How CHARGE Syndrome Impacts Participation at School and Home

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Deafblind Physical Therapy Team

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Objectives

1. Learn how CHARGE syndrome can affect gross motor development
2. Identify areas of support that students with CHARGE syndrome often need
   a. Understand the ways that PTs in various settings can help support those needs
3. Review the purpose of school-based physical therapy services
4. Discuss important considerations regarding equipment

Sensory Systems

- Give us information about the world and about our bodies
- Each system has unique receptors that send information to the brain
- Different receptors react to light, sound, vibration, touch, stretch

Systems that affect balance

- Vision
- Vestibular
- Somatosensory - touch and proprioception

All systems work together in a complex dynamic process

- Multiple senses verify or refute information
- The brain is the processing center
Motor Development in CHARGE

Sensory impairments often lead to motor impairments

- Less motivation to move around without sensory input
- Less information for motor learning and balance

**Key Points**

- Balance confidence is key!
- Be patient! It’s okay if skills take a little longer

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**Areas that PTs lead the CHARGE on!**

**Positioning, Endurance, and Balance**

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**Additional Considerations**

Conditions that PTs may not directly address in IEP goal areas but need to be aware of when providing services:

- Deafblindness - supporting environmental access and communication strategies
- Osteoporosis - time spent in standing and equipment use, exercise prescription, fall risks
- GERD - positioning considerations
- Constipation - increased motility with movement, GI discomfort
- Cardiopulmonary factors - monitoring of vital sign responses during exertion
Positioning Support
Maintaining posture is hard work!

- PTs can help with:
  - Frequent positional changes
  - Use of positioning equipment
  - Interventions to address range of motion limitations and bony anatomy

Endurance
Low tone, balance challenges, and impaired coordination increase the energetic costs of movement!

- PTs can help with:
  - Activity planning
  - Managing energy levels
  - Positioning
  - Environmental modifications

Balance
All parts of the balance system are affected by CHARGE

- PTs can help with:
  - Teaching compensatory strategies
  - Practicing safe falling
  - Improving balance confidence
  - Equipment and bracing use
  - Other safety measures

Practical Application
The challenges we see

- Slow transitions between locations
- May need human guide or hand-held assist
- Increased time needed for sensory activities in order to feel centered and participate
- Need planned routes between destinations

Teamwork Makes the Dream Work!
Other Team Members Play an Important Role

- Orientation & Mobility - Safe navigation strategies
- Occupational Therapy - Proprioceptive and vestibular sensory input
- Adaptive Physical Education - Adapted sporting activities
- & many more! Working as a collaborative team helps to generalize skills across settings and people
  - Family, caregivers, and friends
  - Classroom teachers, teaching assistants, paraprofessionals, interveners
  - Community programs and recreational activities
We can all work together!
Making the connection between home and school

School-Based PT Definition

- Primary purpose is for educational access
  - Physical access to school environment and activities
- Educational model, not rehabilitation model
  - Funded through district instead of insurance
  - Ongoing services instead of episode of care to address injuries or operations
- Focus on promoting independence
  - More than just mobility!
    - Positioning support, equipment and bracing needs, consultation services, etc.

Service Delivery

- Least Restrictive Environment
  - Consultation vs. Direct Services
  - Push-in vs. Pull-out Services
  - Group Therapy vs. Individual Therapy
- School Progression
  - Early school years - more likely to be direct, individualized, and higher frequency to address gross motor development
  - Later elementary/high school - more likely to be in group setting or lower frequency to fine-tune balance skills
  - Transitional age - more likely to be consultative to address healthy lifelong exercise routines and recreational/leisure access

Equipment

- Who pays?
  - District vs. insurance
  - Medical doctors provide prescriptions
- What is the PT's role?
  - Assessment
  - Writing Letters of Medical Necessity (LMNs)
  - Adjustment and modifications
  - School vs. home equipment

Equipment

All equipment needed throughout the school day should be written into the IEP

- Grants and equipment share programs are available!
- CHARGE syndrome foundation has a recreational sport equipment grant!

PTs are here to support your child!
Thank you for coming!
Questions?
References