A Sensory-Based Approach to Sotos Syndrome

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About Me

Educational

- Bachelor's Degree in Human Development and Family Studies at Penn State University
- Master's Degree in Occupational Therapy at Salus University

Professional

- Occupational therapist with 7+ years of experience (outpatient, schools, sub-acute rehab, inpatient rehab)
- Full time OT at St. Christopher's Hospital for Children in their outpatient clinic in Abington, PA
- Per diem OT at Magee Rehabilitation Hospital in Philadelphia, PA

Personal

- Hiking, the outdoors, traveling, spending time with family & friends, finding the best pizza & pastries in the city

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Learning Objectives

1. Gain a brief understanding of what occupational therapy is and the skills it targets.
2. Define sensory processing, identify the sensory systems, and learn how differences in sensory processing can be presented.
3. Through evidence-based practice, review the relationship between sensory processing and Sotos syndrome.
4. Determine what supports and strategies can be used to help a child with Sotos meet their sensory needs.
5. Through case study, learn about the role parents/caregivers can play in helping their child with Sotos meet their sensory needs.

Occupational Therapy

Occupational therapy:

- According to AOTA (American Occupational Therapy Association), “OT enables people of all ages to participate in daily living. Occupational therapy intervention uses everyday life activities (occupations) to promote health, well-being, and your ability to participate in the important activities in your life.”

Occupations:

- Professional job, role at home, role in the community, etc.
- Kids have occupations? **To be kids!**

OT targeted skills:

- Fine and gross motor
- Visual perception/visual motor integration
- Self-care
- Cognition
- Social-emotional
- Executive functioning
- Sensory processing

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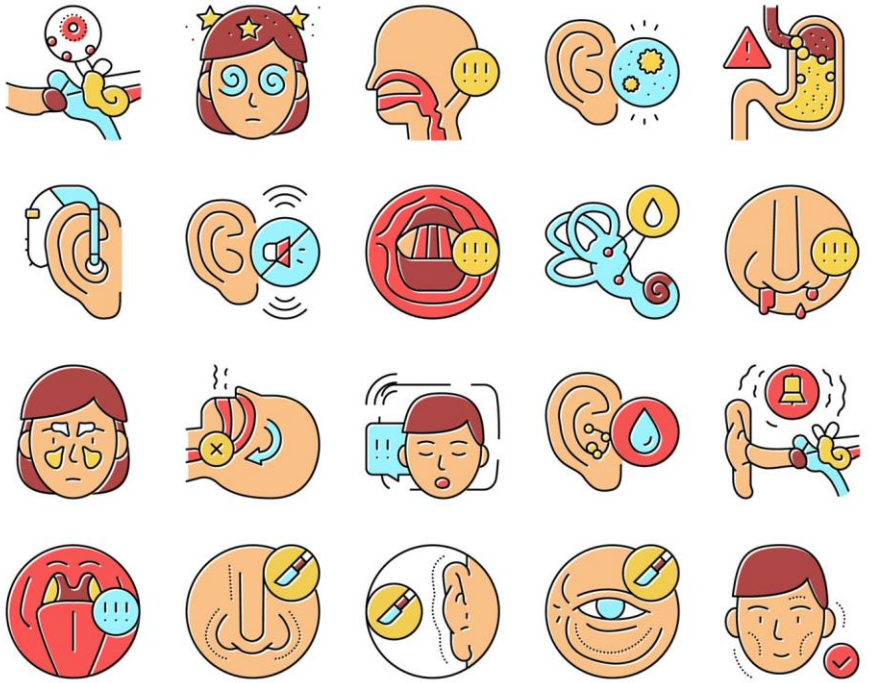
Visualization



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Sensory Systems

01 Visual
Our visual sense helps us to interpret what we see.

02 Auditory
Our auditory sense helps us to interpret what we hear.

03 Olfactory
Our olfactory sense helps us to interpret what we smell.

04 Gustatory
Our gustatory sense helps us to interpret what we taste or eat/chew.

05 Tactile
Our tactile sense helps us to interpret what we touch.

06 Vestibular
Our vestibular sense helps us to interpret our movements, including balance & orientation in space.

07 Proprioception
Our proprioception sense helps us to interpret our muscles & joints (aka body awareness)

08 Interoception
Our interoception sense helps us to interpret our basic primary functions, including hunger, toileting, & breathing.

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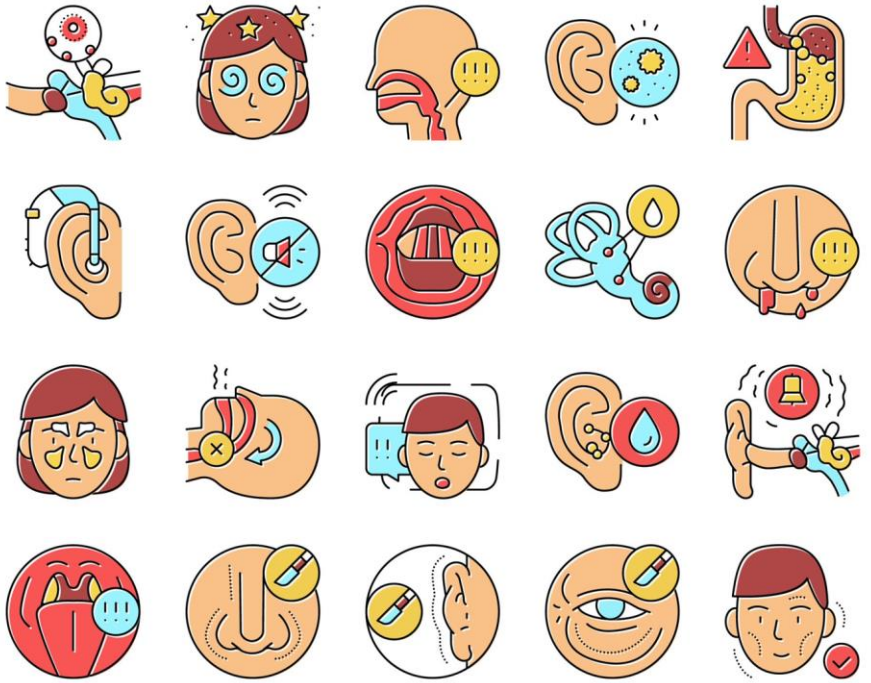

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Sensory Processing

Sensory processing:

- How we process information from the world around us and from what is going on inside of us in order to produce an appropriate behavioral response

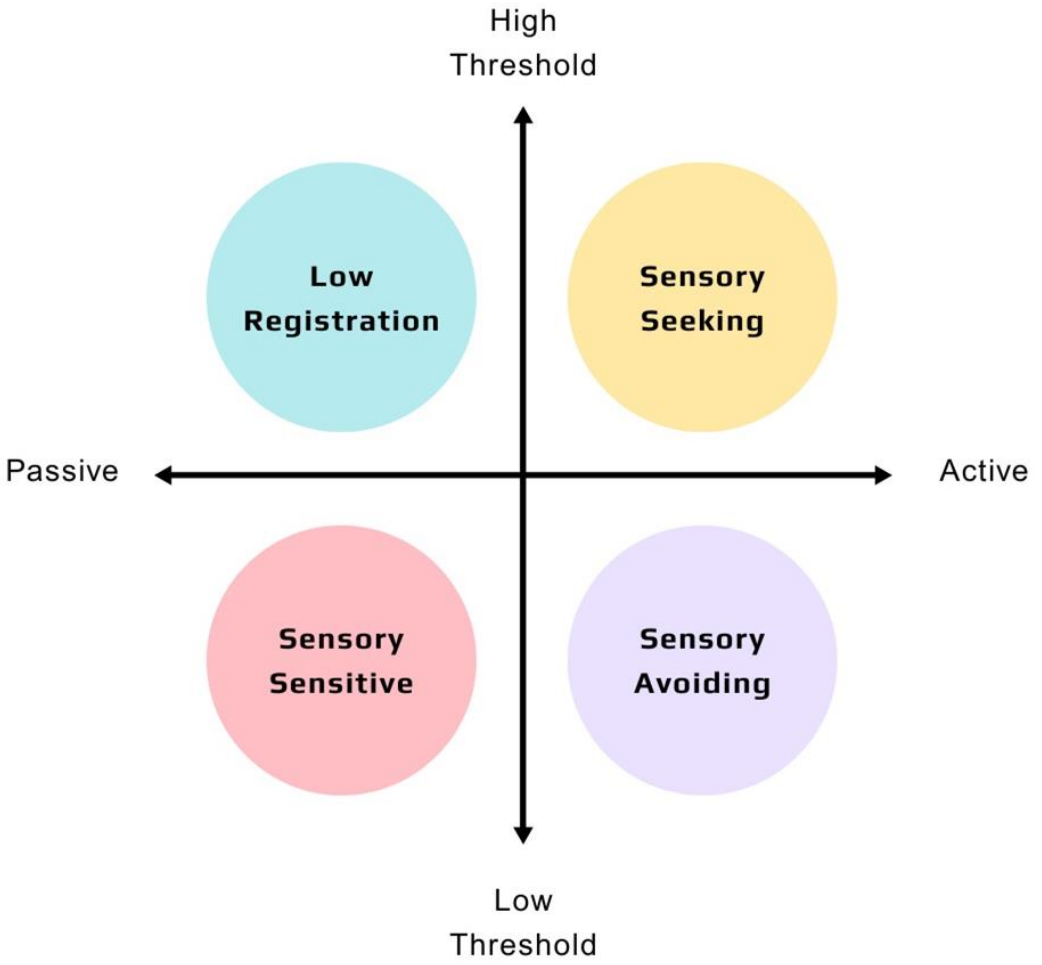
Sensory modulation:

- How we interpret sensory information and regulate our responses to the information we receive

Sensory processing patterns:

1. Sensory seeking
2. Sensory avoiding
3. Low registration
4. Sensory sensitivity

Sensory Processing Patterns



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Sensory Systems

Visual

01

- **Seekers:** typically enjoy very vibrant and colorful pictures, moving objects, bright/flickering/or flashing lights
- **Avoiders:** might be bothered by these things, covering their eyes or squinting
- **Low registration:** may not notice more obvious visual stimuli
- **Sensitivity:** may notice the least obvious visual stimuli right away

Sensory Systems

Auditory 02

- **Seekers**: typically enjoy very loud sounds or upbeat music, enjoy listening to certain parts of videos over and over
- **Avoiders:** may be bothered by the sound of ordinary things such as a fan or vent, busy crowds, background music, and unexpected noises; will often cover their ears
- **Low registration:** may not notice more obvious auditory stimuli
- **Sensitivity:** may notice less obvious auditory stimuli right away

Sensory Systems

Olfactory 03

- **Seekers:** typically enjoy being introduced to new smells, if they smell something they like they will search it out or keep sniffing it
- **Avoiders:** may be bothered by the smell of common tools or items, they might withdraw when introduced to new smells and avoid trying new foods due to their smells
- **Low registration**: may not notice more obvious scents
- **Sensitivity:** may notice less obvious scents right away

Sensory Systems

Gustatory 04

- **Seekers:** typically enjoy being introduced to new foods, eating foods with intense flavors (spicy, salty) and textures (crunchy, chewy), might chew on inedible items
- **Avoiders**: may be bothered by the taste of new foods and withdraw when introduced to new foods
- **Low registration**: don’t really notice the differences in flavors, are typically not very picky about how food taste
- **Sensitivity**: will notice less obvious flavors right away

Sensory Systems

Tactile 05

- **Seekers**: typically enjoy engaging in messy activities, the feeling of different textures
- **Avoiders**: may be bothered by the feeling of different textures, engaging in messy activities, and being touched; might not like trying new or textured foods
- **Low registration**: don’t notice more obvious tactile stimuli
- **Sensitivity**: will notice less obvious tactile stimuli right away

Sensory Systems

Vestibular 06

- **Seekers:** typically enjoy engaging in movement activities, like being upside down or spinning; often appear fidgety in their seats
- **Avoiders**: stay away from movement activities
- **Low registration**: may not recognize when they feel off balance or get dizzy, which could result in feeling nauseous
- **Sensitivity:** might quickly feel off balance or get dizzy as soon as they change their head position, which could result in feeling nauseous

Sensory Systems

Proprioception 07

- **Seekers:** typically enjoy activities that involve deep pressure, show decreased awareness of where they are in space, might use too much force on tools
- **Avoiders:** bothered by activities that involve deep pressure, such as hugs or tight clothes; might use decreased force on tools
- **Low registration**: don't realize how their body is moving through space, may appear clumsy or run into furniture/obstacles
- **Sensitivity**: might notice when something feels too tight or is applying too much pressure right away

Sensory Systems

Interoception

08

Seeking: constantly feeling hungry or needing to use the bathroom, engage in activities that cause pain
Avoiding: will do anything to not have to eat or use the bathroom
Low registration: don't realize when they are hungry or have to go to the bathroom, which might result in having an accident
Sensitivity: as soon as they feel a little hungry or pressure on their bladder, they want to eat or go to the bathroom right away

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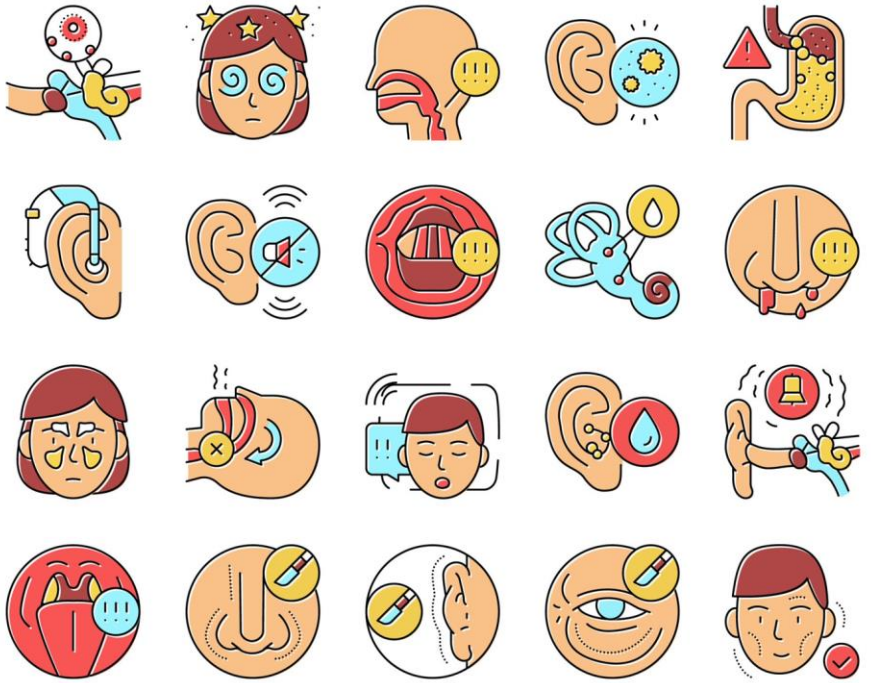
Visualization



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Research: “Sensory Processing in Sotos Syndrome and Tatton-Brown Rahman Syndrome”

Participants:

- 36 parents/caregivers of children with Sotos, 20 parents/caregiver of children with TBRS
- Children between the ages of 3 years and 14 years 11 months

Method:

- Questionnaires regarding sensory processing, adaptive behavior, ADHD, anxiety, and social responsiveness

Results:

- Sensory differences:
  - More than neurotypical children
  - Similar to autistic children
  - Similar to each other (Sotos and TBRS)

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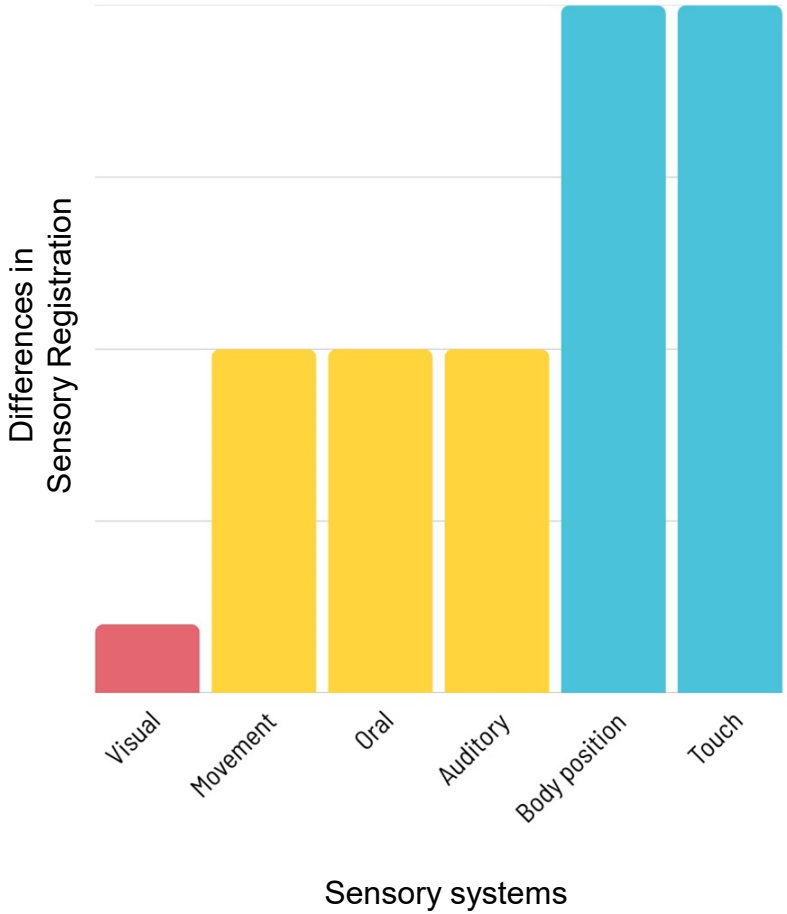
Research: “Sensory Processing in Sotos Syndrome and Tatton-Brown Rahman Syndrome”

Discussion:

- Increased differences in **sensory registration** (low registration)
- Sensory systems:
  - Body position (proprioception) and touch = increased differences
  - Movement (vestibular), oral, and auditory = some differences
  - Visual = few differences
- Present regardless of co-occurring diagnosis of autism
- Increased severity of differences results in:
  - Higher autistic traits
  - Lower adaptive behaviour
  - Higher defiant/aggressive behavior
  - Increased hyperactivity and inattention
  - Increased learning problems



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OT and Sensory-Based Interventions

“Addressing individual sensory needs can help to prevent overstimulation or under stimulation, thereby enhancing participation, learning and daily functioning.” (Smith, H., Lane, C., Al-Jawahiri, R. et al.)

OT! ***consult with an OT***

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Sensory-based strategies & supports based on article results

Low Registration: Proprioception (body awareness)

What does this look like?

- Clumsy
- Bumps into furniture
- Trouble negotiating obstacles
- Impaired balance
- Difficulty imitating gross motor movements
- Clothes not oriented correctly, pants falling down

Supports and strategies to help:

- Provide visual demonstrations
- Provide hands-on assistance with learning
- Use mirror for body positioning
- Clear pathways of obstacles that could be tripped over
- Engage in activities such as yoga, stretching, obstacle courses, playing on the playground, deep pressure, heavy work (e.g. push/pull activities, carry heavy items)
- Clear visual cues (e.g. stickers for foot placement while completing obstacle course)
- Wear pants/shorts with drawstrings to help keep over waist

Sensory-based strategies & supports based on article results

Low Registration: Tactile

What does this look like?

- Food all over mouth after eating
- Hands dirty after messy play or being outside
- Shoe laces untied
- Clothes not oriented correctly, pants falling down
- Touches hot items
- Increased pain tolerance

Supports and strategies to help:

- Look in mirror to clean mouth after eating
- Wash hands after meals, being outside, or messy play
- Select clothes, furniture, and utensils with a variety of textures
- Eat foods with variety of textures (e.g. very crunchy or very chewy)
- Add tactile cues to everyday tools (e.g. textured grip on pencil/toothbrush)
- Be extra careful with hot temperatures (e.g. use red/blue to label)
- Engage in tactile experiences (e.g. sensory bin)

Case Study

Tommy is a 6 year old with Sotos, who demonstrates **low registration** for his **tactile** and **proprioceptive** sensory systems**.** How does his sensory processing patterns affect his performance? What strategies or supports could his mom (you as a parent/caregiver) implement into this scenario to encourage increased independence and improved regulation?

Tommy is playing with his new Hot Wheels on the race track he built. He dumps over the entire bin of cars by the doorway leading from the living room to the kitchen, grabs the lime green one he is looking for, and returns to the track. His mom calls him into the kitchen for lunch. He runs through the door, tripping over the cars on the floor and has a near fall. He arrives in the kitchen where he is met by a hot dog lined with ketchup. He messily eats it while his sister twirls around him showing off her new princess tutu. When Tommy is finished, it's time for him to get changed into his soccer uniform. He has a game in an hour. He grabs his shirt from the laundry pile and puts it on. Uh oh, he spots a ketchup stain on it. Upset, he runs downstairs to show mom. Before noticing the stain, his mom says, "You've got your shirt on backwards! Hurry up, we're going to be late!" Tommy has a melt down.

Case Study

Let’s try this again but with some sensory supports and strategies in place.

Tommy is playing with his new Hot Wheels on the race track he built. He dumps over the entire bin of cars by the doorway leading from the living room to the kitchen, grabs the lime green one he was looking for and returns to the track. On her way to call him into the kitchen for lunch, his mom pushes the pile of cars to the side to leave an open path through the doorway. Tommy safely runs into the kitchen where he is met by a hot dog lined with ketchup. He messily eats it while his sister twirls around him showing off her new princess tutu. When he is finished, it’s time for him to get changed into his soccer uniform. He has a game in an hour. Before Tommy runs upstairs to his bedroom, his mom guides him to the bathroom to take a look at his face in the mirror. He laughs when he realizes he has a ketchup mustache. He grabs a paper towel, wipes it off, and runs upstairs. His shirt is laid out on the bed so that he just has to thread his arms through the bottom and pull it over his head. He grabs his water bottle and heads to the car.

Sensory-based supports

Sensory-based supports

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Sensory-based supports

Resources

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