But I Don’t Do Peds...

Lifespan Considerations for Adults with Developmental Disabilities

2016 Spring OPTA Conference
Joyce Lammers and Lindsay Elchert

Our Background

Lindsay Elchert, PT, Ph.D. Lindsay is a physical therapist with 10 years’ experience treating pediatric and adult patients with developmental disabilities. She is an Assistant Professor at the University of Findlay and teaches, lifespan development, therapeutic exercise, motor control, and neuromuscular content. She received her Ph.D. from Nova Southeastern University in 2013.

Joyce Lammers, PT, MHS, PCS. Joyce is a Certified Pediatric Specialist, NDT and SIPT trained and has more than 25 years’ experience working with developmental disabilities across the lifespan. She is an Assistant Professor at the University of Findlay and teaches research, lifespan, pediatric and adult neuromuscular content. She is a Ph.D. candidate at Nova Southeastern University.

Why this Presentation?

1. Story from one of our graduates
2. Story from a student
3. Our experiences
4. Recent literature
Learning Objectives:

1. Participants will be able to identify key impairments in body function and structure for persons with developmental disabilities such as cerebral palsy, autism, myelomeningocele and Down syndrome over the lifespan.

2. Physical therapists will be able to identify key activity limitations or participation restrictions for persons with developmental disabilities such as cerebral palsy, autism, myelomeningocele and Down syndrome over the lifespan.

3. Physical therapists will be able to identify key precautions, contraindications and safety considerations for persons with developmental disabilities such as cerebral palsy, autism, myelomeningocele and Down syndrome over the lifespan.

4. Physical therapists will be able to design a plan of care for a hypothetical adult patient with a developmental disability.

Barriers for PTs in adult practice working with DD

Background

- Individuals with DD often have long term orthopedic stressors/pathological gait/ abnormal biomechanics
- Individuals with lifelong disabilities living longer (Orlin)
- Peds therapists role(Orlin)
- Aging out
- Healthy People 2020
- ACA
- APTA HOD RC 34-05
  - Continuum of care for Lifelong Disabilities task force
Adulthood with Developmental Disabilities

Aging with a Disability - Health Issues

Musculoskeletal
Metabolic/Endocrine
Genitourinary/Elimination
Fatigue/Sleep

Growing Up with a Lifelong Disability: Rehab

(Moll and Cott)
Quotes

Growing Older With Cerebral Palsy: Insiders’ Perspectives

They pretty much let you go with pretty much no resources...once I was 18...they cut you loose and said 'we can’t do anything for you now, and you’re on your own' and that was it...”

“I will think right now if I went back to therapy I could still learn a lot and improve on different things”

“There’s very limited information; there’s not too many people I can turn to for advice. The medical personnel don’t seem to know whether they’re coming or going half the time—they don’t know enough. They can’t tell you what to expect. The medical expertise drops when you’re 19. Like there doesn’t seem to be anyone that carries through from childhood to beyond...”

Down Syndrome

Impairments in Body Structure and Function

- Hypotonia/reduced postural tone
- Ligamentous laxity/hyperextensibility
- Poor postural control/balance
- Decreased strength (hip abductors and knee extensors)
- LE/Foot alignment
Activity Limitations

- Motor delays leading to compensatory strategies
- Decreased adaptability in motor skills
- Slow and insufficient reactions to perturbations
- Gait deficits (wide BOS, decreased velocity and stride length, increased knee flexion at initial contact)
- Difficulty with activities requiring motor planning
- Decreased physical activity levels

Participation Restrictions

- Decreased ability to keep up with peers
- Decreased work and recreational opportunity

Aging with DS

- Average life expectancy: 60 yrs
- Obesity
- 30% incidence of mental health illness
- Alzheimer’s-type Dementia
- Musculoskeletal concerns
- Decreased bone density
- DJD
Exercise Parameters for Youth with DS

- **Strength Training Recommendations**
  - 2-3 X/wk
  - 1-3 sets of 8-12 reps

- **Aerobic Training Recommendations**
  - Perform aerobic capacity test
  - May have lower max HR

Intervention Considerations for Adolescents and Adults-Lindsay

- Refine postural control and balance strategies
- Weight-bearing activities
- Health promotion
- Increase physical activity level
  - Monitoring and positive reinforcement may be needed

What Does the Research Say?

- Progressive resistance training can increase strength in individuals with DS (Cowley et al, Shields et al, Rimmer et al)
  - Strength gains can translate into functional gains
  - Time to ascend/descend 10 stairs
- Conflicting findings on improvements in aerobic endurance (Barnhart and Connolly)
  - Limited research in adults >30 yrs
Precautions/Contraindications

• S/S SC compression
• S/S respiratory distress, heart failure
• A/A A/O laxity/subluxation
• Potential of joint hypermobility; check alignment during activities

Myelomeningocele

Impairments in Body Structure and Function

• Paralysis complete or incomplete at varying levels
• Sensory loss
• Possible decreased cognitive function
• Incontinence of bowel/bladder
Activity Limitations

• Limitations in walking
• Limitations in standing
• Difficulty with transitions
• Decreased self-care activities

Participation Restrictions

• Difficulty participating/accessing community building and activities
  • Religious activities
  • Arts and entertainment
  • Public transportation
• Difficulty accessing recreational activities
• Underemployment

Aging with Myelomeningocele

• Walking with Myelomeningocele
• Overuse
• Pain
• Osteoarthritis
• Overstretching
• Loss of mobility
Exercise Parameters for Youth with Myelomeningocele

• Strength Training Recommendations
  • Train active muscle groups
  • 2-3X/wk
  • 1-3 sets of 8-12 reps

• Aerobic Training Recommendations
  • If ambulatory, consider progressive treadmill training program

Intervention Considerations for Adolescents and Adults

• Contracture management
• Weight bearing
• Physical activity promotion
• Long-term function

What Does the Research Say?
Precautions/Contraindications

- Shunt malfunction signs
- Cord tethering
- Chairi malformation
- Osteoporosis
- Hip integrity

Cerebral Palsy

Impairments in Body Structure and Function

- Abnormal muscle tone
- Decreased muscle performance
- Decreased postural control
- Reduced selective voluntary control
- Impaired sensory processing
- Impaired endurance
Activity Limitations

- Decreased mobility, all locomotion
- Decreased self-care activities (feeding, toileting, bathing etc.)
- Difficulty with grasp and handwriting

Participation Restrictions

- Difficulty participating/accessing community building and activities
  - Religious activities
  - Arts and entertainment
  - Public transportation
- Difficulty performing and accessing recreational activities
- Underemployment

Gross Motor Function Classification System (GMFCS-E and R)

- **LEVEL I** - Walks without Limitations
- **LEVEL II** - Walks with Limitations
- **LEVEL III** - Walks Using a Hand-Held Mobility Device
- **LEVEL IV** - Self-Mobility with Limitations;
  - May Use Powered Mobility
- **LEVEL V** - Transported in a Manual Wheelchair
Aging with CP

- Pain
- Fatigue
- Joint contractures/malalignment
- Osteoarthritis
- Overuse syndromes
- Nerve entrapments, Radiculopathy, Myelopathy

Precautions/Contraindications

- Osteoporosis - especially if non-ambulatory
- Uncontrolled/new onset seizures

What Does the Research Say???

**Strength**
- Strength deficits: 53-69% (Moreau et al, deGroot)
- Hypertrophy with resistance training for those with CP with no adverse effects (i.e. increased spasticity)

**Power**
- Power deficits: 67-82% (Moreau et al, deGroot)
- Improved muscle power with velocity training
What Does the Research Say???
Moreau et al cont.

Strength group: 6 sets of 5 reps, set slow velocity
Velocity group: 6 sets of 5 reps, increasing velocities
• Both groups: hypertrophy and increased strength
• Velocity group only: increases in peak power and peak velocity; improvements in functional walking:
  • TUG: 12% improvement (1.52 sec)
  • 1-minute-walk test: 9% improvement (7.9 m)

Dosing Resistance Training

<table>
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<th></th>
<th>Intensity</th>
<th>Volume</th>
<th>Speed</th>
<th>Frequency</th>
<th>Rest</th>
<th>Duration</th>
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<tbody>
<tr>
<td>Speed</td>
<td>≤85% 1RM</td>
<td>Build up to 3 sets of 6-10 reps</td>
<td>Slow to moderate; controlled</td>
<td>2-3x/wk</td>
<td>1-2 min. between sets</td>
<td>≥ 8 weeks</td>
</tr>
<tr>
<td>Power</td>
<td>40-60% 1RM</td>
<td>Build up to 3 sets of 6 reps</td>
<td>Concentric phase: as fast as possible; Eccentric phase: slow and controlled</td>
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Exercise Parameters for Youth with Cerebral Palsy

• Strength Training Recommendations
  • 2-3 X/wk
  • 1-3 sets of 6-15 reps
  • Be able to perform 3 sets before increasing intensity
  • Improve 30-50% in 8-12 wks

• Aerobic Training Recommendations
  • Perform aerobic capacity testing
What Does the Research Say??

**Aerobic Fitness/Physical Activity**

Aerobic capacity not significantly different *(deGroot)*

- Although research suggests that adults with CP spend more time in sedentary behavior and less time in physical activity *(Ryan et al)*
- Reference values for aerobic fitness in individuals with CP aged 6-20 yrs.) developed in 2010 *(Verschuren et al)*
- Treadmill training

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**Intervention Considerations for Adolescents and Adults**

- Appropriate dosing
- Many lose ambulation
- Biomechanics

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**Sensory Processing Disorder**
Sensory Processing Disorder

What is it?

Sensory Processing Disorder

Why should I care about it in adults?

1. Defensiveness-
   - sound,
   - fragrance
   - touch
2. Motor Planning and following commands
3. Proprioceptive
4. Other considerations
Sensory Processing Disorder

Great Resources
- APTA Academy of Pediatric Physical Therapy Fact sheets
- The Out of Sync Child
- Occupational therapy practice guidelines for children and adolescents with challenges in sensory processing and sensory integration

What Does the Research Say???

Autism
Definition

DSM-5, Autism Spectrum Disorder. Diagnostic Criteria

• Persistent deficits in social communication and social interaction
• Restricted, repetitive patterns of behavior, interests, or activities
• Symptoms present in the early developmental period
• Symptoms cause clinically significant impairment
• No other better explanation

Key Points for POC all ages persons with Autism

• Ask about pain and comfort
• Don’t insist on eye contact
• Difficulties in reading social cues and body language.
• Don’t get offended
• Don’t talk too loudly or yell
• Do NOT touch without warning.

Key Points for POC all ages persons with Autism

• Find out how the person communicates
• Find out routines, likes and dislikes
• Simple commands, maybe even demonstrate
• Use clear concise CONCRETE LANGUAGE
Exercise Parameters for Youth with Autism

**Strength Training Recommendations**
- PRE according to NSCA

**Aerobic Training Recommendations**
- Moderate-vigorous physical activity may reduce stereotypical behaviors

What Does the Research Say???

Additional hints & summary
Summary

- Consider cardiovasc status
- Consider fitness/recreation
- Consider that some persons may need supervision
- Consider sensory input ---can be overwhelming
  - Firm touch not light touch
  - Sounds
  - Visual

What if you get a referral for Dx you don't know

http://rarediseases.org/

APTA Academy of Pediatric Physical Therapy
Your PT textbooks Campbell, Umphred and O’Sullivan
PT Now
Internet Search for dx and national association

PRACTICAL HINTS

Contact local peds therapists
abnormal biomechanics = you have something to offer
Almost always can address strength/power/core/balance
If you are not sure about communication, ask caregiver
CSM and NEXT and OPTA: consider going to Peds content
See the person first then the disability
References

- Pediatric Practice Forum: Making decisions related to the intensity of pediatric services; Combined Sections Meeting; February 4, 2014; Las Vegas, NV.