Navigating the Transition to Adulthood

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Agenda for Today

1. Background on ASD and Adolescence
2. Impact of ASD on the Family
3. Transition Interventions and Resources
4. Reflection and Discussion
Autism Spectrum Disorder (ASD)

- Areas of Difficulty
  - Social communication
  - Restricted interests/repetitive behaviors
  - 1 in 59 children
  - Lifelong condition
“You have children with autism who are non-verbal, and then you have children with autism who know more words than a university professor. You have children with autism who would rather be by themselves. And then you have those who want friends, but who do not know how to make them.”

– BRENDA SMITH MYLES, Ph.D. Ohio Center for Autism and Low Incidence Columbus, OH
There are 616 combinations of symptoms that meet the minimum criteria for Autistic Disorder.

Maenner, 2012
Challenging Nature of ASD

- Uncertainty surrounding diagnosis of ASD
  - Diagnostic odyssey

- Stressful profile of symptoms and behaviors

- Public misunderstanding of and low tolerance for these symptoms and behavior problems
Transition to Adulthood

• From high school student…
  • College-transfer of rights
  • Employee-

• New daily family routines…
  • Loss of school routine and structure
  • Increase demand independent living skills

• Public school system into adult services
  • May lose services and formal supports
  • Self-determination and readiness
Adolescents and Adults with Autism Study (Mailick & Greenberg)

- Longitudinal study started in 1998 (10 data collection points over 14 years)
- Large sample (n=406 families)
- Wide age range – the “child” was age 10 - 52 at the beginning of the study
- Parallel studies of families of children with fragile X syndrome and Down syndrome as well as studies of families of children without disabilities
Autism Symptoms

- Autism symptoms improved while youth were in high school (symptoms became less severe)

- Improvement continued but slower after HS exit

Taylor & Mailick Seltzer, *JADD*, 2010

Waisman Center, University of Wisconsin – Madison
Figure 1. Change in W−ADL score over time, individual and group trajectories. Quadratic (age^2) mixed−model parameterizations displayed.

Age in years

W−ADL

Intellectual Disability

No ID
Has ID

Daily Living Skills

Smith et al., JAACAP, 2012
What Might Explain This Slowing of Improvement?
Factors Associated with Continued Positive Development

- Inclusion
- Employment
- Positive family relationships
- Family income
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Thinking About the Family

- Individuals with ASD and their family members report high levels of stress.
- This pattern has been observed in families of preschoolers, school-age children, adolescents, and adults.
Diversity of Family Experiences

- “He is all-consuming of our time, energy, patience. It can be emotionally and physically draining to be constantly vigilant of his emotional arousal levels. I cannot work outside the home. It is a full-time job caring for our son.”

- “I’ve tried things and done things I never would have without him, such as running for school board and serving for 15 years. Having him has been a chance to grow in unexpected ways.”
What is the impact of ASD on daily life?
Busy Daily Lives!

- Parents spend more time providing care (almost 5 hours per day) and less time in leisure activities than mothers of children without disabilities

- Just as likely to volunteer and exercise

- High levels of fatigue (50% of days) and interruptions while at work (22% of days)

- Sharp elevation in daily stress
  - Almost 3 times more likely to have a stressful event

Smith et al., JADD, 2010
Impact of Stress on Well-Being

- Stress has long-term effects on health and well-being
  - Depression and anxiety (Barker et al., 2010)
  - Daily emotional well-being (Smith et al., 2010)
  - Cortisol—a stress hormone (Seltzer et al., 2010)
  - Health problems and symptoms (Smith et al., 2012)
How do you handle stress in your life?
Some people . . .

- Laugh
- Drink wine
- Eat chocolate
- Go outside
- Watch TV
- Pintrest
- Yoga
- Listen to music
- Craft

- Take a bath
- Meditate
- Pray
- Pedicure or massage
- Exercise
- Day trip
- Positive self-talk
- Reinterpret situation in positive light
What We Know Works From Research

- Stay connected within and outside of your family
- Keep your environment positive
- Make a plan
- Recognize growth
- Utilize respite and take time for leisure
Role of Social Support

- Having a larger social network was associated with reductions in feeling of depression and increases in positive emotions over time.

- Having less exposure to negative social support (criticism, blaming) also was associated with improvements in well-being.

- The effects of social support were significant above and beyond the impact of difficulties related to the child.

Smith et al., *JADD*, 2012
### Types of Coping Strategies

<table>
<thead>
<tr>
<th>Problem-Focused Coping</th>
<th>Emotion-Focused Coping</th>
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<tbody>
<tr>
<td>Make a plan</td>
<td>Venting</td>
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<tr>
<td>Use problem-solving</td>
<td>Denial</td>
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<tr>
<td>Taking action</td>
<td>Behavioral disengagement</td>
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<td>Seek support</td>
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<td>Relaxation/calming activities</td>
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<tr>
<td>Positivity and growth</td>
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<tr>
<td>Reframe to see the positive</td>
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<tr>
<td>Use positive thoughts</td>
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<tr>
<td>Think about growth</td>
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<td>Adjust expectations</td>
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</table>
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Research Shows Positive Outcomes for Programs that:

- Provide education and support for parents
- Provide opportunities for social interaction and self-determination for adolescents
- Emphasize positivity and problem solving
Problem Solving Process

STEP 1: DEFINE PROBLEM

STEP 2: LIST ALL POSSIBLE SOLUTIONS

STEP 3: DISCUSS ADVANTAGES AND DISADVANTAGES

STEP 4: CHOOSE THE BEST SOLUTION
Support for Families during the Transition to Adulthood

Growing Together

- https://www.waisman.wisc.edu/autism-treatment-programs/growing-together-ages-13-26/
What are Strategies for School Settings?
To improve post-secondary outcomes for students by using high quality professional development and evidence-based interventions to support practitioners, families, and students
Strategies We Can Use

Antecedent Based Intervention
-preparing for what comes next

Functional Behavior Assessment
-listening, understanding, and supporting behavior

Prompting
-providing “just right” cues

Reinforcement
-giving something to look forward to
Strategies We Can Use

Task Analysis
- breaking tasks down into smaller steps (can create a list or schedule)

Time Delay
- giving time to respond/process

Visual Supports
- schedules, lists, pictures, graphics, videos
CSESA Resources

- CSESA is committed to developing high quality resources to meet the needs of staff serving students with ASD
- https://www.facebook.com/csesa.asd
- http://csesa.fpg.unc.edu
Conclusions

- It’s important to understand the family context

- High school teams can:
  - Emphasize peer relationships across settings
  - Provide opportunities to practice job skills
  - Develop and maintain positive relationships with students and their families
Conclusions

- We encourage families to:
  - Reduce exposure to negative/critical people
  - See situations as opportunities for growth
  - Seek support, respite, and leisure
Areas for Community Advocacy

- Services and supports for the entire family across the lifespan
- Quality transition services that emphasize employment opportunities and community involvement
- Within school settings, tailored classes to address social competence and independence
Questions?
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