

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

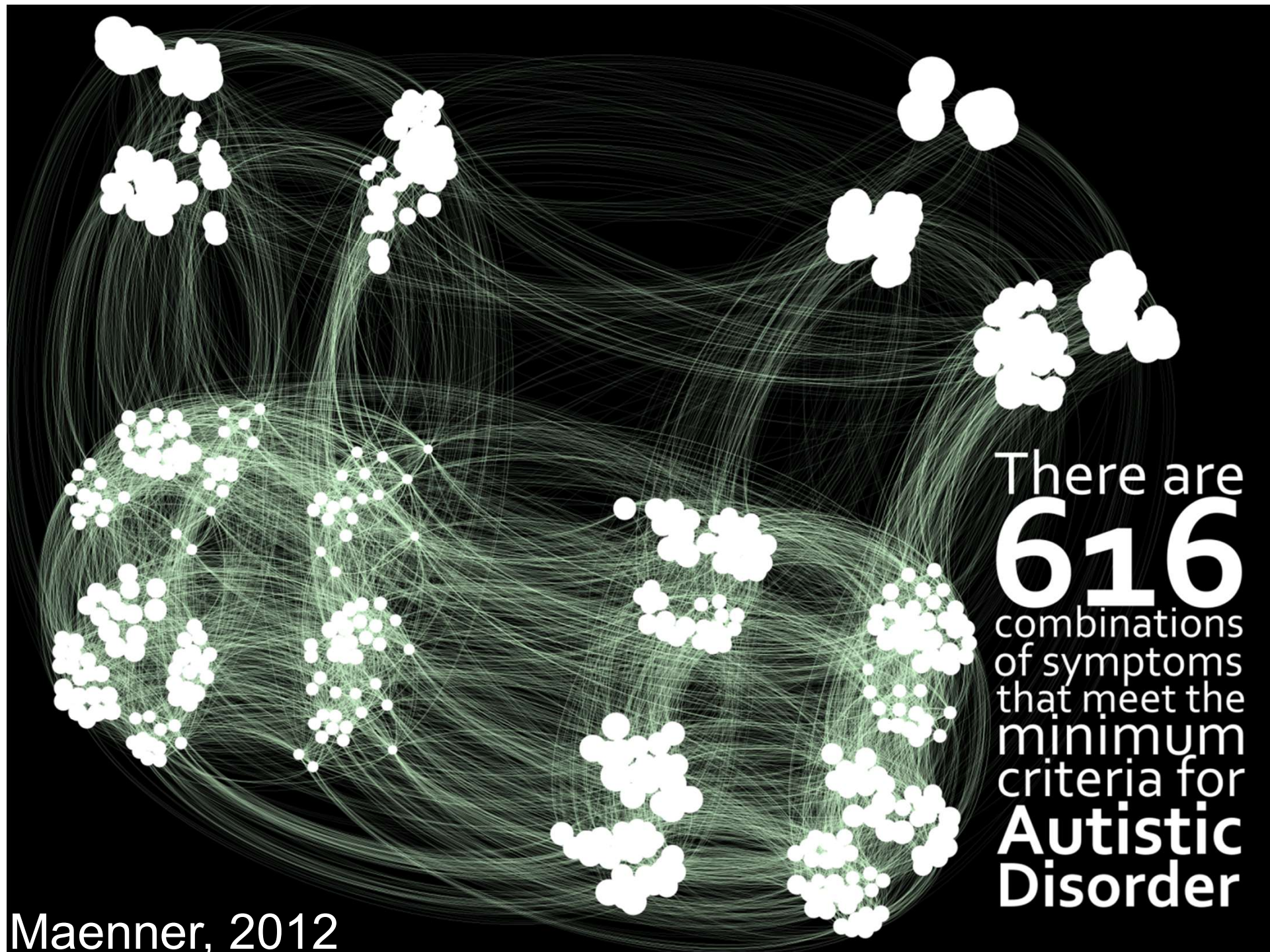


Spectrum of Autism

“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



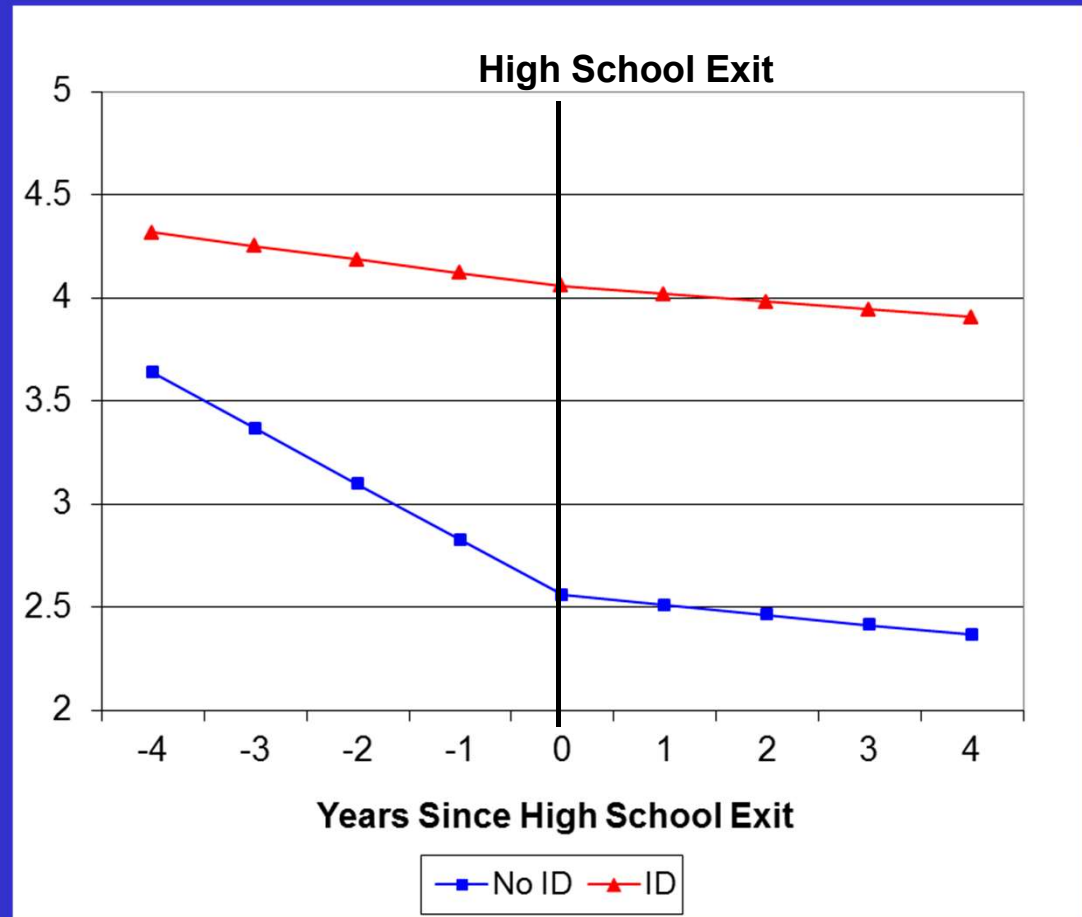
Adolescents and Adults with Autism Study (Mailick & Greenberg)

- 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

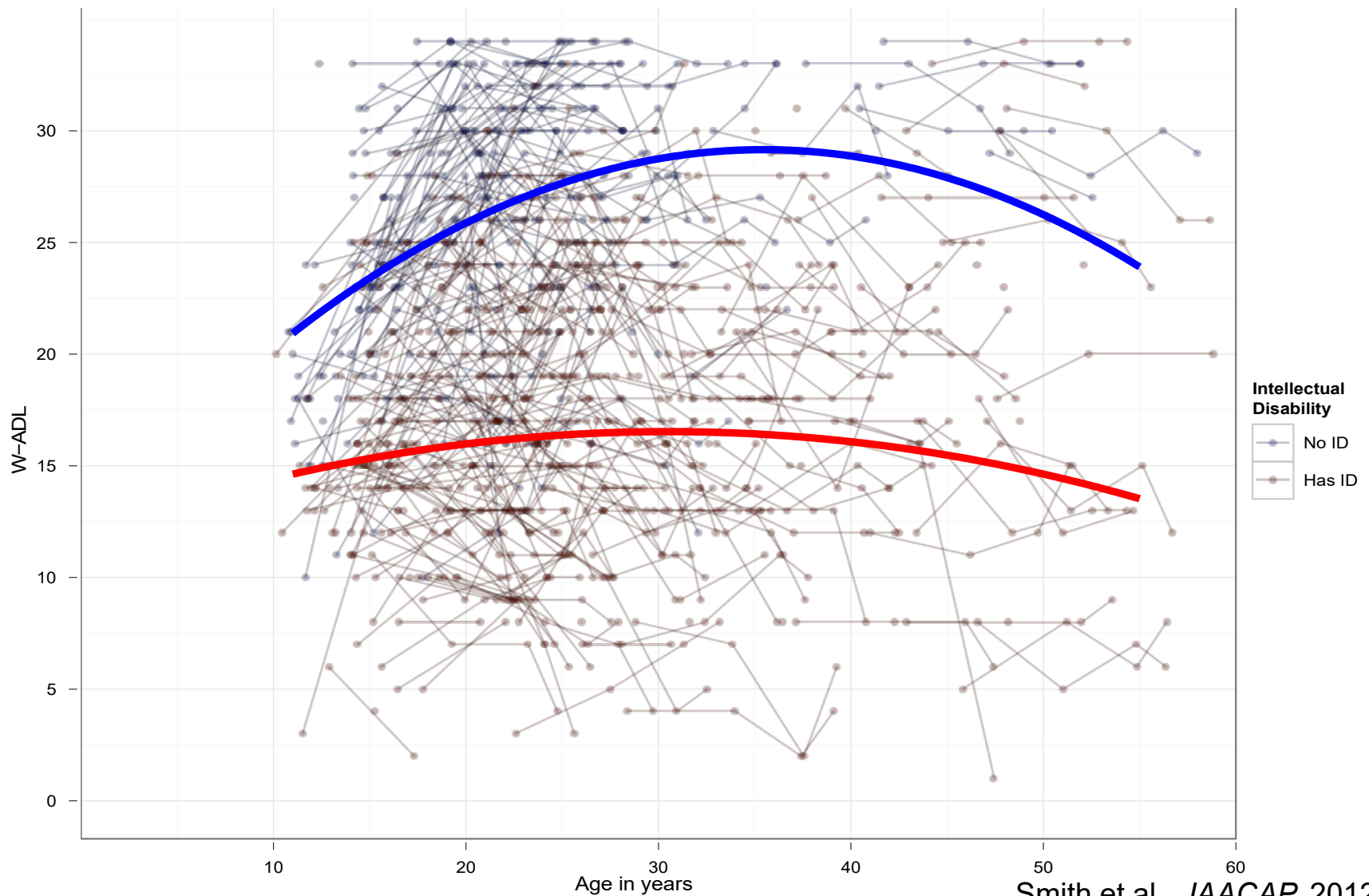


Taylor & Mailick Seltzer, *JADD*, 2010

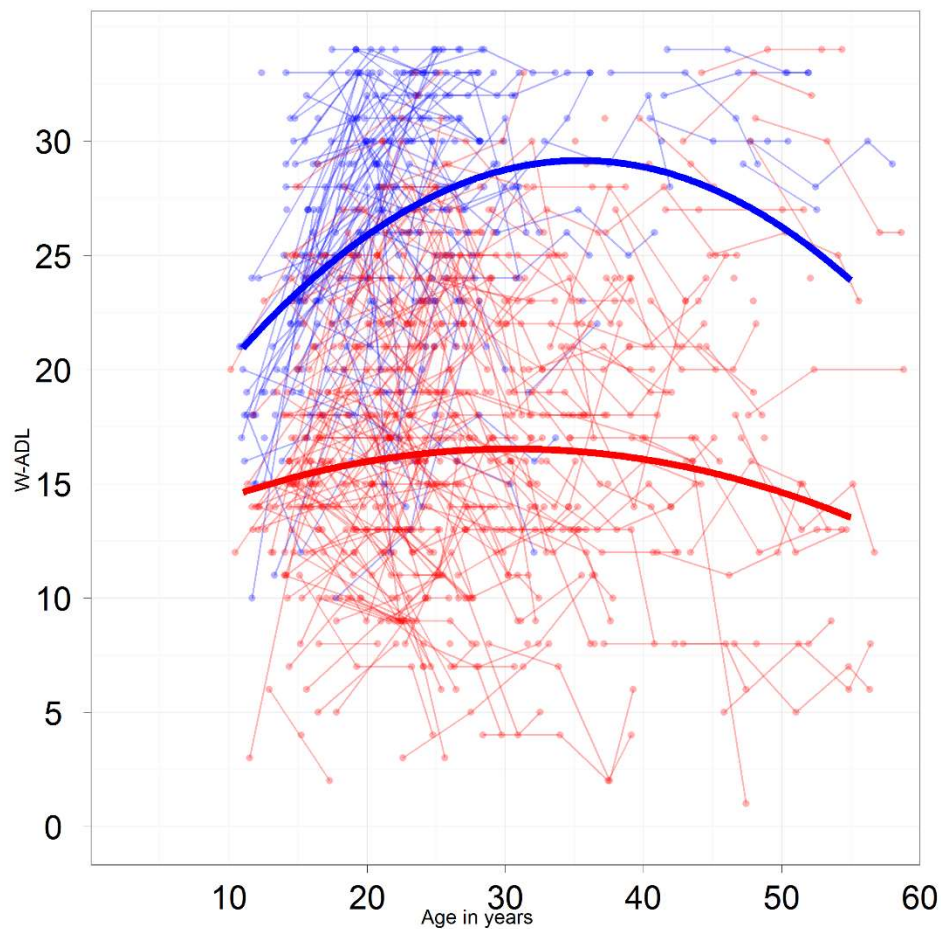


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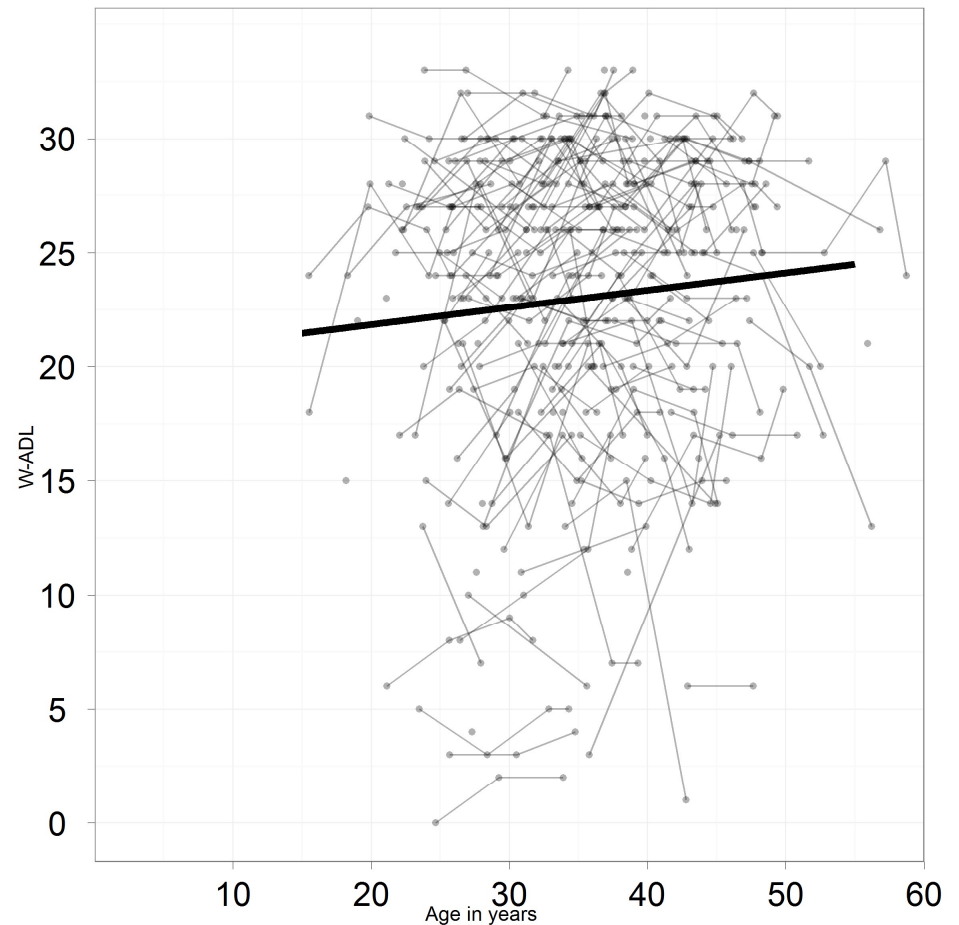
Daily Living Skills



Daily Living Skills--ASD Sample



Daily Living Skills--Down Syndrome Sample



Smith et al., *JAACAP*, 2012



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What Might Explain This Slowing of Improvement?



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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?



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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



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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?



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Some people . . .

- Laugh
- Drink wine
- Eat chocolate
- Go outside
- Watch TV
- Pinterest
- 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 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

Problem-Focused Coping

- Make a plan
 - ▶ Use problem-solving
- Taking action
 - ▶ Seek support
 - ▶ Relaxation/calming activities
- Positivity and growth
 - ▶ Reframe to see the positive
 - ▶ Use positive thoughts
 - ▶ Think about growth
 - ▶ Adjust expectations

Emotion-Focused Coping

- Venting
- Denial
- Behavioral disengagement



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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/>



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What are Strategies for School Settings?



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CSESA

The Center on Secondary Education for
Students with Autism Spectrum Disorders

To improve post-secondary outcomes
for students by using high quality
professional development and
evidence-based interventions to
support practitioners, families, and
students



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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

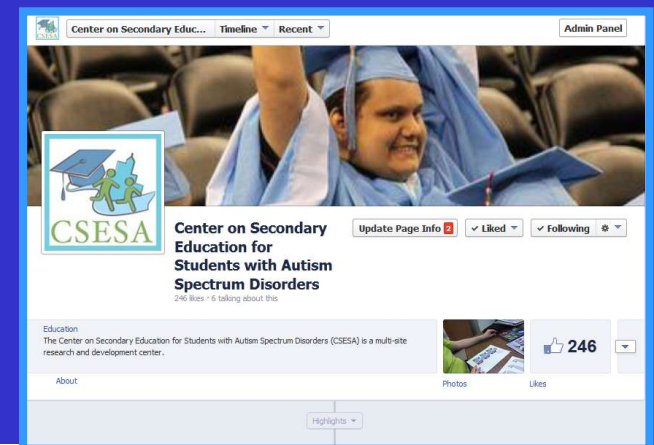
Visual Supports

- 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>



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CSESA Resources

autism at-a-glance

Feb 2014

Autism at-a-Glance is a publication of the Center on Secondary Education for Students with ASD (CSESA)



Supporting Communication in High School

This issue of Autism at-a-Glance focuses on understanding and improving the communication skills of adolescents on the autism spectrum. The content specifically targets the needs of students who are able to communicate conversationally. Examples are provided in the context of academic courses and teacher and peer relationships.

If you serve students with more significant communication needs, please see our Autism at-a-Glance titled Supporting Functional Communication in High School.

Autism at-a-Glance is designed for high school staff members supporting students on the autism spectrum, as well as family members of adolescents on the autism spectrum. Autism at-a-Glance provides a current summary of topics relevant to high school.

Students on the autism spectrum exhibit characteristic difficulties associated with communication. Deficits appear in three main areas: comprehension, expressive communication, and interacting with others.

Comprehension

Understanding verbal and non-verbal communication

Potential Areas of Difficulty Related to Comprehension

- **Speed of processing language.** Students may process comments, questions, and directions more slowly than would be expected for their academic or cognitive abilities or age.
- **Non-literal language.** Students may struggle to understand sarcasm, hyperbole, figures of speech, or other forms of non-literal language.
- **Inferences.** Students may have difficulty reading between the lines or making assumptions based on context.
- **Vocabulary.** the specific words used in a conversation.
- **Point-of-view.** own, which can be challenging.

What This Might Look Like

- Mr. Van Ryn says, "You're a real character," and the student responds with a paper airplane.
- A peer says, "You're a real character," and the student responds with a paper airplane.
- The short story "The Birthday Party" is read aloud.

Signs of Depression in Teens with ASD

Emotions and Mood

- **Increased moodiness** which may include increased anger, irritability, sadness, fearfulness.
- **Feelings of worthlessness or fixation on mistakes.** Alex is noticing that he is different from his peers and this awareness is causing great concern. He often makes comments that he is "not normal" and "will never be normal."
- **Need for excessive reassurance.** Joel is increasingly fearful of black holes and requires frequent reassurance that he will not disappear.
- **Loss of interest or pleasure in previously favorite activities.** Roland always enjoyed swimming at the YMCA but recently is resisting the pool and does not even want to put his swimsuit on.

Behaviors and Skills

- **Aggression.** Caleb is not typically aggressive but in the past month has hit his younger sister several times and pulled his mom when he became frustrated.
- **Indiscreetness.** The choices in the cafeteria suddenly seem overwhelming for Tanelite and she has been getting "stuck" in line.
- **Noticeable decrease in self-care.** Adam has started to move very slowly during his morning routine and is often leaving for school without brushing his teeth, washing his face, or combing his hair.
- **Regression of previously learned skill.** Charley, who usually navigates to the cafeteria and back without assistance, lately is found wandering the halls telling everyone she is lost.
- **Changes in autistic symptoms which may include increased stereotypic behavior or decreased interest in restricted interests.** Kevin used to flap his hands and rock on the floor when he was young. Since he started high school, he is rocking again every day after school.
- **Thoughts or expressions of suicide or self-destructive behavior.**

Health and Wellness

- **Hyperactivity.** Alex usually enjoys reviewing meteorology reports in detail each evening. Lately, however, he has not been able to settle and concentrate at all together.
- **Agitation or restlessness (e.g., handwringing, pacing, inability to sit still).** Hal has been nervous during class periods, and has been tapping her feet continually and getting up to walk around during class time.
- **Fatigue or loss of energy.** Xavier keeps falling asleep in class, even when the class is watching YouTube videos about space, his favorite topic in science.
- **Sleeping too much or too little.** Eli, who is usually the first one up in the morning, is having great difficulty getting out of bed in the morning.
- **Changes in appetite leading to weight loss or gain.** Jackson has stopped eating some of his favorite foods and is coming home with the food in his lunchbox half eaten.
- **Complaints of unexplained body aches and head aches.** Sophie has asked more than once this week to go to the school nurse saying that her arm hurts but the nurse keeps sending her back saying there is nothing wrong with her.

Promoting Social Competence and Peer Relationships for Adolescents with Autism Spectrum Disorders

FPG Snapshot

#75 | March 2014

The interactions and relationships students experience with their peers during secondary school can contribute to successes both during and after high school, influencing academic, vocational, and self-determination skills, as well as personal well-being. The social world during adolescence is multi-faceted. Peer relationships grow in importance and complexity as adult support and presence fades. In addition, students encounter more peers and teachers throughout the day in secondary schools, and the expectations for social interactions are often nuanced across different environments.

While much attention has focused on addressing social competence of young children on the autism spectrum, less is known about promoting the social competence of adolescents with autism. Yet, the social-related challenges associated with autism spectrum disorder (ASD) become even more pronounced as the gap between existing social skills and social expectations widens.

Challenges for Adolescents on the Autism Spectrum



Suggestions for School Staff and Parents

1. Check in with the teen with ASD. Although some individuals with ASD may struggle to communicate emotions and feelings, it is important to check in with teens and see how they are feeling. You can incorporate some type of visual representation of emotions like an emotion meter or a 5-point scale for a regular check-in.
2. Look for changes in behavior. Since individuals with ASD often have characteristics that can mimic or mask depression, it is important to look for changes in behavior. For parents, it might mean paying attention to eating and sleep habits, and looking for changes in mood and behavior around the home and community. For teachers, it might be looking for changes in mood or behaviors during class, or paying particular attention during other times such as transitions, lunch, or clubs.
3. Communicate regularly with team members. Given that behaviors changes may be subtle or may manifest differently across environments, it is important that families and school staff are staying in touch with each other. Parents and school staff should be in regular communication about any changes in behavior in home, school, and community environments.
4. Seek out professional help. If you are concerned about possible depression in a teen with ASD, talk to a professional. Parents can talk to a health care professional who should be knowledgeable of ASD, and then determine if a referral to a mental health professional is needed. For school staff, schools or school districts typically have counselors and psychologists who are trained in recognizing depression, and may be able to support the student.

If you will be meeting with a health professional, make a list of:

- Any major stresses or recent life changes
- Anything different observed lately, even if it does not seem related to depression
- Information from discussions with other people in the teen's life such as school personnel



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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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