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Keys For Success

Strategies for Working With Teens and Young Adults With Autism Spectrum Disorders

Melissa Moran Tovin, PT, MA, PhD, PCS

Associate Professor
Department of Physical Therapy
mtovin@nova.edu

Self-assess

• What do I know about children, teens and adults with ASD?
• What are the unique needs of individuals with ASD, and their families, throughout the lifespan?
• What interventions can PT provide for children, teens and adults with ASD?
• What are the significant transition periods for these individuals and their families?
• What role can PT play before, during and after these transitions?
Presentation Objectives

• Describe current statistics and research on intervention outcomes, educational attainment, independent living, health status, and employment for individuals with ASD as they exit the school system.

• Summarize the impact of commonly seen childhood impairments on life transitions and overall wellness of teens and adults with ASD.

• Explain the barriers faced by teens and adults with ASD, and their families, for participation in physical, social, community, and employment activities.

• Identify assistive technology, sensory and other strategies and resources to support and promote successful transitions to adulthood for individuals with ASD, including health management, wellness, employment, and independent living.

• Analyze existing and potential opportunities for physical therapists to provide transitional services for individuals with ASD within the interprofessional practice arena.

• Some Background
DEFINITIONS, FACTS, & STATISTICS

Autism Spectrum Disorder

• Autism spectrum disorder (ASD) is a developmental disability that can cause significant social, communication and behavioral challenges. (CDC, 2016).
• “Autism spectrum disorder (ASD) and autism are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors. “
  – autistic disorder
  – childhood disintegrative disorder
  – pervasive developmental disorder-not otherwise specified (PDD-NOS)
  – Asperger syndrome

(www.AutismSpeaks.org, 2016)

• Autistic Disorder—“classic” autism
  – Significant language delays
  – Social and communication challenges
  – Unusual behaviors and interests
  – May have intellectual disability.
• Asperger’s Syndrome
  – Milder symptoms of autistic disorder.
  • Have social challenges and unusual behaviors and interests.
  • Typically do not have problems with language or intellectual disability.

• Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)- “atypical autism”
  – Meet some of the criteria for autistic disorder or Asperger’s syndrome, but not all.
  – Usually have fewer and milder symptoms than those with autistic disorder.
  – The symptoms might cause only social and communication challenges.
Some Statistics

• According to CDC’s ASD monitoring 2012 report, the incidence is 1 in 68 in the U.S
  — 1 out of 42 boys and 1 in 189 girls
• During the 1990’s, autism increased at a rate of 172%
• http://www.cdc.gov/ncbddd/autism/data.html

Lifetime Costs of ASD

• $1.4-2.4 million per individual
  • Closer to 2.4 million if ID is present
  • Child- special ed, lost parental income
  • Adult- residential care, unemployment

• Yearly cost to U.S. is approx. $236 billion per year

(Autismspeaks.org)
Caring across the lifespan

- Are we failing these individuals and their families?
- Can we do a better job assisting and supporting individuals and families with transitions across the lifespan?
  - Reduce need for and level of care?
  - Facilitate improved overall health and wellness?
    - What does this mean?
      - For the individual?
      - Family?
      - Society?

Family Perspectives

- “Lost at Sea”
- Tovin & Braunius, 2014
Family Perspectives


Transitioning to adulthood: “The Perfect Storm”

How do we help prepare for the family to effectively navigate through the storm?

What is their final destination?

How Do we help them get there?
We can help families find their way through the storm...

IMPAIRED, ACTIVITY LIMITATIONS, PARTICIPATION RESTRICTIONS
Impairments

• Commonly seen sensorimotor impairments
  – Delayed gross and fine motor development
  – Persistent reflexes
  – Low tone
  – Structure and alignment issues
  – Impaired balance and coordination
  – Sensory processing disorder
  – Low levels of fitness
  – Obesity/overweight

* Social, emotional, behavioral, language and communication impairments
  – Social-emotional-behavioral
    • Anxiety
    • Depression
    • ADD/ADHD
    • OCD
  – Language and communication
    • Receptive/expressive
    • Includes non-verbal communication
• Intellectual Disability
• Impaired Executive Functioning
ICF Framework

• Thinking about participation
  – Life skills
  – Community
    • PBS Newshour (August 9-10, 2016)
  – Social network
  – Employment
  – Health and wellness

When thinking about transitions, think about participation at the greatest level achievable...

We can help individuals with ASD fulfill their potential in education, employment, social participation, and leisure pursuits in their adult life.
**LITE**

**Leadership**
- Advocacy, seat at the table/Paradigm shift
- Utilize transition concepts within IEP process
- Initiating dialogue about transition with parents, team

**Ingenuity**
- PAL Model
- Future thinking
- Opportunities

**Team**
- Strengthen process with other members of the team
- Work with coaches, employers, community
- Family centered care

**Environment**
- Temporal context
- Community
- Sensory environment
- Social environment

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**THE TEAM APPROACH**
Members of the Team

CONTEXTUAL ISSUES: THE TEAM

• Who is at the table? *Who is not...?*
• Traditional roles: How are they serving as barriers to the transition process?
  – PT- Gross motor, coordination, balance
  – OT- Fine motor, hand writing, sensory processing
  – A lack of understanding exists among parents, other professionals and physical therapists themselves regarding the role PT can play in treating children with ASD (Tovin & Braunius, 2013; Mieres et al, 2012)
    • Growing body of literature on motor impairments of ASD and the role of PT (Downey & Rapport, 2012)
• **Paradigm shift:** Advocating for a place at the table to benefit the student/family
  – Overlap and interprofessional collaboration
  – Roles re-defined
  – Advocacy through leadership at state, county, and school district levels
**LITE: ACTION PLAN**

- Get to the table
  - Inter-professional opportunity to enhance power
  - Consistent language

- Focus on evidence-based approaches
  - Think outside the box
  - Re-Routing

- Temporal context: long term needs and scaffolding of skills

**EVIDENCE BASED PRACTICE**
Obesity

• Some research indicates that obesity rates are greater in children with ASD, and that children with autism are 40% more likely to be obese than children without autism. (Curtin et al., 2010; Rimmer et al., 2010)

• Many factors contribute to obesity in this population
  – Low physical activity levels
  – Poor nutrition
  – Medication use
  – Metabolic abnormalities
  – Lack of knowledge or awareness
    (Rimmer et al., 2007; Srinivasan et al., 2014)
• Social and communication impairments, behavioral issues, sensory processing difficulties, and motor incoordination may preclude participation in school-based or recreational physical activities. (Tovin, 2013)

• Obesity rates are greater for older children with autism because they are significantly more physically inactive than younger children (MacDonald et al., 2011)

• This can have important ramifications as these children transition into adulthood
  – diabetes
  – other obesity-related health issues
  – Participation restrictions
• Obesity is correlated with deficits in executive functioning (EF) (Barkin, 2013)
• Sleep problems are more prevalent in ASD, role of PA (Reynolds & Malow, 2011; Brand et al., 2015; Wachob & Lorenzi, 2015)
  – Exercise can promote improved sleep

**EBP: Physical activity**

• Positive effects of physical activity and exercise beyond health benefits related to weight management and obesity prevention
  – Improved motor function and exercise capacity (Pitetti et al., 2007)
  – Reduced self-stimulatory behaviors (Petrus et al., 2008)
  – improved self-esteem, mood, and attention (Oriel et al., 2011)
  – social interaction and participation.
  → improved ability and desire to participate in peer group physical activities and sports.

✔ This level of engagement can further improve self-esteem, reduce depression, reduce social stress, and facilitate self-management skills (Muller et al., 2008)
Physical Activity and Physical Fitness

• Important for wellness and participation at all levels, and increasingly important as the child grows older.
  – Toddler Years
  – Childhood Years
  – Teenage Years
  – Adult years

Barriers

• Barriers to participation in community-based physical activity and fitness programs
  – Behavior (SPD, tantrums, OCD, anxiety)
  – Executive functioning
  – Safety concerns
  – Financial limitations
  – Time
  – Fear of bullying
  – Lack of support
  – Lack of appropriate programming to meet wide range of needs
  – General lack of information, poor outreach and a burden for the parent to seek out a program which meets the individual need of their child.

(Tovin & Braunius, 2014)
Executive Functions (EF)

- You already work on this...
- We lack consistent taxonomy, but typically
  - Attention
  - Problem solving
  - Sequencing
  - Self monitoring
  - Initiating and completing tasks
  - Goal setting
  - Metacognition

- Foundational building blocks:
  1. Impulse control
  2. Cognitive flexibility
  3. Working memory

Developmental Sequence:

Welsh (2001)

- **Cycle I: 18 mos-5 years**
  - Inhibition, working memory, simple flexibility
  - Primarily *motor-related*
- **Cycle II: 5-10 years**
  - Dramatic increase in tasks that require planning, working memory, inhibition, self-monitoring
- **Cycle III: 10-14 years (and on)**
  - Emphasis on integration of processes
Environment and EF: Garon et al. (2008)

**Dysfunction**
- If attention is the basic building block of EF,
- Frontal lobe heavily depends on environment for emerging EF
  - Experience: expectant development of frontal networks (slow pace, dependent on environmental stimulation, and reliance on varied basic cognitive skills)
  - THEREFORE: Extremely vulnerable to dysfunction

**Function**
- EF problems found in neurodevelopmental disorders and other pediatric disorders
- Nature of EF that makes it vulnerable is a source of untapped opportunity...
  - "AMENABLE TO ENVIRONMENTAL REMEDIATION"
  - Perfect for motor learning, SI, physical activity in nature

6 Approaches for EF School Years: EBP (Diamond & Lee, 2011)

- **Martial arts/Mindfulness**
- **Aerobic exercise**
- **Montessori approach**
- **School based programs**
- Computerized trainings*
- Hybrid of computer and non-computer games
EBP with EF

- Use evidence-based approaches to link PA and health/well-being and PA with executive functioning and life skills training
  - Physical outlet—pick one of interest, tie to personal and IEP goals
  - Self-management, planning, setting goals for wellness and self advocacy
  - Endorphins—anxiety
  - Sensory—choosing activities that fit with sensory processing style and needs to promote self-regulation and potential sensory competence

PARTICIPATION NEEDS AND TRANSITIONS FOR TEENS AND YOUNG ADULTS
PAL Model (Quint N, 2014)

Plan
- Assess client, environment/context, health needs, development
- Relate to transition process/Temoral
- Developmental

Access
- Participation
  - Physical activity routine
  - Extracurricular Activity
  - Community integration and engagement

Learning
- Motor Learning as key
- Physical activity and EF
- Embedded EF
- Social skills and social thinking
- Physical Activity: Self regulation and sensory to control anxiety
- PROCESS and outcome
PAL: Temporal Context

- Prepare for the storm and “build a bigger” boat
  - Age 16 is federally mandated
  - Evidence supports: elementary school years (14 latest)
  - Elementary can involve initial components of EF
    - Impulse control
    - Working memory
    - Cognitive flexibility
      - Embed within current goals with focus toward future needs

Adolescent/Teen
Middle school → High school

<table>
<thead>
<tr>
<th>School</th>
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<tbody>
<tr>
<td>• Participation:</td>
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<tr>
<td>• Group learning activities</td>
</tr>
<tr>
<td>• Modulation; Self-regulation; Communication</td>
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<tr>
<td>• Positioning</td>
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<tr>
<td>• Chair</td>
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<td>• Carpet/floor</td>
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<tr>
<td>• Peer socializing/friendships</td>
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<tr>
<td>• Relationships</td>
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<tr>
<td>• Extra-curricular (sports, clubs, arts)</td>
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<td>• School day transitions</td>
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<tr>
<td>• Safety</td>
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<td>• Self; others</td>
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<table>
<thead>
<tr>
<th>Home/Community</th>
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<tbody>
<tr>
<td>• Participation-</td>
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<tr>
<td>• Socialize with peers/siblings</td>
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<tr>
<td>• Family Activities (includes siblings)</td>
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<tr>
<td>• Routines (in home, out of home)</td>
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<tr>
<td>• Leisure (play, recreational activities, vacation)</td>
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<tr>
<td>• Chores</td>
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<tr>
<td>• Homework</td>
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<tr>
<td>• Self-care</td>
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<tr>
<td>• Employment</td>
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</tbody>
</table>
- Challenges
- PT Roles
- Resources

### Adults- Post-Secondary Placement

<table>
<thead>
<tr>
<th>College; voc training; adult day program</th>
<th>Home</th>
<th>Community</th>
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<tbody>
<tr>
<td>- Participation:</td>
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<tr>
<td>- Group learning activities</td>
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<tr>
<td>- Modulation; Self-regulation;</td>
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<td>Communication</td>
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<td>- Positioning</td>
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<td>Chair</td>
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<td>Carpet/floor</td>
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<tr>
<td>- Peer socializing; friendships</td>
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<tr>
<td>- Relationships (intimacy)</td>
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<tr>
<td>- Transitions</td>
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<td>- Extra-curricular (sports, clubs, arts)</td>
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<td>- Safety (Self, others)</td>
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<tr>
<td>- Participation</td>
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<tr>
<td>Independent living</td>
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<td>Self-care</td>
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<tr>
<td>Household Chores</td>
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<td>Routines</td>
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<td>Relationships</td>
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<td>Leisure</td>
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<tr>
<td>Money management</td>
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<tr>
<td>- Socialize with peers, coworkers</td>
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<tr>
<td>- Leisure (play, recreational activities, vacation)</td>
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<tr>
<td>- Community events</td>
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<tr>
<td>- Healthy living (nutrition, exercise)</td>
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<td>- Transportation</td>
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<td>- Employment</td>
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<tr>
<td>- Understanding and interpreting others' behaviors</td>
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<tr>
<td>- Judging character</td>
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<tr>
<td>- Responding to unpleasant or dangerous situations</td>
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</tbody>
</table>
• Challenges
• PT Roles
• Resources

ASSESSMENT OF PHYSICAL ACTIVITY, FITNESS, AND PARTICIPATION
Physical Activity

• Activity Tracker/Pedometer
• Accelerometer
• Seven-Day Physical Activity Recall (PAR)
  – http://sallis.ucsd.edu/measures.html
• Godin Leisure Time Questionnaire

Physical Fitness

• BMI for Age Percentiles (Barlow 2007, CDC)
  – For children age 2 through 20 years old, BMI is interpreted relative to a child’s age and sex
  – Percentiles specific to age and sex classify underweight, healthy weight, overweight, and obesity in children.

<table>
<thead>
<tr>
<th>Less than 5th percentile</th>
<th>Underweight</th>
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<tbody>
<tr>
<td>5th percentile to less than 85th percentile</td>
<td>Healthy</td>
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<tr>
<td>85th percentile to less than 95th percentile</td>
<td>Overweight</td>
</tr>
<tr>
<td>Equal to or greater than the 95th percentile</td>
<td>Obese</td>
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</table>
• Abdominal Waist Circumference
• Fitnessgram
• Brockport Physical Fitness Test
• 3,6, or 12MWT
• TUDS
• Timed Sit to Stand
• BOT-2
• 1-mile walk/run

Participation

• Starts with an interview
  – Patient (Child, Adolescent, Teen, Adult) and family
  – Participation goals, participation needs
  – Personal and environmental factors
    • eg, sensory, social, emotional, behavioral, cognitive, communication, motivation, etc. (of patient and also others!)
  – Helps establish communication and trust
  – Good interview skills are essential
• Participation Measures
  – Canadian Occupational Performance Measure (COPM)
  – Child and Adolescent Scale of Environment (CASE)
  – Children’s Assessment of Participation and Enjoyment (CAPE)
  – Preferences for Activities of Children (PAC)
  – Participation and Environment Measure for Children and Youth (PEM-CY)
  – School Function Assessment (SFA)
  – (PEDI-CAT)
    • Social/Cognitive Domain

PROVIDING SUPPORT FOR PHYSICAL ACTIVITY, FITNESS AND PARTICIPATION
PT Roles *(LITE)*

- Gross/Fine Motor Function and Development
- Motor Coordination/Control/Planning/Sequencing
- Sensory Integration/Promote Self-regulation
- Skeletal Alignment/Posture/Prevent Deformities
- Physical Fitness
- Self-management of Healthy Lifestyle
- Self-advocacy

- Family Advocate
- Transition Planning/Resources
- Education, Education, Education…
Educate

• Educate families and individuals about the importance of physical activity and fitness, and its relationship to not only health, but *participation and wellness.*

• Provide age-appropriate physical activity guidelines
• Provide options
• Consider values, needs, and lifestyle
• Provide tools to assist with participation and adherence
• Stay connected
• Locate existing programs in the local community
  – Offer assistance and training to staff
  – Provide guidelines
  – Provide tools
  (Tovin, 2013)

Leadership

• Create/develop programs to serve the ASD population in the local community
  – Identify a need
  – Identify and obtain resources
  – Train staff
  – Provide support
PROGRAM EXAMPLES

Two very different cases...
Common Themes from Cases

• Participation
  – Facilitate highest potential for participation for the child/teen/young adult
  – Independence
    • Living
    • Social engagement
    • Occupation
      – School, employment (paid, volunteer, supported)
    • Post-secondary options
    • Wellness/fitness
  – Self-esteem
    • Self-awareness; social awareness
    • Pride- sense of accomplishment
    • Self-worth

Barriers Across the Lifespan

• Poor understanding of how the disability impacts all aspects of performance and participation
Some Take-Aways

• Don’t give up-anticipate barriers
  – Get to the table
  – Find alternatives and options
  – Recruit and train others
  – Be a leader and an advocate
• Transition to other forms of activity when discharging from PT
• Periodic follow-ups
• Get involved in physical activity program development in local community and schools
• Be sensitive, but honest

Self-assess

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• What interventions can PT provide for children, teens and adults with ASD?
• What are the significant transition periods for these individuals and their families?
• What role can PT play before, during and after these transitions?
Knowledge Translation

• KT Steps
  – Identify problem
  – Get buy-in
  – Adapt to local context
  – Anticipate barriers
  – Implement
  – Collect data

  – Rivard et al. 2010; Bornbaum et al. 2015; Schrieber et al 2015

Knowledge Broker-facilitate KT
• Knowledge managers
• Linkage agents
• Capacity builders

Resources
• Transitions tool- Autism speaks
• Autism Speaks Health and Wellness Page
  https://www.autismspeaks.org/family-services/health-and-wellness
• CARD
• Children’s Services Council- Teens Transitions Summit conference for teens and families
• Lynn University- Transitions
• Supported Employment Programs
• Social Stories- http://carolgraysocialstories.com/social-stories/
Questions?

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