Sunday, August 4, 2019

Breakout Session G37 • 2:45-3:45 pm • Grand Ballroom A/B

Preparing the body and the environment. Orientation and mobility for individuals with CHARGE syndrome

Suzanne Dinwiddie, M.Ed., Tennessee Deaf-Blind Project
Lee Ellen Whitefield, M.Ed., Metro Nashville Public Schools
Kristi Jones, Tennessee Deaf-Blind Project

Presenter Information

Suzanne Dinwiddie, M.Ed., COMS, CTVI, CEIM is an educational consultant for the Tennessee Deaf-Blind Project. Suzanne is a certified teacher of individuals who are blind or visually impaired, an early childhood assessment specialist and a certified orientation and mobility instructor with over 44 years of experience. Suzanne is a reoccurring lecturer for Vanderbilt University and conducts regional and statewide workshops regarding best practices in early intervention, literacy for children with complex learning/medical needs, Deaf-Blindness, and orientation and mobility strategies for individuals with dual sensory loss, physical limitations and infants/toddlers.

Lee Ellen Whitefield has worked in the field of Exceptional Education for over 20 years. She holds a Bachelor's Degree in Education of Students who are Deaf and Hard of Hearing Pre K–12, and Elementary Education K–5 from Eastern Kentucky University (1996). She earned a Master's Degree in Education of Students with Visual Impairments Pre K–12 at Vanderbilt University (2001) as well as an additional certification in Orientation and Mobility from Pennsylvania College of Optometry (2005). Lee Ellen is currently working as an Orientation and Mobility Specialist in Metro Nashville Public Schools. She enjoys encouraging students with visual impairments, who have a wide range of abilities, to move and travel as independently as possible.

Kristi Jones currently works as the Family Specialist for Tennessee Deaf-Blind Project and the Tennessee Parent Liaison for the CHARGE Syndrome Foundation. Most importantly a mother of a 19-year daughter named Gabby, who has CHARGE Syndrome. Kristi has invaluable insight to the importance and difficulty that travel can be for individuals with CHARGE Syndrome.

Presentation Abstract

Orientation and Mobility (O&M) develops the skills necessary for purposeful travel. For individuals with CHARGE Syndrome moving through different environments can be difficult because CHARGE is a multi-sensory impairment that affects all aspects of an individual's life, especially movement. Individuals must develop a sense of "where they are" before they can move beyond their personal space. This awareness is exceptionally difficult with individuals who have vestibular and proprioceptive dysfunction. To expand their world, a person first needs to understand and explore the setting "within reach" in a meaningful way. Practical strategies such as "anchoring" the body to a stable site, embedding a movement into daily routines, and using consistent communication methods will be explored.

Once oriented, strategies can be implemented to promote meaningful movement and travel. Programs can include teaching those with CHARGE Syndrome how to optimize sensory abilities, how to engineer surroundings to address sensory needs, and literacy opportunities through travel journals and route books. Strategies implemented should be in alignment with every person's unique sensory impairments and needs in mind and used across all settings.

Learning Objectives

- Participants will be provided with information related to orientation for individuals with CHARGE Syndrome.
- Participants will be provided with practical orientation and mobility strategies for educators and families to implement with individuals with CHARGE Syndrome.

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Orientation and Mobility Strategies to Address Balance and Stability

TN Deaf-Blind Project

CHARGE Syndrome Conference

August 2, 2019

Lee Ellen Whitefield, M.Ed., CTVI, D/HH, COMS

Suzanne Dinwiddie, M.Ed., CTVI, COMS, CEIM

IDEAs that Work
Office of Special Education Programs
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Where to Begin…

- "Traditional" O&M did not address balance issues
- Team Approach (educators, related services, parents)
- How strategies to increase brain/body connection affect orientation and purposeful movement

International Journal of Orientation & Mobility. VOLUME 1 , ISSUE 1 , ISSN (Online) ,
DOI: 10.21307/ijom-2008-014, April 2008 © 2008.

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It is difficult for individuals with CHARGE to maintain oriented because their balance and stability is affected by unique positionings, sensory needs, and visual field loss.

Orientation- Where Am I?

- Understanding what internal and external sensory information is sending to the brain
- Understanding the environment within reach, including the body
- Beyond arm's reach- awareness of my position in space in relation to other objects and people that might be outside of my touch, vision, and hearing

Hill & Ponder, 1976
DbI Structuring the Environment

Adaptive behaviors develop to increase brain/body connection and compensate for sensory loss

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Behaviors that compensate for balance issues can interfere with knowing "where I am" and functional movement

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Child may seek to enlarge their base of support to increase stability, get more external information and address proprioceptive needs

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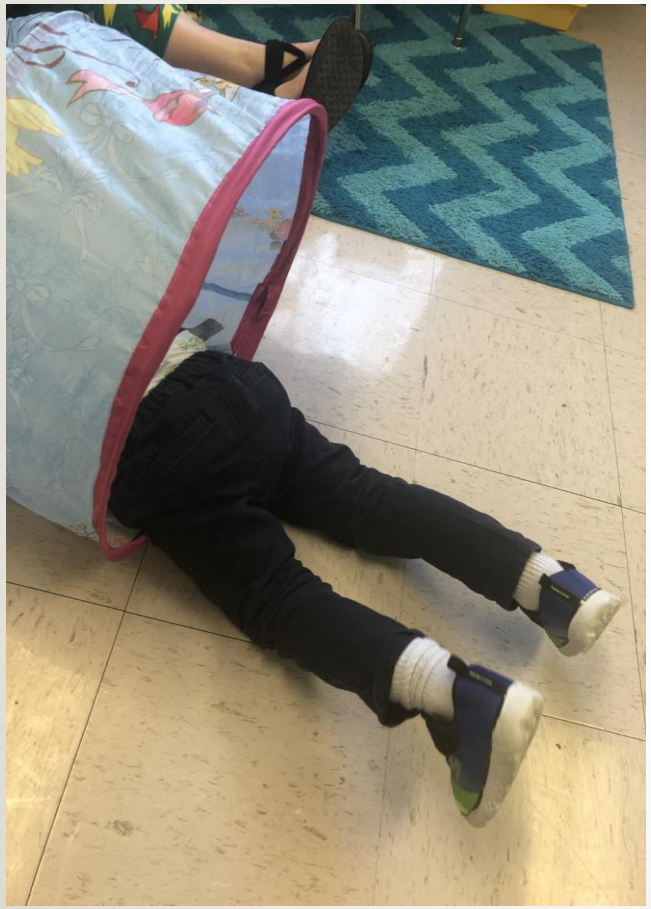
Ways to prepare the body to move or travel!- ask your OT!



Proprioceptive – tunnels and taco!

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Vestibular – swing!

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Strategies for Orientation

- “Anchor” the child
- Use body as “reference point”
- Defined or designated areas with boundaries to create “holistic” picture of working space
- Landmarks and defined spaces that can be tactual, visually, or auditorily realized and used consistently
- Decrease “extra” external stimulation
- Establish movement routines

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(Skellenger&Sapp, 2010)

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Structured or defined spaces help to create a "holistic" mental image of a specific area.

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Bentzen & Marston, 2010a, p. 297

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Environmental Adaptations:

"CLAP"

Contrast/Color

Lighting

Amount of information

Position of person and materials

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Example of orientation routines after addressing sensory needs:

- Slide body down mom's chest until feet hit the floor
- Adult pauses and holds onto child's waist and waits for child to regain postural control
- Child pivots to a stable landmark for balance
- Verbally and tactually redirected to next activity
- Bright artificial landmark to designate the next location

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Strategies: Encouraging Movement and Travel for Individuals with CHARGE!

Consult with team members:

- Create a Travel Plan: All Hands on Deck!
- Incorporate literacy
- Address continued stability needs – increased support
- Adaptive mobility devices, touch cues, Haptics
- To address continued sensory needs – input

Strategies: Encouraging Movement and Travel for Individuals with CHARGE!

- Adapt environment by using landmarks that maximize needed sensory information while traveling
- Make time and wait!
- Modify movement activities that increase body awareness

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TRAVEL PLAN

- Create a document or book of plan as reference for team
- Label parts of routes or landmarks for same language used by all
- Team members use same routes to chain together landmarks
- Team members have the same expectations
- Provide pictures and be specific
- Most importantly plan helps students know what to expect
- Ultimately promotes student success!

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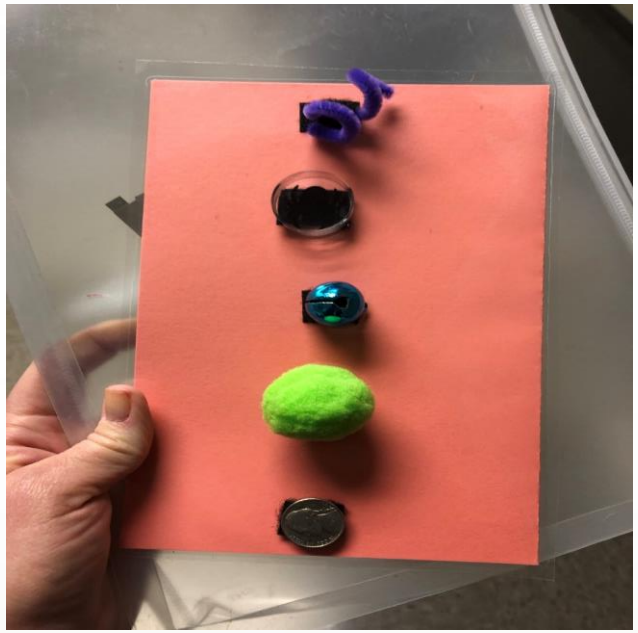
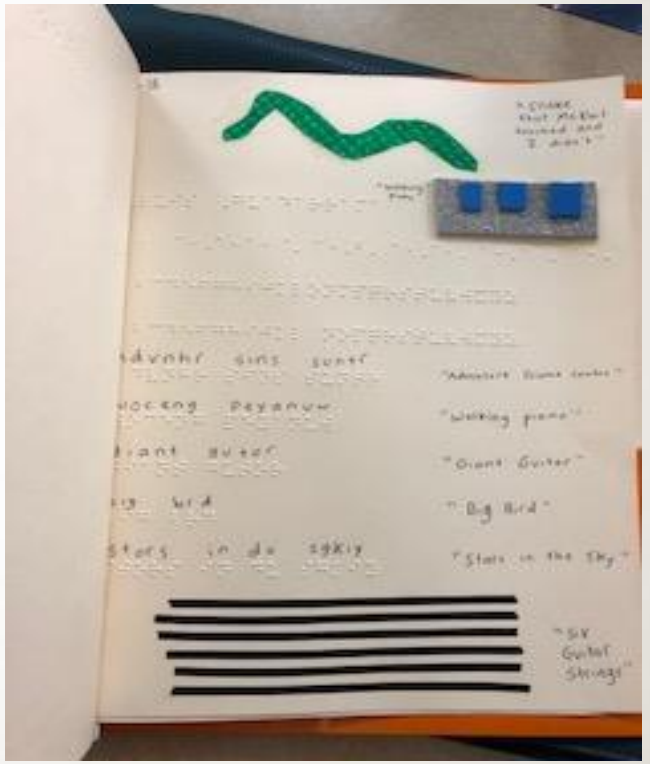
Incorporating Literacy: Tactile, print or picture route books, route lists, & Journals!





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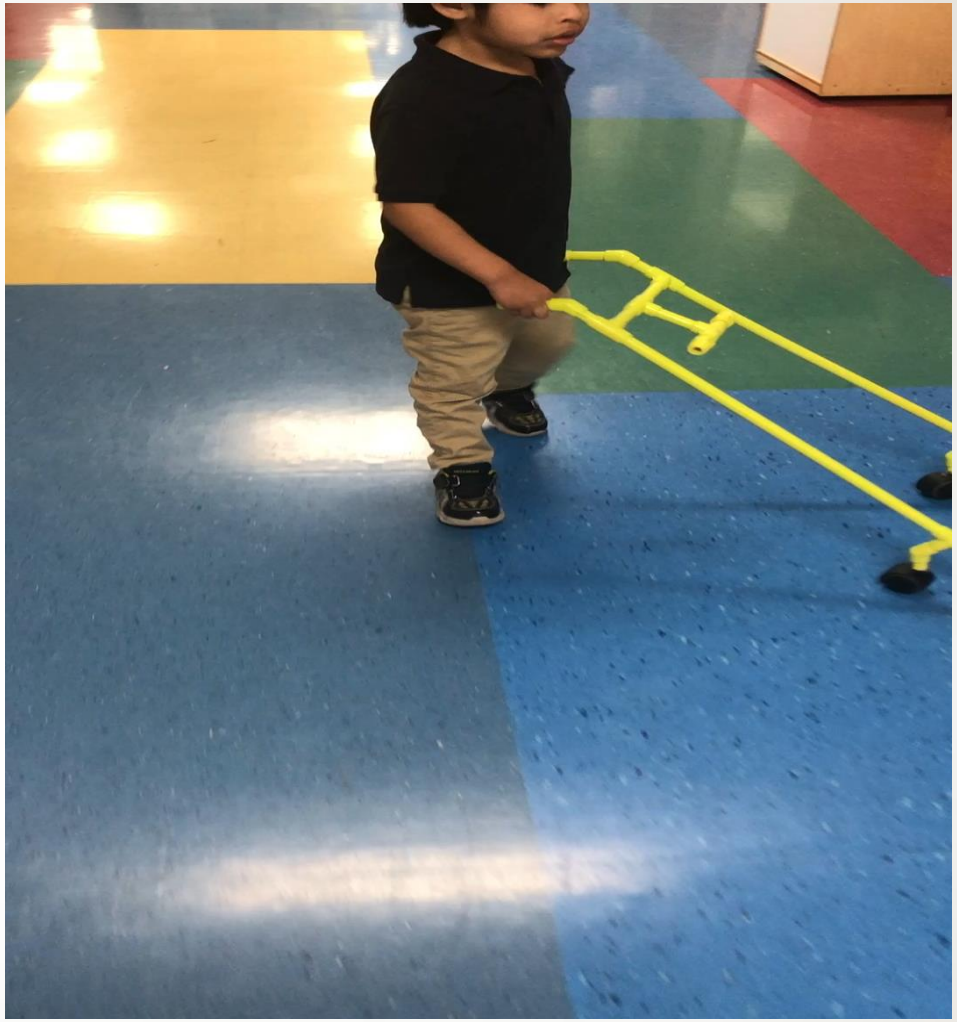
Students may need additional sensory information while traveling in order to maintain stability and therefore assist in orientation.



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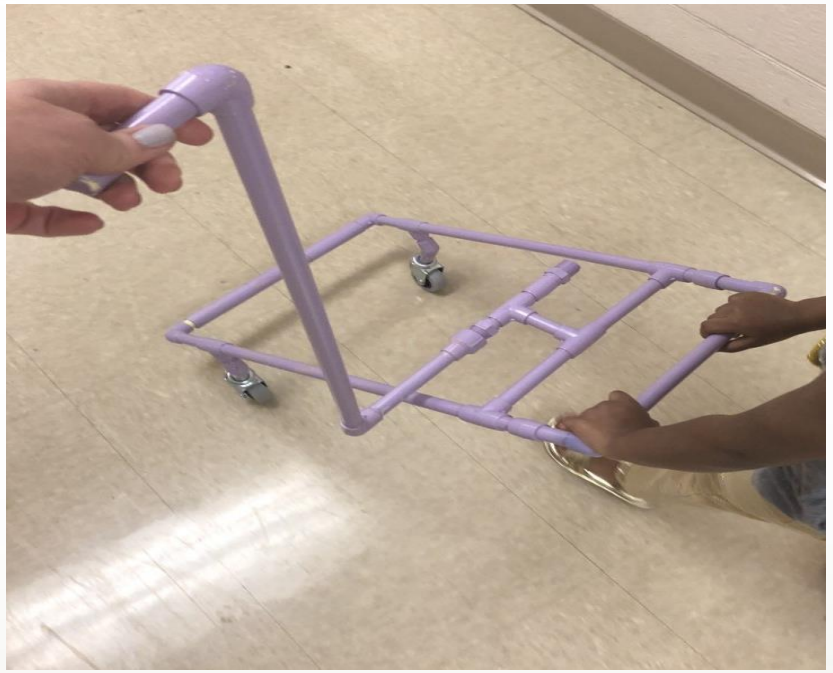
Continued or Intermittent Input Options

Intermittent or Continuous Trailing

Backpack = Input

Adaptive Device



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Continued Support Examples: ask the PT!

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Touch cues and Haptics for increased sensory information about body placement and additional support during travel.

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Touch cues for increased sensory information about body placement and additional support throughout experiences improving body awareness.

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Landmarks

- Landmarks can provide a point of reference in a large area
- Landmarks assist in maintaining orientation during travel
- Can be chained together to complete route
- Landmarks can provide an opportunity to stop travel and reestablish balance, take in sensory information, and orientation
- Landmarks can provide sensory input based on needs: visual, auditory, tactile, olfactory, proprioceptive, vestibular
- Landmarks help students be active participants in travel
- Landmarks can be used for literacy

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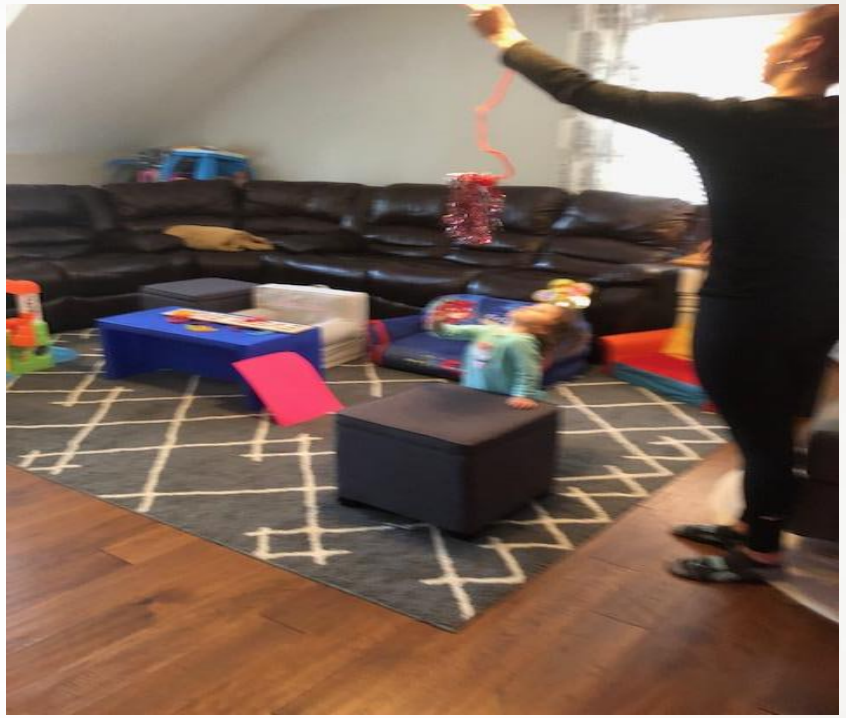
Reestablish Balance



Point of Reference

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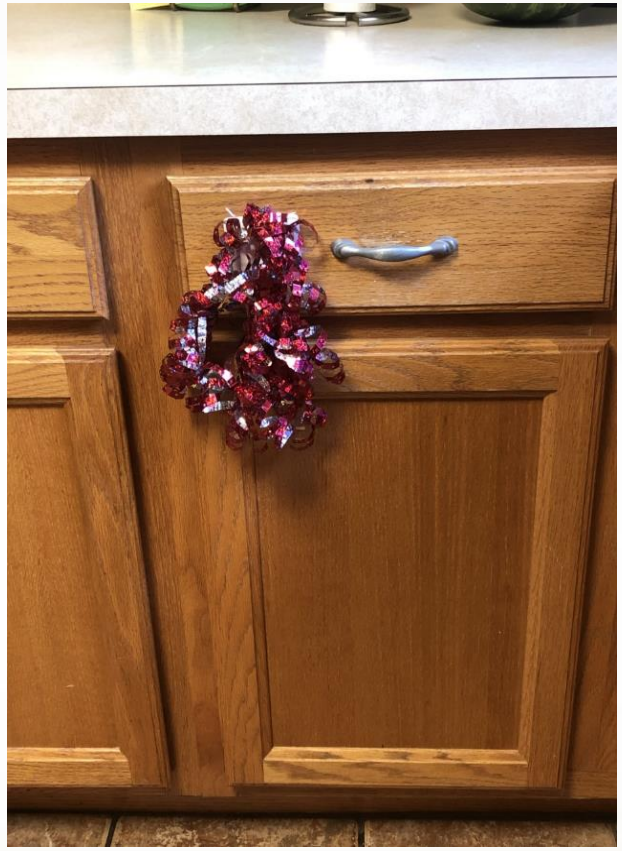
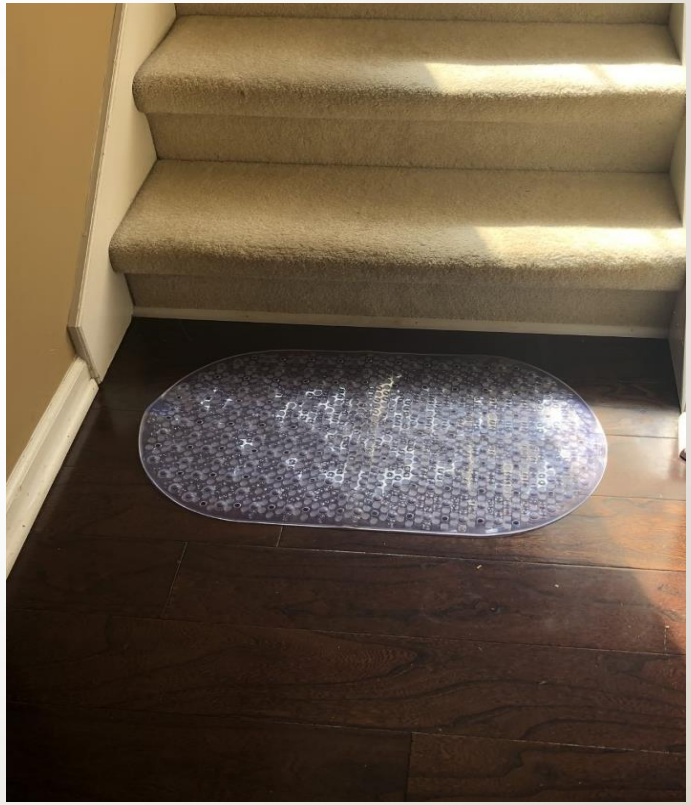
Landmarks may occur naturally

Or CYOL: Create Your Own landmarks!





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Adapting movement activity that improves body awareness. Tai Chi!

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Questions?

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- lee.whitefield@mnps.org

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Preparing the Body and the Environment

Orientation and Mobility for Individuals with CHARGE Syndrome

TN Deaf-Blind Project

CHARGE Syndrome Conference August 2, 2019

Lee Ellen Whitefield, M.Ed., CTVI, D/HH, COMS

Suzanne Dinwiddie, M.Ed., CTVI, COMS, CEIM

Kristi Jones, CHARGE Family Liaison

Consultation with Bailey Garcia, OT

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Where Do We Begin…..

Begins with a TEAM APPROACH

- Consistent expectations
- Clear understanding of individual's vision and hearing
- Don't quit- work at the student's pace
- The process is more than mastery of a skill (i.e., turn taking, active participant, social interaction)
- Consistent use of the same communication strategies, vocabulary, routines, and daily routes

Orientation- Where Am I?

- Understanding what internal and external sensory information is sending to the brain
- Understanding the environment within reach, including the body
- Beyond arm's reach- awareness of my position in space in relation to other objects and people that might be outside of my touch, vision, and hearing

Adaptive behaviors develop to increase brain/body connection and compensate for sensory loss

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Behaviors that compensate for balance issues can interfere with knowing "where I am" and functional movement

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Child may seek to enlarge their base of support to increase stability, get more external information and address proprioceptive needs

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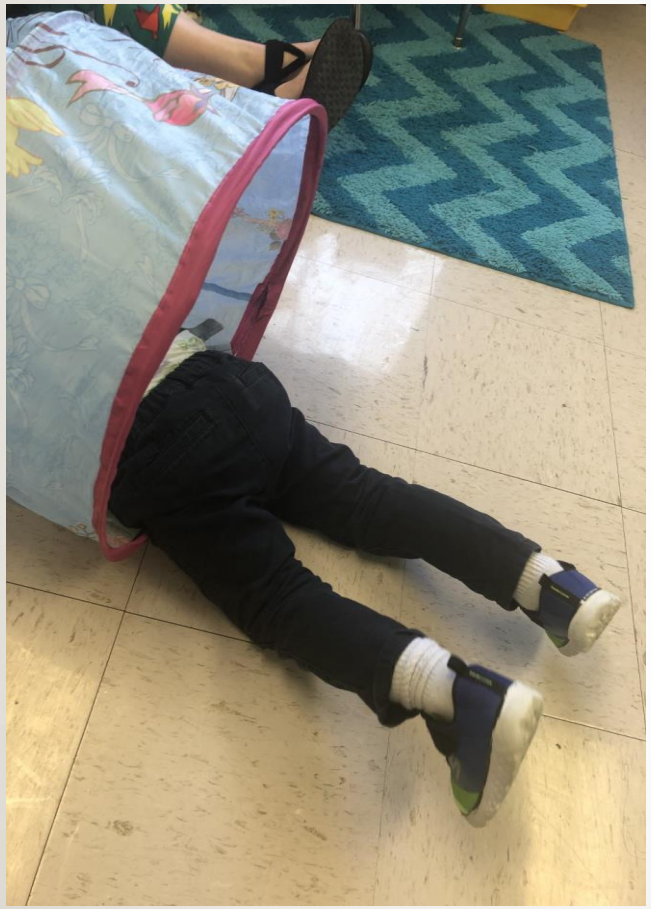
Ways to prepare the body to move or travel!- ask your OT!



Proprioceptive – tunnels and taco!

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Vestibular – swing!

Strategies for Orientation

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(Skellenger&Sapp, 2010)

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Structured or defined spaces help to create a "holistic" mental image of a specific area.

Bentzen & Marston, 2010a, p. 297

Environmental Adaptations:

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Example of orientation routines after addressing sensory needs:

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- Bright artificial landmark to designate the next location

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Mobility- How to I get where I want to go?

- **Feedback**- use information from what a person HAS traveled

- **Feedforward**- use residual senses and external supports to anticipate what environment that WILL be traveled

Mobility – Navigating environments safely!

- How do I get where I want to go? Planning. Point A to point B
- As independently and efficiently as possible.
- Orientation and Mobility training includes movement activities to build body image and awareness.

Strategies: Encouraging Movement and Travel for Individuals with CHARGE!

Consult with team members:

- Create a Travel Plan: All Hands on Deck!
- Incorporate literacy
- Address continued stability needs – increased support
- Adaptive Mobility Devices, Touch Cues, Haptics
- To address continued sensory needs – input

Strategies: Encouraging Movement and Travel for Individuals with CHARGE!

- Individual as active participant
- Adapt environment by using landmarks that maximize needed sensory information while traveling
- Make time and wait!
- Modify movement activities that increase body awareness

TRAVEL PLAN

- Create a document or book of plan as reference for team
- Label parts of routes or landmarks for same language used by all
- Team members use same routes to chain together landmarks
- Team members have the same expectations
- Provide pictures and be specific
- Most importantly plan helps students know what to expect
- Ultimately promotes student success!

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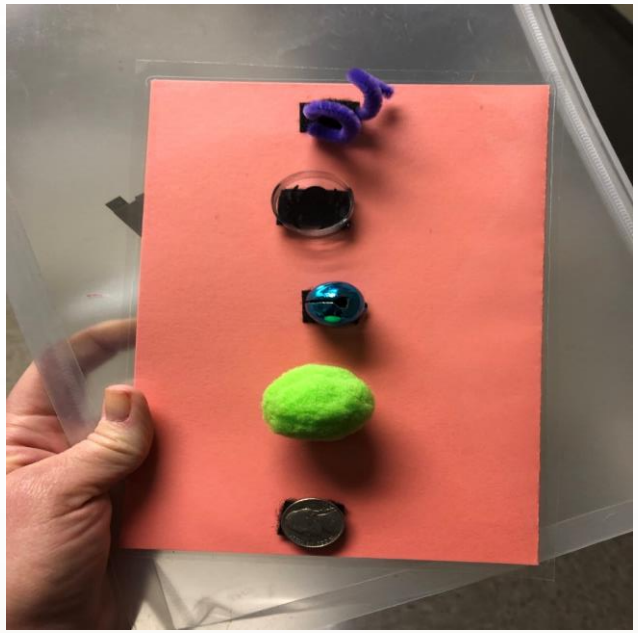
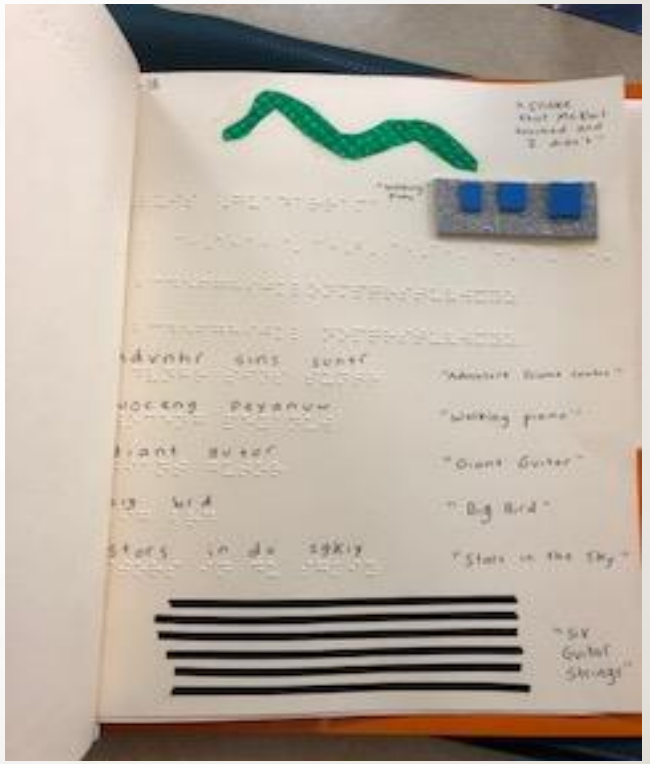
Incorporating Literacy: tactile, print or picture route books, route lists, & journals!





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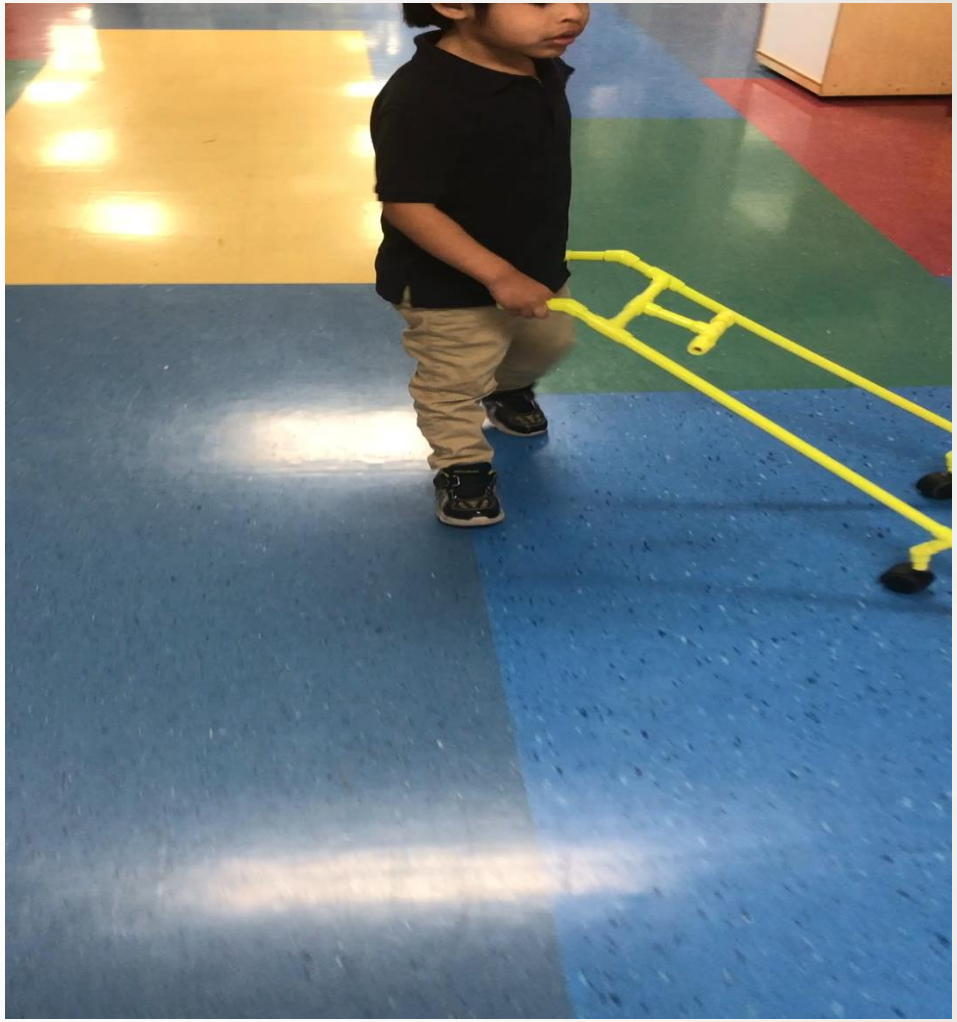
Students may need additional sensory information while traveling in order to maintain stability and therefore assist in orientation.



- Video 112
- Haptic street corner external support

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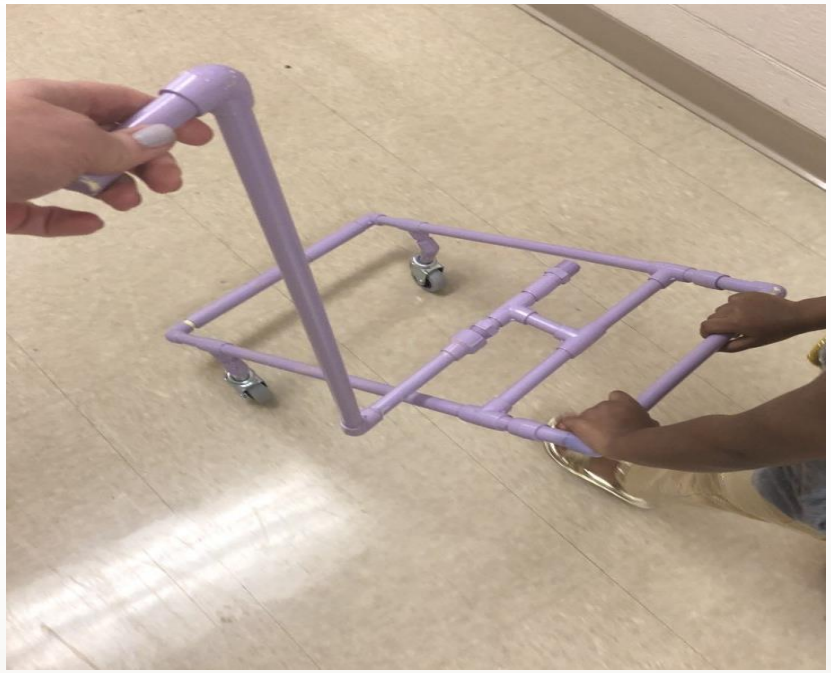
Continued or Intermittent Input Options

Intermittent or Continuous Trailing

Backpack = Input

Adaptive Device



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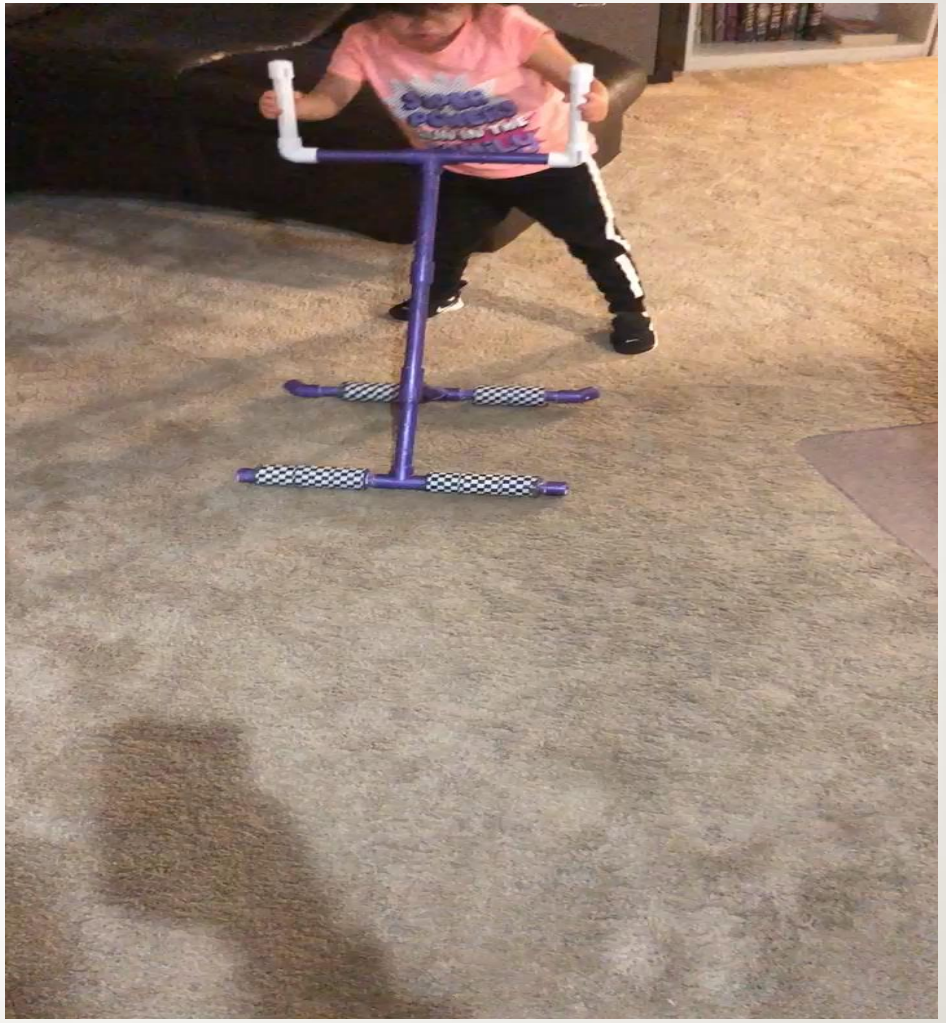
Continued Support Examples: ask the PT!



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- Lunch chart

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Touch cues and Haptics for increased sensory information about body placement and additional support during travel.

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Touch cues for increased sensory information about body placement and additional support throughout experiences improving body awareness.

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Landmarks

- Landmarks can provide a point of reference in a large area
- Landmarks can provide an opportunity to stop travel and reestablish balance, take in sensory information, and orientation
- Assist in maintaining orientation during travel by chaining together to to complete a route
- Landmarks can provide sensory input based on needs: visual, auditory, tactile, olfactory, proprioceptive, vestibular……
- Landmarks help students be active participants in travel
- Landmarks can be used for literacy

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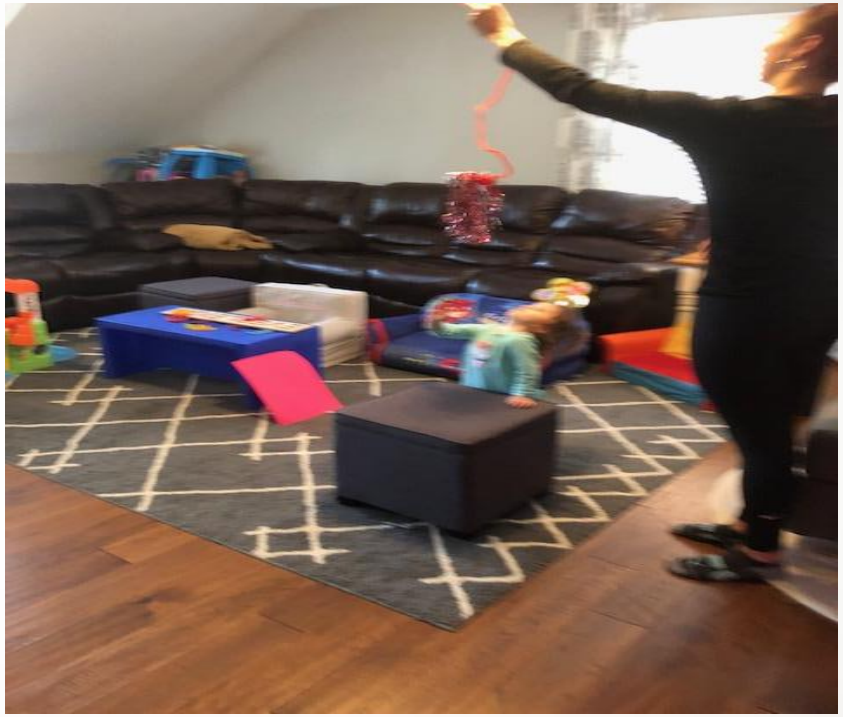
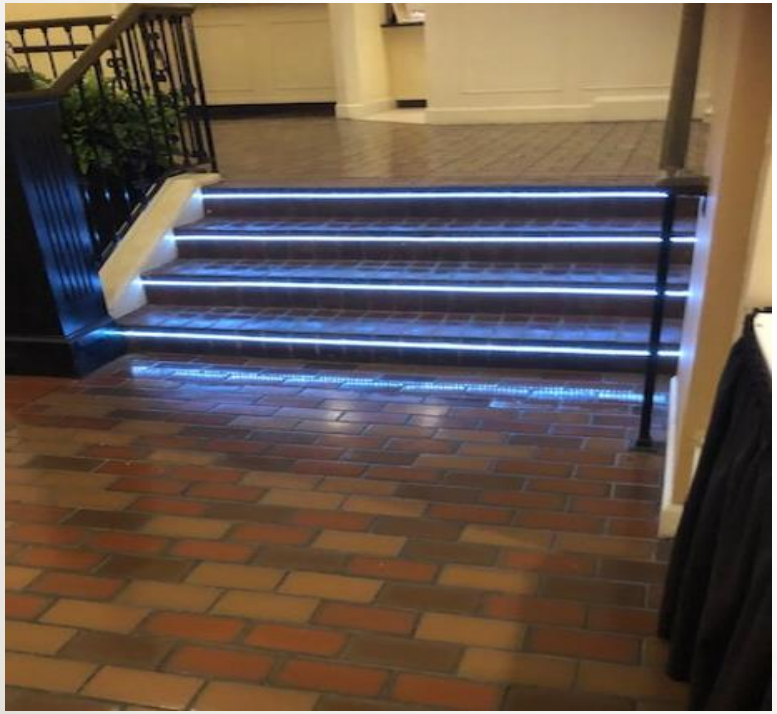
Reestablish Balance

Point of Reference



Landmarks can occur naturally in environments



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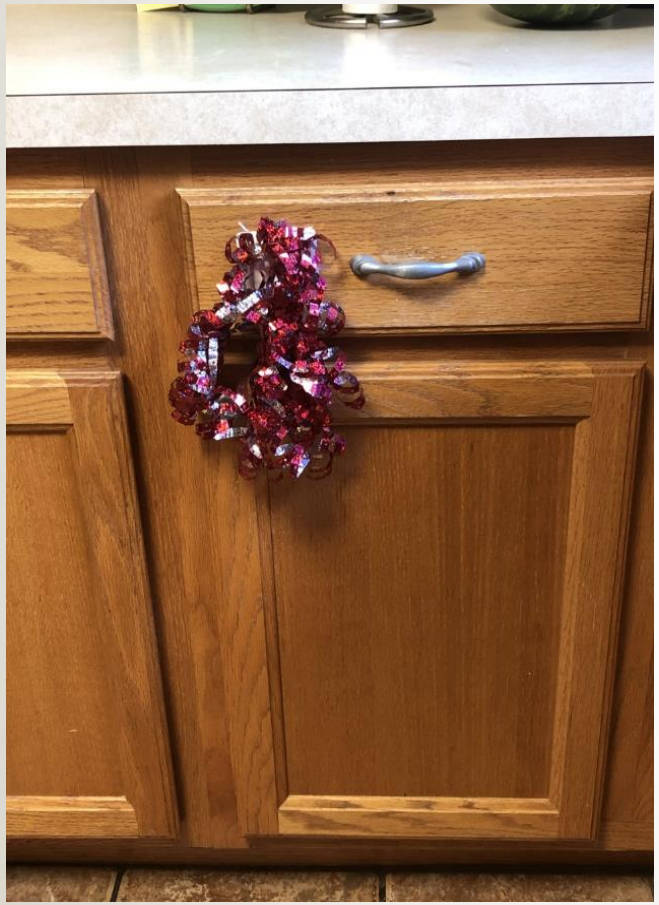
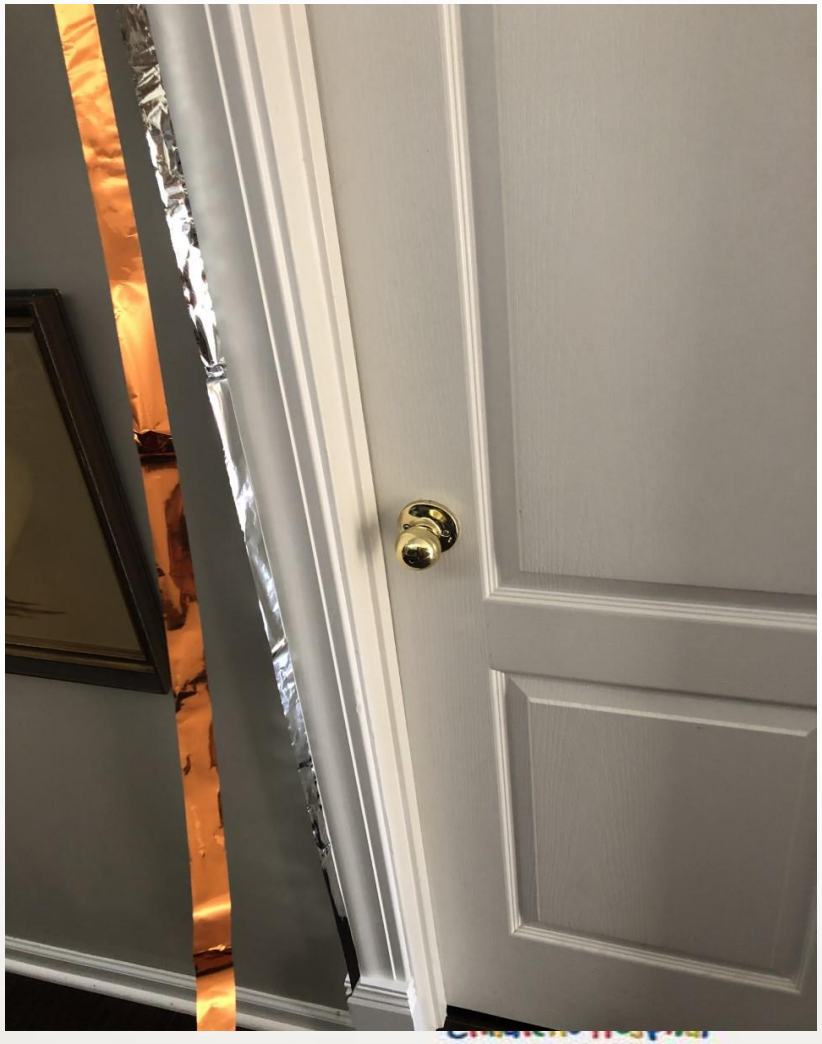
Or CYOL: Create Your Own landmarks!





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Adapting movement activity that improves body awareness. Tai Chi!

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Questions?

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