Physical Therapy for Adolescents thru Adulthood with Down syndrome

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Patricia Shimanek PT, DPT is a Physical therapy at Advocate-Aurora Lutheran General Hospital, and has been a PT for almost 30yrs. Graduated from Northwestern University in 1988 with a bachelors in PT and from Rosalind Franklin University in 2011 with her doctorate in Physical Therapy. She has been treating Ortho/Sports Medicine clients for 28 years. She is also a parent with a 22 y. o. male with Down syndrome.
Objectives

1. Understanding Medical issues in a person with Down syndrome
2. Understanding physical characteristics of a person with Down syndrome
3. Understanding gait tendencies, shoe wear and orthotics
4. Understanding why exercise/Physical Therapy is important
5. Functional Physical Therapy Goals
There are multiple medical issues related to Down syndrome:

1. Heart Problems (50%)
2. Gastrointestinal Issues 12%
3. Umbilical hernias
4. Epilepsy
5. Orthopedic Issues
6. Ears, nose, and throat issues
7. Blood problems
8. Thyroid issues 4-18%
9. Eye Issues
10. Skin/dermatology concerns
11. Dental issues
12. Alzheimer’s
13. Obesity
14. Obstructive sleep apnea 50-79%
15. Pelvic floor dysfunction
Heart Issues

- Approximately 40-60% of infants have some type of heart issue.
- These are mostly correctable.
- As the children age, periodic rechecks with the cardiologists are still important.
- Coronary Artery disease is not common in Down syndrome, but risk can increased with obesity and sedentary lifestyle as age.
- Valvular heart disease: mitral and aortic valve regurgitation, and aortic and pulmonic stenosis is higher.
Gastrointestinal Issues

- Celiac disease: sensitivity to gluten
- Lactose Intolerance
- Irritable Bowel Disease (IBS)
- Gastrointestinal Reflux Disease (GERD)
- Constipation
Hernias

- Defect in the abdominal wall:
  - 1. Inguinal: in the groin
  - 2. Umbilical: at the belly button
  - 3. Epigastric: above the belly button
  - 4. Site of previous abdominal surgery
Orthopedic Issues

2 types that involve bones, joints, ligaments, or tendons

1. **Problems caused by ligament laxity**
   a. Atlantoaxial instability (AAI) 15%
   b. Hallux Valgus (bunions)
   c. Over pronation of the ankles
   d. Subluxation of the patella 5-9%
   e. Scoliosis 50%
   f. Hip instability 5-8% / Subluxations 12%

2. **Problems associated with aging**
   a. Osteoarthritis at a young age
   b. Spinal stenosis
   c. Osteoporosis
Alzheimer’s disease

- Is a progressive degenerative neurological condition that affects the brain
- In the general population, the incidence of Alzheimer’s is 10% of people in their 60’s, 20% in the 70’s, 40% in the 80’s and 50% above 85
- It appears that the incidence of AD is the same in the Down syndrome world, but starts 20 years earlier
Physical Characteristics

- Hypotonia
- Decreased strength
- Increased joint flexibility/hypermobility
- Short arms and legs
- Stature
- Facial features: nose, eyes, mouth, ears, teeth and head shape
- Hands and feet
Hypotonia

- Decreased or low tone
- Muscle tone is different then strength
  1. Tone is the resting tension of the muscle.
  2. Muscles feel more “floppy” or relaxed
- This is determined by the lack or decreased resistance, stiffness or tension of the muscle when passively moved
- Usually affects all the muscles, but can be different in various locations in the body: L side may be less than R, Uppers more than Lower extremities.
- Predominant in infants, and slowly reduces with age
Decreased strength

- Muscle strength is defined as the force needed to overcome resistance.
- With time, repetition and practice, strength can be improved.
- As gross motor movements are learned, strength needs to be developed in the desired movements.
  - With the baby’s own movements, compensatory patterns may develop and then stay thru adulthood.
Increased Joint Flexibility/Ligamentous Laxity

- Ligaments' role is to hold bones together
- They are looser in people with Down syndrome
- This allows excess movement in the joints
- Joints most laxity seen in: hips, shoulders and neck
- What to do:
  1. teach gross motor skill
  2. prevent further stretching
  3. strengthen muscles around the joints
  4. lift carefully
Examples
Children with Down syndrome have short arms and legs in relation to their torsos.

This will make it more difficult to learn to:

1. Sit since cannot reach hands to floor
2. Climb onto sofa, stairs and curbs
3. Pedal or steer a bike; may need to wait till older or look for more proportioned equipment
Babies with Down syndrome are usually born with typical heights/weights.

They do not grow as fast as children without Down syndrome.

* Average height for males with DS is 5 feet, 2 inches
* Average height for females with DS is 4 feet, 9 inches

(These are from most recent studies for the United States)
Examples of short arms/legs and stature
Facial Features

- Nose: may be broader and flatter and smaller nasal passages
  * easier to get congested and last longer
- Eyes: May slant upward and have small extra fold of skin in the corners
- Mouth: may be small and roof shallow
  * tongue may protrude, especially with low tone
- Teeth: May come in late, different order or not at all
- Ears: Small, tops fold over, small passages
  * easily blocked by wax, cause hearing loss, increased infections
- Head shape: smaller than normal, flatter back of head and shorter neck
Hands and Feet

- Hands:
  1. smaller
  2. shorter fingers

- Feet:
  1. Gap between 1\textsuperscript{st} and 2\textsuperscript{nd} toe
  2. Flat feet
Example
Examples
Gait, Posture, Shoe wear and Orthotics
Gait Tendencies

Heavy footed pattern
Flat arches, primary weight bearing on inside border of foot
Walk with feet turned out
Complaints of foot pain and significant callousing
Tight heel cords/resulting in rigidity at the ankles
Benefit of good shoe wear

Improves posture - not just at the feet but up the chain
Foot alignment - improved mechanics at the feet/endurance
Improves balance - uneven ground/reducing risk of ankle/knee instability
Examples of good vs poor shoe wear

**Good**
- Athletic shoes- New Balance, Asics, Brooks
- Dress shoes- Merrils, Clarks,
- Sandal-built in arch support/heel strap

**Poor**
- Athletic shoes- with no support- Nike free, Sketchers
- Canvas shoe with no support- Converse, Toms
- Flip flops, high heels/wedge
- Ugg
Benefit and limitations of inserts/orthotics

Extension of the shoe
All of the benefits for that you get shoe but more of it
Does not fit in every shoe
Helps if you are able to take out the insole
Does not work with a sandal but some can have them built into them-Birkenstock/Langer
## Differences between devices

<table>
<thead>
<tr>
<th>Inserts/over the counter</th>
<th>Semicustom orthotics</th>
<th>Custom Orthotics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arch support-no posting</td>
<td>Prefab orthotics- Vasyli</td>
<td>Casted- to exact size and shape of foot</td>
</tr>
<tr>
<td>Vary in stiffness from gel to harder plastic</td>
<td>Sizing-small, medium, large</td>
<td>Customize the material</td>
</tr>
<tr>
<td>Found in many stores-Walgreens, Dicks, Running shoe stores</td>
<td>Density-low, med, high</td>
<td>Can tailor to shoe type and activity-dress shoe, soccer cleat</td>
</tr>
<tr>
<td>Last a few months to a few years</td>
<td>Post built in-heat out or add to it</td>
<td>Can add lift, first ray cut out, flanges, deepen heel seat</td>
</tr>
<tr>
<td>Least expensive</td>
<td>Take home same day</td>
<td>Cast is sent out so a delay to receiving</td>
</tr>
<tr>
<td></td>
<td>Less expensive than a custom</td>
<td>Most expensive</td>
</tr>
<tr>
<td></td>
<td>Last 1-3 years</td>
<td>Last 3-5 years</td>
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Why is Physical Therapy important for my person with Down syndrome?

- “Physical therapy is a critical service, not because it will accelerate a child’s rate of development, but because it will improve a child’s long-term functional outcome” Patricia Winders, PT

- “The goal is to minimize the development of Abnormal compensatory movement patterns that children with Down syndrome are prone to develop” Patricia Winders
Four critical areas to improve

1. Normalized gait pattern:
   a. walk with feet and knees pointing straight ahead
   b. a narrow base of support
   c. a long stride
   d. to be able to toe off

2. Postural alignment
   Optimal alignment of hips, knees and ankles to support this walking pattern
Four critical areas continued

3. Postural strength
   a. Strong, upright trunk
   b. Balanced strength between back and abdominal muscles

4. Extremity strength
   a. Strong arms/shoulders
   b. Shoulders should be in middle of side view not forward
Postural alignment
Why is it important to correct these?

- When these four areas are achieved:
  - 1. The child can develop a body with a solid foundation
  - 2. This will support exercise and fitness throughout their life span

*Typical children develop naturally, but a child with Down syndrome is prone to develop compensations
*Therefore, developing physical problems as they grow
So… Why need Physical Therapy and exercise

**Decrease CAD (coronary artery disease)**
- Exercise has shown decrease risk in development of CAD

**Decrease obesity**
- Less weight to carry around
- Ease of movements
- Less strain/pressure on joints
- Improved posture
- Decrease OA (osteoarthritis)

**Decrease sedentary lifestyle**
- Decrease osteoporosis risk
- Become a more functioning part of society
Why Physical Therapy and exercise continued

Improve overall mobility/function
- Less wear and tear on joints
- Participation in general physical education
- More active in home, school and community activities
- Normalize movement patterns
- Improved gait patterns
- Improve postural alignment
Physical therapy and exercise continued

**Improve muscle strength**
- allow improved ability to walk, sit, stand
- dress independently
- balance activities
- overall wellness
- improved postural alignment
- Improved control of ligament laxity
Physical therapy and exercise

Decrease constipation
  increased core strength
  increased exercise can promote improved digestion/motility

Decrease/slow down Alzheimer’s symptoms
  Physical activities may improve cognition

Decrease Osteoarthritis/osteoporosis
  Improved activity level
  Increase strength around joints/dec. ligament laxity movements
  Maintain ideal body weight
Functional Physical Therapy Goals

1. Improve muscle strength to allow standing for 3-4 hours in the home, community/work
2. Improve balance to allow independent gait on level/unlevel surfaces
3. Increase balance to allow independent dressing at home, school and in the community
4. Increase balance to allow stair climbing
5. Improve foot positioning to improve gait mechanics
6. Improve foot positioning to allow longer standing /walking in the community/work/school

7. Improve lower extremity (LE) posturing to return to more normalized loading thru joints

8. Increase LE/core strength to help support posture to normalize load thru joints

9. Restore normal movement patterns to decrease wear and tear on joints
Resources

1. Special Olympics: have exercise videos on line
2. Local SRA have exercises classes, sports activities, nutritional classes, etc.
3. Adult Down syndrome clinic: has videos and classes
4. Physical therapy locations
5. Local fitness centers and workout clubs: some specific to people with special needs
Any questions?

Thank you for letting us present to you today!!!


