance in the classroom.





## Children with Poor Registration *con't*

- Benefit from experiencing more sensory information so they meet their thresholds, notice the sensation, and respond.
- Need enhancing contrast of stimuli and contextual clues, like using contrasting colors on papers, decreasing predictability of routines, or adding multisensory experiences to learning.



## Children with Sensitivity to Stimuli

- Have low neurological thresholds and a tendency to act in accordance with those thresholds.
- Tend to be distractible and may be hyperactive. They direct their attention to the latest stimulus they receive.
- May have overactive neural systems that make them hyperaware of every stimulus and do not have the ability to habituate to these stimuli.
- Benefit from receiving tactile input that supports organized patterns of information to the brain without generating more arousal.
- May need firm touch-pressure on the skin, predictable patterns of visual and auditory cues, and routines.



## Sensation Seeking Children

- Have high neurological thresholds with a tendency to act to counteract these thresholds.
- Tend to be active, excitable, and continuously engaged in their environments. They add sensory input to every experience, such as making noises while working, rubbing objects, fidgeting, chewing things, wrapping feet around furniture to increase sensory input, and appearing unaware of safety issues.



## Sensation Seeking Children *con't*.

- May have inadequate neural activation, but are driven to meet their thresholds.
- Need to observe what types of sensation they crave, and incorporate those into daily routine so their thresholds can be met. Letting them load up on that sensory input helps them stay alert. Children who rock and fidget need vestibular input; children who rub on or handle objects need tactile input.



## Children with Sensation Avoiding

- Have low neurological thresholds for sensation with a tendency to act to counteract these thresholds.
- May engage in disruptive behaviors because meeting their sensory thresholds occurs too often; this is uncomfortable or frightening to them.
- Cope by preventing these events, by either withdrawing or engaging in an emotional outburst that lets them get of the situation.



## Children with Sensation Avoiding *con't*.

- Are resistant to change, and might create rituals to control their environment and avoid sensations.
- Need intervention honoring their need to reduce sensory input. To avoid power struggles, slowly introduce a wider range of sensory experiences for them to habituate.
- Need changes introduced slowly, allowing them time to process. This will help them to gradually broaden their sensory experiences.



## Behavioral Response Continuum

<b>Neurological Threshold Continuum</b>	<b>Acting in ACCORDANCE With Threshold</b>	<b>Acting to COUNTERACT Threshold</b>
<b>High (habituation)</b>	<i>Poor Registration</i>	<i>Sensation Seeking</i>
<b>Low (sensitization)</b>	<i>Sensitivity to Stimuli</i>	<i>Sensation Avoiding</i>



## Other Tools to Assess Sensory Dysfunction

- The Sensory Processing Measure (SMP)
- Sensory Integration Inventory-Revised, for Individuals with Developmental Disabilities
- Sensory Integration and Praxis Test (SIPT)





## Sensory Diets

- After diagnostic testing, children being seen by an occupational therapist (OT) may be given a sensory “diet” that is generally geared toward meeting their sensory needs.
- A sensory diet is a plan for providing specific sensory activities to children in order to prevent behaviors that often accompany dealing with their sensory issues. This diet can be used either according to a strict schedule or at frequent intervals as needed.
- Most children do not require an individual-specific sensory diet, but many children can benefit from the basic use of sensory supports in the classroom.



# Sensory Diet: Example 1

	SUGGESTED ACTIVITIES	TAKE A BREAK AND DO THIS ACTIVITY BETWEEN WORK OR BEFORE A STRESSFUL TASK	DO THIS ACTIVITY DURING WORKTIME AND/OR A STRESSFUL TASK
<b>Vestibular and proprioception Sensory Break</b> (movement and deep pressure/heavy work)	Perform the following 1-3x/day: 1) Jump on trampoline for 2-3 minutes (always followed by) 2) deep pressure activity (Down Dog Position, Push Wall, crab/bear walk, sandwich)	1-3x/day in OT room	
<b>Vestibular and proprioception Classroom Intervention</b> (movement and deep pressure/heavy work)	See attached list of sensory activities for the classroom	X	X
<b>Tactile (touch)</b>	Allow "fiddle" object in classroom as needed		X
<b>Visual</b>	Decrease visual distractions during difficult times		X
<b>Auditory</b>			



NOTE: The sensory activities included in a sensory diet are intended to help the student obtain the best possible level of alertness in order to improve task focus and manage stress. These activities should not be used as contingencies to shape behavior. Rather, these activities should be incorporated in the student's day to day as part of his/her routine to provide the needed sensory input before the student displays inappropriate behavior.

<b>Time</b>	<b>Key Event In the Day</b>	<b>Sensory Diet Activity</b>
7:00	Wake Up	Wake Up Routine
7:30	Breakfast	Sit on Cushion to Eat
8:15	Bus to School	
8:30	Arrival at School	Take down chair from table/desk; bounce while sitting on ball with help from support staff
	Circle Time	Sit on cushion for circle time
	Morning Work	Jump on trampoline before sitting at seat for morning work
11:00	Special	Ride scooter from class to special
12:00	Lunch	
12:30	Recess	Pull wagon with outdoor toys to recess, climb playground equipment, swing on swing
	Afternoon Work	Stand at a table for first part of afternoon work to remain aroused/alert
3:00	Bus Home	
3:15	Arrival Home	Motor Break: outside play
	Homework	Play-doh or finding puzzle pieces in rice or beans before homework
6:00	Dinner	
7:30	Bedtime	Bedtime Routine
8:00	Lights Out	



## Sensory Diet: Example 2

### **WAKE UP ROUTINE:**

- Open blinds, turn on lights
- Massage back, arms, legs with lotion before getting dressed
- Brush teeth with vibrating toothbrush

### **BED TIME ROUTINE:**

- Bath
- Massage with lotion before putting on pajamas
- Brush teeth with vibrating toothbrush
- Wrap up like a hot dog in a blanket, then unroll
- Lights out



## Sensory Support Activities for Home & School

- Sensory Supports are activities that facilitate a child's ability to organize sensory information, thus enhancing the ability to perform and succeed in a specific setting.
- Regular use of sensory supports may assist children in regulating and organizing the sensory input they receive to help them reduce negative reactions and promote positive responses.
- Sensory supports may prevent some acting out behaviors and help improve attention.



## Sensory Support Activities for Home & School *con't.*

- It is important to teach children socially appropriate ways to get the sensations they crave or avoid what they dislike, thus decreasing unwanted attention and possibly ridicule. Suggestions include:
  - Use small earplugs instead of covering his ears or bolting during a loud assembly.
  - Chew gum instead of mouthing items or biting his shirt or nails.
  - Wear sunglasses instead of avoiding bright lights.
  - Doodle or play with a fidget toy instead of pulling at hair.



# Types of Supports

Types of support can include:

- Visual
- Auditory
- Restructuring of the classroom or home environment







# Visual Supports

Include:

- Posted schedules
- Routines
- Line markers on floors





# Auditory Supports

Include:

- Simple directions
- Supplement with pictures





# Restructuring the Environment

- *Motor breaks* can be planned, as needed, or both.
- A *safe spot* is a quiet and inviting place for the child to calm.
- *Sensory Motor Equipment* can include:
  - Chair cushions (Move-N-Sit, Dynadisc, etc)
  - Ball chairs
  - T-stools
  - Mini trampolines
  - Fidgets





## Timing of Motor Breaks

- Use scheduled or planned motor breaks as part of daily routine.
- Schedule motor breaks logically between transitions.
- Schedule motor breaks before and after prolonged attending.
- Picture schedules may promote improved understanding of what to expect and when.



# Ideas for Planned Motor Breaks

- Get a drink of water
- Take a bathroom break
- Carry a weighted object such as a stack of books to a shelf
- Stack chairs after an activity
- Climb on jungle gym/playscape during recess
- Climb up/down stairs in a loop
- March in the hall from class to special
- Run a lap in the gym before class or lunch starts
- Pull a wagon (filled with outdoor toys) to recess
- Ride a scooter between special and class
- Jump on a mini-trampoline between activities
- Crawl through a tunnel from the bookshelf to desk





## Ideas for Spontaneous Motor Breaks

- Allow children to do movements like these at their desks to help them focus:
  - Push palms together
  - Armchair sit-ups
  - Use hand fidgets items
  - Chew gum
- Allow child to engage in purposeful movement within the classroom, such as to sharpen pencil or get materials.
- Assign a word, letter or number to the class. When students need a sensory break, call out the word, letter or number. Class then does a prearranged activity, such as standing up and jumping, jumping jacks, standing up and sitting back down, etc.



# Classroom Environment & Supports

- Individualize
  - Provide preferential seating for those with poor attention span, poor visual skills, poor auditory processing.
  - Decrease visual distractions when possible.
  - Give alternative seating opportunities for those with difficulty sitting still or staying in their seat:
    - T-Stools
    - Balls
    - Seat cushions
    - Rocking chairs





## Classroom Environment & Supports *con't.*

- Modify schedules
  - Create visual schedule at student's reading level.
  - Post in accessible spot or at the desk.
  - Add additional motor breaks specifically tailored to student's needs.
- Safe and Secluded Area
  - Make a safe spot for children to withdraw to if needing to calm down.
  - Do not use as a time out spot.





## Classroom Environment & Supports *con't.*

- Area should be secluded and inviting, and may include:
  - Hand fidgets
  - Bean bag chair
  - Head phones with tapes
  - Books
  - Lowered lighting
  - Weighted blanket or lap pad
  - Rocking chair
  - Soft stuffed animal
  - Relaxing music or environmental sounds
  - Aromatherapy/pleasant scents
- Be aware of how to provide more specific sensory supports for different purposes.





# Sensory Activities for Calming, Alerting and Maintaining Alertness

## General Terms:

- *Proprioceptive*
  - Heavy work or deep pressure activities
  - Felt by the body' s joints
- *Vestibular*
  - Fast or slow movement activities
  - Circular (spinning) pattern or linear (straight line) pattern
  - Perceived by the inner ear mechanisms
- *Tactile*
  - Light moving touch or feeling textures
  - Felt by receptors in the skin



# Calming Activities

General Principles (the line between some activities overlaps)

- *Proprioceptive Activities*
  - Provide heavy compression to joints and muscles
  - These generally produce a calming effect
- *Vestibular Activities*
  - Provide slow, linear movement
  - Are thought to produce a calming effect
- *Tactile Activities*
  - Provide constant pressure or neutral warmth
  - Are thought to produce a calming effect



## Calming Activities *con't.*

- Children may benefit from participating in 3-5 minutes of these types of activities to help calm them when:
  - they have been upset or agitated
  - are doing self-stimulatory or destructive behaviors
  - when they need to focus and be calm





## Calming-Proprioceptive /Heavy Work Examples

- Carry a weighted backpack or wear a weighted vest
- Stack chairs
- Wheel-barrow walk or crawl
- Push a cart or pull a wagon filled with books or other objects
- Deep pressure to shoulders/hips/back
- Hang on bars, climb ropes, pull on theraband
- Joint compression, crawling on hands and knees, leaning against wall
- Chair or wall push-ups, climbing stairs, marching down hall
- Pushing palms together or on table, leaning on table, chair sit-ups
- Balance a bag of rice or beans on head (held on by a hat)
- Press or hammer a peg into a pegboard
- Climb jungle gym or playscape
- Sit with weighted lap cushion or weighted blanket
- Wrap up in a “CuddleLoop” (stretchy cloth band)



## Calming-Repetitive Slow Vestibular Activities

- Slow rocking in a rocking chair, on hands and knees, or in a lap
- Slow rocking in a hammock surrounded by pillows
- Slow swinging or gliding
- Body rocking or swaying to slow, relaxing music
- Slowly, repetitively erasing a chalkboard or washing a dry-erase board



## Calming-Tactile Pressure Activities

- Sitting in a beanbag chair/sandwiching between cushions
- Wrapping in a blanket or snuggling in a sleeping bag
- Rolling in a mat or rug and wiggling out of it
- Giving bear hugs
- Wearing Lycra body/chest suit
- Using a rolling pin, massage rollers or vibrator on back
- Curling up in a box with pillows
- Sitting with a weighted lap cushion or covered by a weighted blanket
- Deep pressure lotion rubbing to arms, legs or shoulders
- Wearing a Stabilizing Pressure Input Orthosis (SPIO) Suit



# Stimulating Activities

## General Principles:

### *Vestibular Activities*

- Provide quick movement opportunities
- Are thought to provide a stimulating effect

### *Tactile Activities*

- Provide light moving touch or a variety of textures, experiences
- Are thought to be stimulating
- Have the added effect of assisting in desensitizing children who are tactile defensive

It may be beneficial for children to participate in three to five minutes of these types of activities:

- Prior to requiring him to sit and attend/focus for extended periods of time
- Coupled with regular movement breaks between activities





## Stimulating-Vestibular (Quick Movement) Activities

- Jumping on a mini-trampoline
- Spinning on a sit 'n spin
- Sliding on a slide
- Going up and down on a see-saw
- Using a scooter board to self-propel or be pulled on
- Fast rocking in a rocking chair
- Skipping or running activities
- Balancing on a rocker board
- Rolling in a padded barrel
- Playing hopscotch



## Stimulating-Tactile Activities

- Finding objects hidden in a bucket of rice or beans
- Play-doh play
- Water play
- Making letters in shaving cream
- Playing at a sand table
- Finger-painting
- Rubbing lotion on the hands
- Making/playing with goop or gak
- Sand box play



## Maintaining Alertness

- Allowing a low level of subdued movement during periods of prolonged focusing may help child maintain arousal level and attend.
- Engaging in small movements that provide subtle self-stimulation may help prevent episodes involving their need to seek out more extreme movement that can cause disruption.
- May help avoid the passivity of habituating too much to their sitting still and zoning out or daydreaming.
- Use a seat cushion, squeeze a hand fidget, sit on a T-stool, chew gum.



## Maintaining Alertness *con't*.

- Think of using sensory supports to maintain alertness.
- Use calming activities to decrease arousal of kids who are overly stimulated or “running high” (How Does Your Engine Run? Program).
- Use stimulating activities to increase alertness when feeling tired or “running on low.”
- Make kids aware of which way they are feeling and slowly teach them supports they can use to regulate themselves.



## Signs to End or Decrease Use of a Sensory Support

**Be careful to avoid providing more stimulation than a child can process. If any of the following signs occur, decrease the amount or intensity of the experience:**

- Sweating
- Sleepiness
- Pale or flushed face
- Rapid respiration and heart rate
- Slow respiration and heart rate
- Loss of bladder or bowel control
- Nausea/vomiting
- Very significant overactivity or underactivity from previous levels



# Equipment

- Borrow equipment to try out in the classroom.
- During longer movement breaks between activities, a child may be brought to the OT, physical therapy (PT), or motor room to use equipment if the room is not in use.
- Most OT and PT rooms have a variety of equipment that can be used or borrowed, which may include items like:
  - Balls
  - Bolsters
  - Trampolines
  - Swings
  - Balance beams
  - Rocker boards





## Occupational and Physical Therapy Team Members

- Your OT and/or PT is available to consult with you on whatever equipment you want to try.
- S/he can give you equipment recommendations on items you can order (for classroom or home).
- S/he may assist you with ideas for room set-up or transition scheduling.
- S/he can help in-service assistants/aides in use of sensory-related equipment in the classroom,
- S/he can provide general sensory support guidelines.
- S/he is here to help empower you to provide sensory supports to your learners and help make sense out of sensory issues!



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