

## Autism Update: Applying the Latest Science to Understand, Evaluate, and Educate and Treat Children with Autism Spectrum Disorders with a Focus on Post High School Transition



Sam Goldstein, Ph.D.  
Assistant Clinical Professor,  
University of Utah School of Medicine  
Clinical Director,  
Neurology, Learning and Behavior Center

[www.samgoldstein.com](http://www.samgoldstein.com)  
[info@samgoldstein.com](mailto:info@samgoldstein.com)  
[@drsamgoldstein](https://twitter.com/drsamgoldstein)  
[@doctorsamgoldstein](https://www.facebook.com/doctorsamgoldstein)



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## Relevant Disclosure

- Co-author of the Autism Spectrum Rating Scales (MHS, 2009).
- Co-author of Assessment of Autism Spectrum Disorders 1<sup>st</sup> and 2<sup>nd</sup> Editions (Guilford, 2009, 2018).
- Co-author/presenter Assessment of Autism Spectrum Disorders CEU (APA, 2009).
- Co-author of Raising a Resilient Child With Autism Spectrum Disorders (2011, McGraw Hill).
- Co-author of Treatment of Autism Spectrum Disorders (2012, Springer).
- Co-author of the Autism Spectrum Evaluation Scales (in development, MHS).
- Compensated speaker.



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## COVID 19 and ASD

- Children and youth with ASD are as vulnerable to the effects of prolonged isolation or quarantine as other children but may experience greater difficulty adapting to our new norms, especially as inflexibility and insistence on sameness are hallmark characteristics of this disorder.
- The consequences of a pandemic and the measures put in place to decrease transmission of COVID-19 have the potential to adversely affect children and youth with ASD and their families, including siblings.
- Parental anxiety around job loss, economic uncertainty, lack of access to health care facilities and treatment centers and extension of wait-lists for early intervention programs may cripple a caregiver's or parent's ability to cope with the COVID-19 pandemic.

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### Current COVID/ASD Resources

- Handle the Autism Spectrum Condition during Coronavirus (COVID-19) *Stay at Home* Period: Ten Tips for Helping Parents and Caregivers of Young Children. <https://doi.org/10.3390/brainsci10040207>
- Autism and COVID-19: A Case Series in a Neurodevelopmental Unit <https://doi.org/10.3390/jcm9092937>
- Could Autism Spectrum Disorders Be a Risk Factor for COVID-19? <https://doi.org/10.1016/j.mehy.2020.109899>
- An Expert Discussion on Autism in the COVID-19 Pandemic <https://doi.org/10.1089/aut.2020.29013.sjc>
- Neuropsychology of COVID-19: Anticipated Cognitive and Mental Health Outcomes <https://doi.org/10.1037/neu0000731>

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### What Benefits Do We Derive From Socialization?



- Support
- Survival
- Affiliation
- Pleasure
- Procreation
- Knowledge
- Friendship

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The social development of children with ASD is qualitatively different from other children.




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In normal developing children perceptual, affective and neuroregulatory mechanisms predispose young infants to engage in social interaction from very early on in their lives. They must in order to maximize chances of survival.




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Socialization Begins Early:  
Reina and Her Mother




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When we look at babies  
our brain responds  
uniquely.

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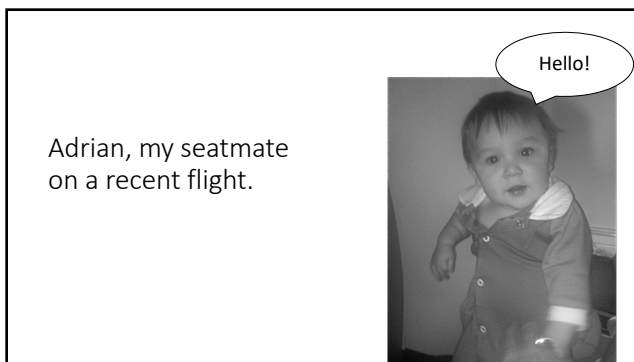
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Adrian, my seatmate  
on a recent flight.

Hello!

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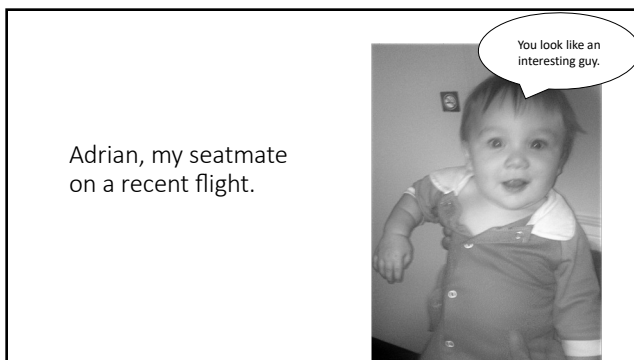
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Adrian, my seatmate  
on a recent flight.

You look like an  
interesting guy.

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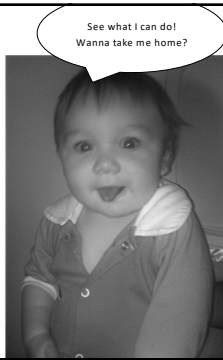
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Adrian, my seatmate  
on a recent flight.



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Pointing



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Observing and Imitating



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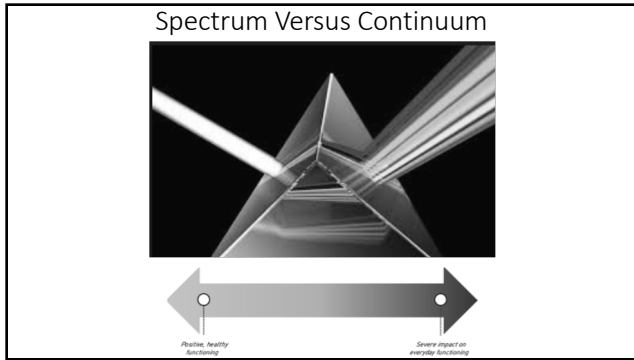
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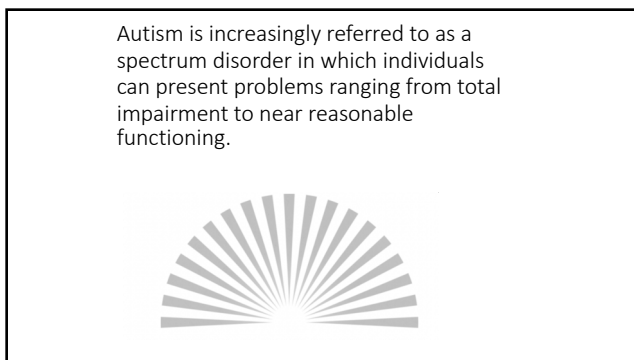
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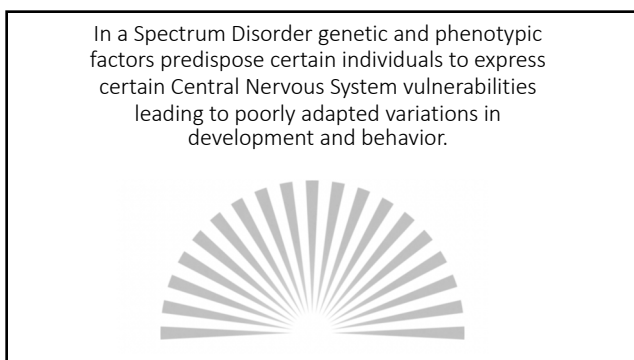
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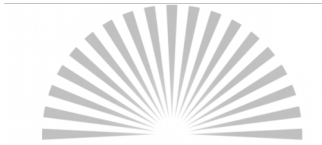
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In a Spectrum Disorder all symptoms are considered relevant to the extent they present in each disorder. Thus a symptom is not exclusive to a disorder.



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The form that a Spectrum Disorder assumes is determined by its composite symptoms. These symptoms often have complex relationships.



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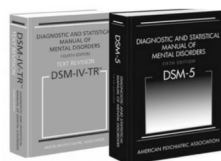
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The DSM 5 Criteria



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## DSM 5

- Combined social and communication categories.
- Tightened required criteria reducing the number of symptom combinations leading to a diagnosis.
- Omitted Retts and Childhood Disintegrative Disorder.
- Clarified co-morbidity issues
- Eliminated PDD NOS and Aspergers in favor of Autism Spectrum Disorder.

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## DSM 5

- Five criteria.
- Seven sets of symptoms in the first two criteria – Social/Communication and Restrictive/Repetitive behaviors, interests or activities.
- All three symptoms are required to meet the first criteria (although a typo omits this).
- Two out of four are needed for the second criteria.
- Some symptoms have been combined. Sensory sensitivity has been added.

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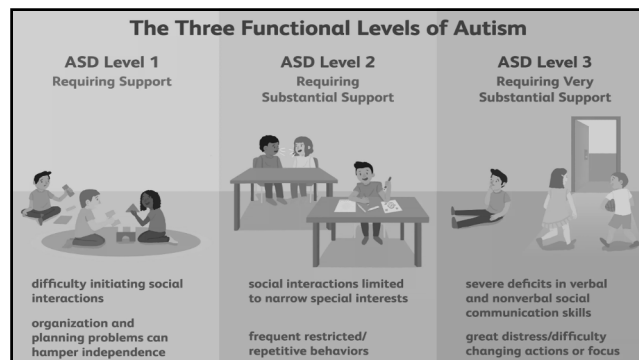
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### DSM 5 Social (Pragmatic) Communication Disorder Criteria A

Persistent difficulties in the social use of verbal and nonverbal communication as manifested by all of the following:

- Deficits in using communication for social purposes, such as greeting and sharing information, in a manner that is appropriate for the social context.
- Impairment of the ability to change communication to match context or the needs of the listener, such as speaking differently in a classroom than on a playground, talking differently to a child than to an adult, and avoiding use of overly formal language.
- Difficulties following rules for conversation and storytelling, such as taking turns in conversation, rephrasing when misunderstood, and knowing how to use verbal and nonverbal signals to regulate interaction.
- Difficulties understanding what is not explicitly stated (e.g., making inferences) and non-literal or ambiguous meanings of language (e.g., idioms, humor, metaphors, multiple meanings that depend on the context for interpretation).

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### DSM 5 Social (Pragmatic) Communication Disorder Criteria B, C, and D

B. The deficits result in functional limitations in effective communication, social participation, social relationships, academic achievement, or occupational performance, individually or in combination.

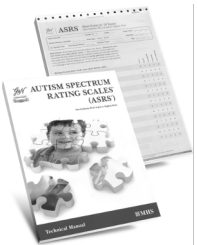
C. The onset of the symptoms is in the early developmental period (but deficits may not become fully manifest until social communication demands exceed limited capacities).

D. The symptoms are not attributable to another medical or neurological condition or to low abilities in the domains of word structure and grammar, and are not better explained by autism spectrum disorder, intellectual disability (intellectual developmental disorder), global developmental delay, or another mental disorder.

NO DISCUSSION OF THIS DIAGNOSIS IN ADULTS!

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### A Statistically Derived Model of ASD



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### Exploratory Factor Analysis for 2-5 Years

- A two-factor solution was best for parent and teacher raters
  - **Factor I:** included primarily items related to both socialization and communication (e.g., keep a conversation going, understand how someone else felt) - **Social/Communication**
  - **Factor II:** included items related to behavioral rigidity (e.g., insist on doing things the same way each time), stereotypical behaviors (e.g., flap his/her hands when excited), and overreactions to sensory stimulation (e.g., overreact to common smells)- **Unusual Behaviors**

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### Exploratory Factor Analysis for 6-18 Years

- A three-factor solution was best for both parent and teachers versions of the ASRS
  - **Factor I:** included primarily items related to both socialization and communication - **Social/Communication**
  - **Factor II:** included items related to behavioral rigidity, stereotypical behaviors and overreactions to sensory stimuli - **Unusual Behaviors**
  - **Factor III:** included items related to attention problems (e.g., become distracted), impulsivity (e.g., have problems waiting his/her turn), and compliance (e.g., get into trouble with adults, argue and fight with other children) - **Self-Regulation**.

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### Factor Consistency

- The consistency of the ASRS scale structure across several demographic groups (gender, age group, race, and clinical status) was studied
- The factor loadings for the groups were correlated using the coefficient of congruence
  - results revealed a very high degree of consistency between all groups
  - indicating that the factor structure of the forms generalized across the demographic groups

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### Current View of ASD In ASRS

- Based on the factor analysis, we suggest that ASD is best described as having two clusters of behaviors for children ages 2-5 and three for those aged 6 to 18 years of age.
  - Ages 2 – 5 years
    - Social / Communication
    - Unusual Behaviors
  - Ages 6 – 18 years
    - Social / Communication
    - Unusual Behaviors
    - Self-Regulation
- This is the organizational form of the ASRS.



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### DSM IV TR Autism and Asperger Syndrome

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### DSM IV TR Autism vs Asperger

- ASRS means for ages 2-5 years were typically somewhat higher for children with Autism than those with Asperger's syndrome
  - Exception being Unusual Behaviors where the two groups were similar
- ASRS means for ages 6-18 years were consistently higher for children with Autism than those with Asperger's syndrome

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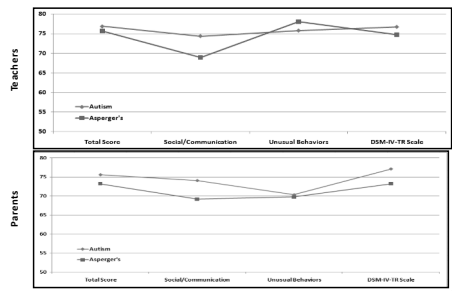
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### DSM IV TR Autism vs Asperger 2-5 Years



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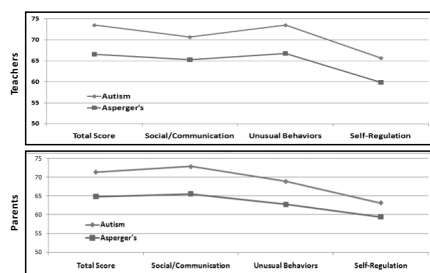
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### DSM IV TR Autism vs Asperger 6-18 Years



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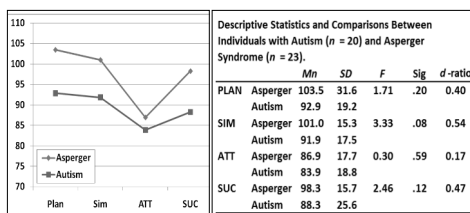
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### DSM IV TR Autism vs Asperger 6-18 Years



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### ASRS 2 Adult Data collection

- Pilot Data collection for the ASRS 2 took place in 2016-2018
- Data was collected from General population and clinical samples
- Data was collected from:
  - Individuals 19 years and older (For the Self-Report form)
  - The individual's spouse, parent or family member (For the Observer-Report Form)
- Data collection resulted in:

Form	General Population	ASD	Other Clinical
Self-Report	466	30	47
Observer-Report	452	22	26

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### Other Clinical Groups Included in the Pilot

- Attention Deficit Hyperactivity Disorder (ADHD)
- Major Depressive Disorder (MDD)
- Generalized Anxiety Disorder (GAD)
- Bipolar Disorder
- Obsessive Compulsive Disorder (OCD)
- Adjustment Disorder

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### Scales For the Adult ASRS 2 Pilot

- Atypical Language
- Attention
- Behavioral Rigidity
- Sensory Sensitivity
- Socialization
- Social/Emotional Reciprocity
- Stereotypy
- DSM 5 ASD

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## Scale Reliability

► **Summary of the Reliability of each scale as measured by Cronbach's alpha** (a measure of internal consistency, that is, how closely related a set of items are as a group).

► **Overall, the alpha values indicate high level of reliability for each scale.**

Scales	Self-Report		Observer-Report	
	General Population	Clinical	General Population	Clinical
Atypical Language	0.88	0.89	0.87	0.94
Attention	0.86	0.86	0.90	0.90
Behavioral Rigidity	0.90	0.94	0.93	0.91
Sensory Sensitivity	0.85	0.90	0.84	0.87
Socialization	0.85	0.92	0.86	0.90
Social/Emotional Reciprocity	0.90	0.93	0.91	0.94
Self-Injurious Behavior	0.86	0.79	0.90	0.82
Stereotypy	0.87	0.91	0.88	0.90
DSM-5 ASD	0.92	0.96	0.93	0.96

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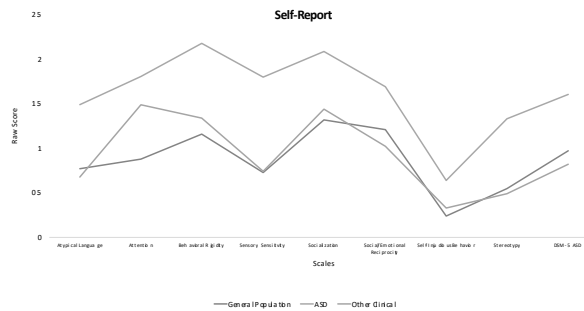
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## Clinical Group Differences (Raw scores)



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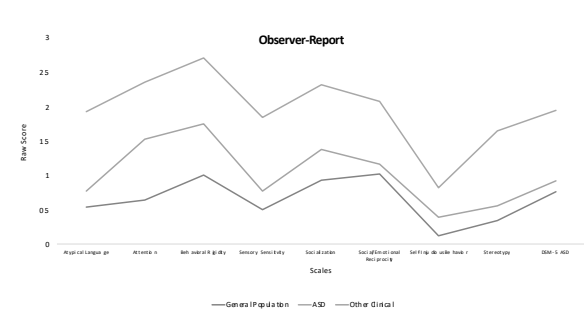
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## Clinical Group Differences (Raw scores)



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## Clinical Group Differences (Cohen's d)

Scales	Self-Report		Observer-Report	
	ASD vs. General Population	ASD vs. Other Clinical	ASD vs. General Population	ASD vs. Other Clinical
Atypical Language	1.21	1.36	2.46	1.38
Attention	1.66	0.49	2.93	1.24
Behavioral Rigidity	1.61	1.19	2.47	1.57
Sensory Sensitivity	1.74	1.60	2.39	1.91
Socialization	1.30	0.94	2.51	1.61
Social/Emotional Reciprocity	0.86	1.23	1.80	1.53
Self-injurious Behavior	0.88	0.62	1.76	0.70
Stereotypy	1.34	1.31	2.62	1.62
DSM-5 ASD	1.49	1.70	2.67	2.36

d= 0.2-0.4 Small  
d= 0.5-0.7 Med  
d >=0.8 Large

For the most part, Large d-values are observed across comparisons, indicating the ability of the assessment to identify individuals with ASD

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We are collecting data for additional new scales for the Adult ASRS 2 including camouflage or coping behaviors and anxiety.

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Evaluating Compensatory Behaviors:  
Social Camouflage in ASD

- Social camouflaging is defined as the use of strategies by autistic people to minimize the challenges of autism during social situations (Lai et al. 2011).
- Social camouflage has recently been a focus of researchers, but has been recognized by clinicians as coping strategies. It is now recommended that clinicians evaluate masking or coping behaviors when assessing autism in the newly released 11th edition of the International Classification of Diseases (Zeldovich 2017).
- This phenomena may be a widespread in ASD, especially in intellectually strong individuals.

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### Social Camouflage in ASD

- Social camouflaging reflects an explicit effort to 'mask' or 'compensate' for autistic characteristics; and to use conscious techniques to minimize an autistic behavioral presentation (Hull et al. 2017; Lai et al. 2017; Livingston and Happé 2017).
- Examples of camouflaging behaviors described in the current literature include as example: forcing oneself to make eye contact during a social interaction; pretending that one is doing so by looking at the space between someone's eyes or at the tip of their nose; or using working memory strategies to develop a list of appropriate topics for conversation.

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### Social Camouflage in ASD: Unanswered Questions

- Do autistic females camouflage more than males, and does this partly account for gender disparities in the rate and timing of diagnosis (Begeer et al. 2013; Loomes et al. 2017)?
- What is the relationship between camouflaging and mental health outcomes?
- How should camouflaging be accurately measured? Is a discrepancy method sufficient to assess the gap between how a person with ASD mediates their internal autistic status and their overt behavior (external autistic presentation)?

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### Measuring Social Camouflage

Livingston and Happé (2017) suggest that camouflaging is a component of social compensation.

The "processes contributing to improved behavioral presentation of a neurodevelopmental disorder such as ASD, despite persisting core deficit(s) at cognitive and/or neurobiological levels".

As such they should be measured at the behavioral, cognitive, and even neurobiological levels.

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Performance on tests of cognition relevant to autism, or scores on self-reported measures of autism traits can only serve as a proxy measure of internal autistic status.

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### Measuring Social Camouflage

- An alternative to the discrepancy approaches is one based on observational recognition of camouflaging; measuring the specific behaviors and experiences which represent camouflaging.
- Observational/reflective methods circumvent the limitation of being unable to measure an individual's internal autistic state. Camouflaging can be measured consistently and compared between individuals, and behaviors can be identified regardless of how successful they may be.
- This approach to camouflaging has the advantage of allowing for variation in camouflaging behaviors and their success. Techniques learned and used in some situations may not be successful in others.
- An individual's overall camouflaging skill may partly depend on their flexibility/generalizable capacity to adapt to different situations.

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### Measuring Social Camouflage

- Both the discrepancy and observational/reflective approaches offer ways to define and measure camouflaging in ASD.
- All the methods used or suggested have their own strengths and weaknesses, thus combining multiple methods may allow for greater accuracy in measuring and identifying a complex phenomenon such as camouflaging.

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### Camouflaging Autistic Traits Questionnaire (CAT-Q)

- Compensation
- Masking
- Assimilation

Laura Hull, William Mandy, Meng-Chuan Lai, Simon Baron-Cohen, Carrie Allison, Paula Smith & K. V. Petrides. Development and Validation of the Camouflaging Autistic Traits Questionnaire (CAT-Q)  
*Journal of Autism and Developmental Disorders*. doi.org/10.1007/s10803-018-3792-6

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### Social Camouflage: Compensation

- Copy others facial expression or body language.
- Learn social clues from media.
- Watch others to understand social skills.
- Repeat others phrasing and tone.
- Use script in social situations.
- Explicitly research the rules of social engagement.

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### Social Camouflage: Masking

- Monitor face and body to appear relaxed.
- Adjust face and body to appear relaxed.
- Monitor face and body to appear interested in others.
- Adjust face and body to appear interested in others.
- Pressured to make eye contact.
- Think about impression made on others.
- Aware of impression made on others.

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### Social Camouflage: Assimilation

- Feel a need to put on an act.
- Conversation with others is not natural.
- Avoid interacting with others in social situations.
- "Performing" e.g. not being oneself in social situations
- Force self to interact with others.
- Pretending to be normal.
- Need support of others to socialize.
- Cannot be oneself while socializing.

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### CAT-Q Sample Items

- When I am interacting with someone, I deliberately copy their body language or facial expressions.
- I learn how people use their bodies and faces to interact by watching television or films, or by reading fiction.
- I have tried to improve my understanding of social skills by watching other people.
- I will repeat phrases that I have heard others say in the exact same way that I first heard them.
- I practice my facial expressions and body language to make sure they look natural.
- I have spent time learning social skills from television shows and films, and try to use these in my interactions.

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### CAT-Q Sample Items

- In my own social interactions, I use behaviors that I have learned from watching other people interacting.
- I have researched the rules of social interactions to improve my own social skills.
- I have developed a script to follow in social situations.
- I monitor my body language or facial expressions so that I appear relaxed.
- I adjust my body language or facial expressions so that I appear relaxed.
- I monitor my body language or facial expressions so that I appear interested by the person I am interacting with.

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### CAT-Q Sample items

- I adjust my body language or facial expressions so that I appear interested by the person I am interacting with.
- I don't feel the need to make eye contact with other people if I don't want to (Reversed scored).
- In social interactions, I do not pay attention to what my face or body are doing (Reversed scored).
- I always think about the impression I make on other people.
- I am always aware of the impression I make on other people.

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### CAT-Q Sample Items

- I rarely feel the need to put on an act in order to get through a social situation (Reverse Scored).
- When talking to other people, I feel like the conversation flows naturally (Reverse Scored).
- When in social situations, I try to find ways to avoid interacting with others.
- In social situations, I feel like I'm "performing" rather than being myself.
- I have to force myself to interact with people when I am in social situations.

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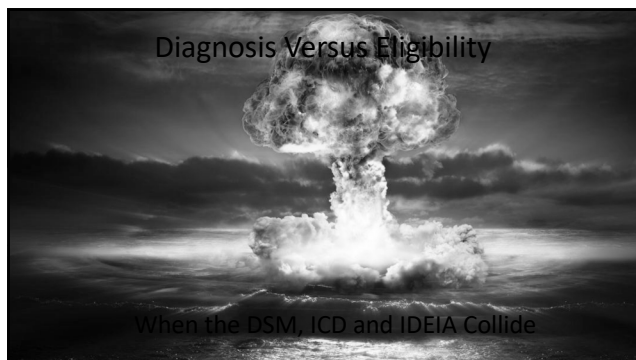
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Students that have a DSM or ICD diagnosis are not automatically eligible for special education services, according to the Individuals with Disabilities Education Improvement Act (IDEIA).

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Educational eligibility and subsequent services are determined by conducting assessments and testing performed by a school's multidisciplinary team and not that of medical diagnostic tests.

These can include observations, history, developmental information, behavior information and a documented prevalence over a period of time.

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### Federal Guidelines For Autism Eligibility

**(a) General.**

**(1) Child with a disability** means a child evaluated in accordance with §§ 300.304 through 300.311 as having mental retardation, a hearing impairment (including deafness), a speech or language impairment, a visual impairment (including blindness), a serious emotional disturbance (referred to in this part as "emotional disturbance"), an orthopedic impairment, autism, traumatic brain injury, an other health impairment, a specific learning disability, deaf-blindness, or multiple disabilities, and who, by reason thereof, needs special education and related services.

**(2)**

**(i)** Subject to paragraph (a)(2)(i) of this section, if it is determined, through an appropriate evaluation under §§ 300.304 through 300.311, that a child has one of the disabilities identified in paragraph (a)(1) of this section, but only needs a related service and not special education, the child is not a child with a disability under this part.

**(ii)** If, consistent with § 300.39(a)(2), the related service required by the child is considered special education rather than a related service under State standards, the child would be determined to be a child with a disability under paragraph (a)(1) of this section.

**(b) Children aged three through nine experiencing developmental delays.** *Child with a disability* for children aged three through nine (or any subset of that age range, including ages three through five), may, subject to the conditions described in § 300.111(d), include a child -

**(1)** Who is experiencing developmental delays, as defined by the State and as measured by appropriate diagnostic instruments and procedures, in one or more of the following areas: Physical development, cognitive development, communication development, social or emotional development; or adaptive development; and

**(2)** Who, by reason thereof, needs special education and related services.

(Authority: 20 U.S.C. 1401(3); 1401(30))

[ 71 FR 46753, Aug. 14, 2006, as amended at 72 FR 61306, Oct. 30, 2007]

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## Federal Guidelines For Autism Eligibility

**(i) Autism** means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.

**(ii)** Autism does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance, as defined in paragraph (c)(4) of this section.

**(iii)** A child who manifests the characteristics of autism after age three could be identified as having autism if the criteria in paragraph (c)(1)(i) of this section are satisfied.

(Authority: 20 U.S.C. 1401(3); 1401(30))  
[ 71 FR 46753, Aug. 14, 2006, as amended at 72 FR 61306, Oct. 30, 2007]

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## Determining Eligibility for Autism Under IDEIA

- Administering a measure of neuropsychological functioning examining planning, sequencing, critical thinking and behaviors related to executive functioning.
- Administering a basic academic battery.
- Administering observational narrow band questionnaires to Teachers (and Parents?).
- Interviewing and observing the student.
- With verbal students, administering self-report measures assessing self-concept, resilience, worry, camouflage behaviors and unhappiness.
- With teens, administering a brief personality measure specifically focused on the development of schizoid personality traits.

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## Determining Eligibility for Autism Under IDEIA

- Many school districts now require the administration of quasi standardized, interactive tools to determine Autism eligibility.
- However, based on these IDEIA criteria and the fact that eligibility determination *is not* the equivalent of a diagnosis, is the administration of such instruments needed?
- Do they add to the accuracy of eligibility determination? Do they add to IEP goal setting?
- It's undetermined at this time. Such tools may provide a practical and convenient framework to interview the student, but are they a necessity as mandated by some school districts?

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## Considering Co-morbidity

- Considerable overlap exists between autism spectrum disorder (ASD) and mental health disorders.
- High rates of overlap are significant because they affect the nature and type of problems displayed by persons with ASD and how the disorders are assessed.
- ADHD, anxiety disorders and depression are among the disorders most commonly associated with ASD.
- Symptom presentation is similar whether ASD occurs alone or with other conditions.
- Multiple assessments after initial diagnosis of ASD are frequently necessary.
- ASD can be diagnosed very early, while symptoms of other disorders emerge at different points in human development.

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Educational Care and Treatment

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## Educational Care and Treatment

- Despite strong claims no curative treatment has been vigorously studied.
- "In the absence of a definitive cure there are a thousand treatments" (Klin).
- Behavior modification, educational intervention and pharmacology have been studied.



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<http://autism.pdpc.unc.edu/content/briefs>

THE NATIONAL PROFESSIONAL DEVELOPMENT CENTER ON  
AUTISM SPECTRUM DISORDERS

It is authorized by statute to provide the use of evidence-based practice for children and adolescents with autism spectrum disorders.

EVIDENCE-BASED PRACTICES Briefs

Home  
About the Center  
Evidence-Based Practices  
Comparison with National Standards Project  
Autism Internet Modules  
Additional Resources  
News and Events  
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**Evidence-Based Practice Briefs**  
Evidence-based practice (EBP) briefs have been developed for at 24 identified evidence-based practices. Select a practice below to access the overview of the practice and downloadable PDF files for the EBP brief and the individual components. An evidence-based practice brief consists of the following core components:

**EBP BRIEF COMPONENTS**

**Overview:**  
A general description of the practice and how it can be used with learners with autism spectrum disorders.  
**Step-by-Step Directions for Implementation:**  
Explicit step-by-step directions detailing exactly how to implement a practice, based on the research articles identified in the evidence base.  
**Implementation Checklist:**  
The implementation checklist offers a way to document the degree to which practitioners are following the step-by-step directions for implementation, which are based on the research articles identified in the evidence base.  
**Evidence Base:**  
The list of references that demonstrate that the practice is efficacious and meets the National Professional Development Center's criteria for being identified as an evidence-based practice.  
Some practices include supplemental materials such as data collection sheets.

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<http://autism.pdpc.unc.edu/content/briefs>

**EVIDENCE-BASED PRACTICES FOR CHILDREN AND YOUTH WITH ASD**

Antecedent-Based Interventions (ABI)  
Computer-Aided Instruction  
Differential Reinforcement  
Discrete Trial Training  
Extinction  
Functional Behavior Assessment  
Functional Communication Training  
Naturalistic Intervention  
Parent-Implemented Interventions  
Peer-Mediated Instruction and Intervention  
Picture Exchange Communication System (PECS)  
Pivotal Response Training  
Prompting  
Reinforcement  
Response Interruption/Redirection  
Self-Management  
Social Narratives  
Social Skills Groups  
Speech Generating Devices/VOCA  
Structured Work Systems  
Task Analysis  
Time Delay  
Video Modeling  
Visual Supports

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## Components of an Effective Treatment Program

- Structured behavioral treatment
- Parent involvement
- Treatment at an early age
- Intensive intervention
- Social skill development
- Coping and camouflage skill development
- Focus on generalization of skills
- Appropriate school setting
- Medication?

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### Components of an Educational Treatment Program

- There has been a shift away from treatment within highly controlled clinical settings to more natural contexts with caregivers and teachers acting as agents of change.
- This has allowed for collaborative treatment and opportunities to teach skills within the context of children's daily routines.
- This approach, known as family/school centered intervention, has also been demonstrated to lead to positive outcomes for ASD.
- Intensive community-based interventions based on PBS and positive support strategies have yielded positive outcomes with respect to enhanced language and communication as well as reductions in problem behavior.

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### Components of an Effective Educational Program

- Determining the effectiveness of any educational program for students with ASD should be accomplished using methods that reflect specific behaviors as well as a larger conceptualizations of the disorder (e.g., social, communication, and atypical behavior problems). The key questions are:
  - How are these behaviors identified?
  - How are these behaviors measured?
  - How do these behaviors change with intervention?
  - What reference point or points will behavior change be calibrated?

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### Medications

- Symptom focused medications: stimulants for attention, anti-depressants for mood, anti-psychotics for "oddities".
- Condition focused medications?



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New Drug  
May Treat  
ASD

30 J. Child. Med. 19 September 2012  
Vol. 4, Issue 152, p. 152n127  
Sci. Transl. Med. DOI: 10.1126/scitranslmed.3004214

RESEARCH ARTICLE

FRAGILE X SYNDROME

Effects of STX209 (Arbaclofen) on Neurobehavioral Function in Children and Adults with Fragile X Syndrome: A Randomized, Controlled, Phase 2 Trial

Elizabeth M. Berry-Kravis<sup>1</sup>, David Heuss<sup>2</sup>, Barbara Rothwell<sup>3</sup>, Peter Zarevski<sup>4</sup>, Maryam Cherubini<sup>5</sup>, Karen Walton-Bowen<sup>6</sup>, Yi Mu<sup>7</sup>, Danh V. Nguyen<sup>8</sup>, Joseph Gonzalez-Heydrich<sup>9</sup>, Paul F. Wang<sup>10</sup>, Randall L. Carpenter<sup>1</sup>, Mark F. Bear<sup>10</sup> and Randi J. Hagerman<sup>2</sup>

<sup>1</sup> Author Affiliations

<sup>10</sup>To whom correspondence should be addressed. E-mail: pwang@seasidetherapeutics.com

ABSTRACT

Research on animal models of fragile X syndrome suggests that STX209, a γ-aminobutyric acid type B (GABA<sub>B</sub>) agonist, might improve neurobehavioral function in affected patients. We evaluated whether STX209 improves behavioral symptoms of fragile X syndrome in a randomized, double-blind, placebo-controlled crossover study in 63 subjects (55 males, ages 6 to 39 years, with a full mutation in the *FMR1* gene (>200 CGG triplet repeats). We found no difference from placebo on the primary endpoint, the Aberrant Behavior Checklist–irritability (ABC–i) subscale. In the other analyses specified in the protocol, improvement was seen on the visual analog scale ratings of parent-nominated problem behaviors, with positive trends on multiple global measures. Post hoc analysis with the ABC–Social Avoidance scale, a newly validated scale for the assessment of fragile X syndrome, showed a significant beneficial treatment effect in the full study population. A post hoc subgroup of 27 subjects with more severe social impairment showed improvements on the Vineland II–Socialization raw score, on the ABC–Social Avoidance scale, and on all global measures. STX209 was well tolerated, with the incidences of sedation and of headache as the most frequent side effects. In this exploratory study, STX209 did not show a benefit on irritability in fragile X syndrome. Nonetheless, our results suggest that GABA<sub>B</sub> agonists have potential to improve social function and behavior in patients with fragile X syndrome.

Copyright © 2012, American Association for the Advancement of Science

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Psychostimulants for ADHD-like symptoms in individuals with autism spectrum disorders.

Cortese S, Castellano F, Morello C, Roux S, Bonnet-Brihault F.

Institute for Pediatric Neuroscience, NYU Child Study Center, Langone Medical Center, 215 Lexington Avenue, 14th Floor, 10016 NY, USA. [samuel.cortese@nyu.edu](mailto:samuel.cortese@nyu.edu).

Expert Rev Neurother. 2012 Apr;12(4):461-73.

We conducted a comprehensive review of studies assessing the efficacy and tolerability of psychostimulants for ADHD-like symptoms in individuals with autism spectrum disorder (encompassing autism disorder, Asperger's syndrome and pervasive developmental disorders not otherwise specified). PubMed, Ovid, EMBASE, Web of Science, ERIC and CINAHL were searched through 3 January 2012. From a pool of 348 potentially relevant references, 13 citations (13 studies) were retained as pertinent. Four of the included studies had a randomized controlled design. Most of the studies assessed methylphenidate immediate release. Despite inter-study heterogeneity, taken together, the results of the selected reports suggest that psychostimulants may be effective for ADHD-like symptoms in autism spectrum disorder individuals. The most common adverse events reported in the included trials were appetite reduction, sleep-onset difficulties, irritability and emotional outbursts. We discuss future directions in the field, including the need for trials assessing more ecological outcomes and combined treatment strategies tailored to the specific individual features.

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Positive Effects of Methylphenidate on Social Communication and Self-Regulation in Children with Pervasive Developmental Disorders and Hyperactivity

Laudan B. Jahromi, Connie L. Kasari, James T. McCracken, Lisa S-Y. Lee, et. al.

Journal of Autism and Developmental Disorders, 2009)

Drugs that increase serotonin transmission may be useful in reducing interfering repetitive behaviors and aggression as well as improving social relatedness (few controlled studies).

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#### Promoting Social Behavior With Oxytocin in High-Functioning Autism Spectrum Disorders

- Published (2/10) online in the Proceedings of the National Academy of Sciences.
- Oxytocin is a hormone known to promote mother-infant bonds.
- A French research group investigated the behavioral effects of oxytocin in 13 subjects with autism.
- Under oxytocin, children with ASD responded more strongly to others and exhibited more appropriate social behavior and affect, suggesting a therapeutic potential of oxytocin through its action on a core dimension of autism.

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#### Oxytocin May Have Many Effects

The screenshot shows the journal's website with the article title 'Oxytocin and Human Social Behavior' by Anne Campbell. The abstract discusses the effects of oxytocin on social behavior and the need for more rigorous research designs.

**Personality and Social Psychology Review**

Home | OnlineFirst | All Issues | Subscribe | RSS | Email Alerts

Search this journal

**Oxytocin and Human Social Behavior**

Anne Campbell  
Durham University, Durham, UK, a.c.campbell@durham.ac.uk

**Abstract**

Despite a general consensus that oxytocin (OT) has prosocial effects, there is no clear agreement on how these effects are achieved. Human research on OT is reviewed under three broad research initiatives: attachment and trust, social memory, and fear reduction. As an organizing perspective for scholars, current knowledge, a tentative model of the causes and effects of alterations in OT level is proposed. The model must remain provisional until conceptual and methodological problems are addressed that arise from a failure to distinguish between traits and states, offering research paradigms used in relation to OT as an independent versus dependent variable, and the possibility that OT effects depend on the initial emotional state of the individual. Social and personality psychologists have important roles to play in developing more rigorous and creative research designs.

**This Article**

Published online before print April 16, 2010, doi:10.1177/1089266109345555  
First Published Online August 18th 2010  
10.1177/1089266109345555  
10.1177/1089266109345555

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Medication and Parent Training in Children With Pervasive  
Developmental Disorders and Serious Behavior Problems:  
Results From a Randomized Clinical Trial

MICHAEL G. AMAN, PH.D., CHRISTOPHER J. MCDUGLE, M.D. et al.

**Conclusions:** Medication plus PT resulted in greater reduction of serious maladaptive behavior than Medication alone in children with PDDs, with a lower risperidone dose.

J. AM. ACAD. CHILD ADOLESC. PSYCHIATRY,  
48:12, DECEMBER 2009).

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**Comorbid ADHD and Anxiety Affect Social Skills Group  
Intervention Treatment Efficacy in Children With Autism  
Spectrum Disorders**

Kevin M. Antshel, PhD, Carol Polacek, PhD, NP, Michele McMahon, CSW, Karen Dygert, NP, Laura Spenceley, MA, Lindsay Dygert, BS, Laura Miller, BA, Fatima Faisal

**ABSTRACT:** Objective: To assess the influence of psychiatric comorbidity on social skill treatment outcomes for children with autism spectrum disorders (ASDs). Methods: A community sample of 83 children (74 males, 9 females) with an ASD (mean age = 9.5 yr; SD = 1.2) and common comorbid disorders participated in 10-week social skills training groups. The first 5 weeks of the group focused on conversation skills and the second 5 weeks focused on social problem solving skills. A concurrent parent group was also included in the treatment. Social skills were assessed using the Social Skills Rating System. Ratings were completed by parents at pre- and posttreatment time periods. Results: Children with ASD and children with an ASD and comorbid anxiety disorder improved in their parent reported social skills. Children with ASD and comorbid attention deficit/hyperactivity disorder failed to improve. Conclusion: Psychiatric comorbidity affects social skill treatment gains in the ASD population.

(J Dev Behav Pediatr 32:439-446, 2011) **Index terms:** autism spectrum, social skills, ADHD.

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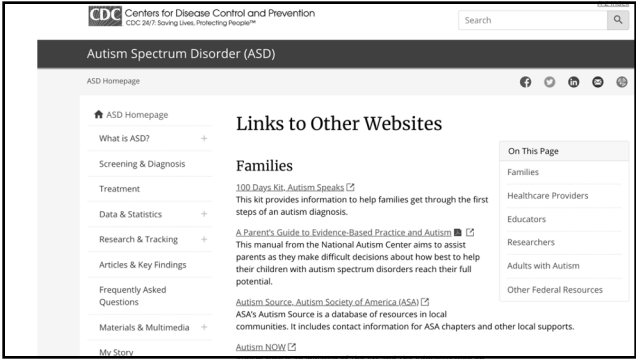
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**Some Possible Challenges to Counseling Youth  
With ASD**

- Concrete thinkers
- Difficulty with humor
- Problems regulating affect
- Difficulty interpreting other's feelings
- Rule bound
- Diminished empathy
- Decreased desire to please others.

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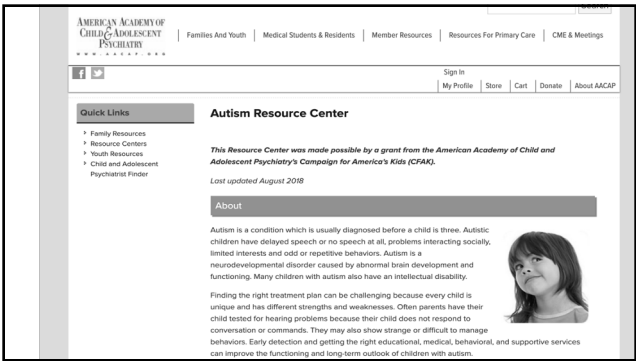
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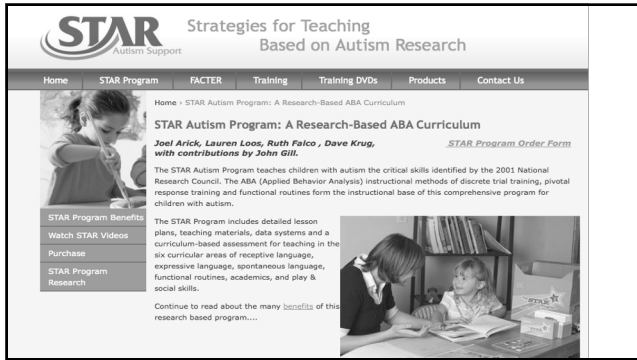
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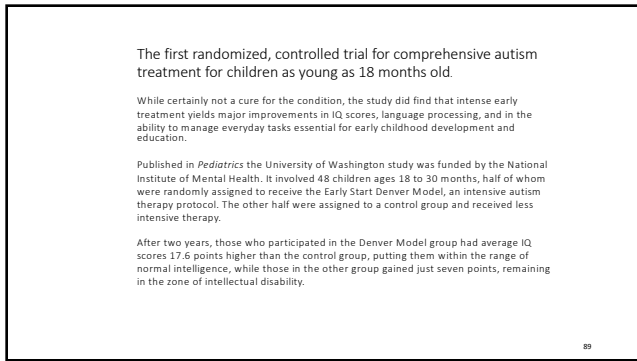
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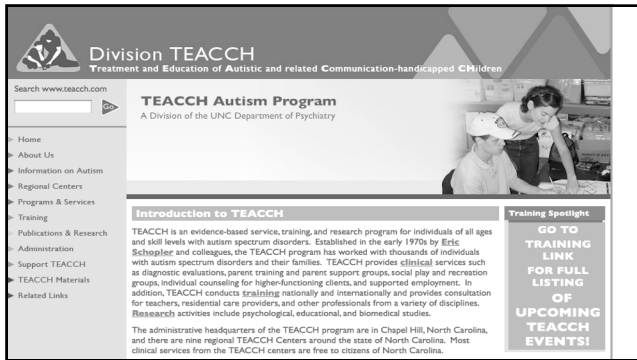
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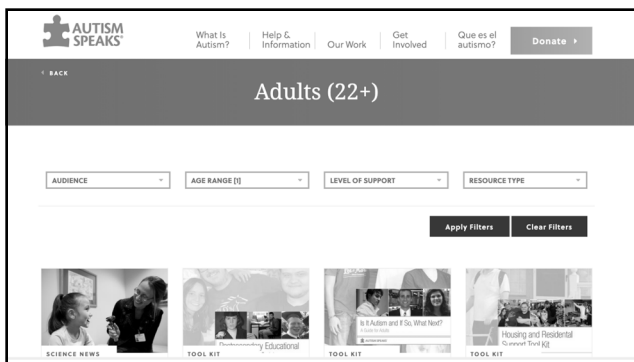
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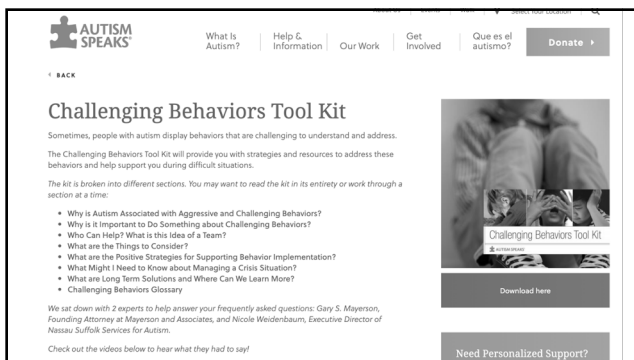
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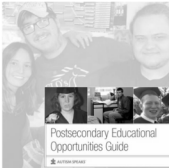
## Postsecondary Educational Opportunities Guide

Deciding what to do after high school can be a difficult process. This guide will help you and your family explore the various options available to you.

The guide provides a closer look at four-year universities, community colleges, vocational/technical school, life skills programs and more. The information will help you find the program that is right for you.

The Postsecondary Educational Opportunities Guide is broken up into the following sections:

- Introduction
- Preparing for Postsecondary Education
- Types of Postsecondary Education Programs
- Obtaining Services and Asking for Accommodations
- Life on Campus
- Learning to Live Independently: A Personal Perspective
- Peer-to-Peer Advice
- Advice for Parents
- Alternative Learning for People With Autism: A Personal Perspective
- A Retrospective on Postsecondary Educational Opportunities
- Resources



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Need Personalized Support?  
Our Autism Response Team (ART) is

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## Employment Tool Kit


Autism Speaks would like to help you find the right job by providing you with tools and resources, including our Employment Tool Kit.

We have written this kit to help you research, find and keep employment. We compiled job-related stories, tips and information from a collaboration of people, including adults with autism.

Although this guide is written for you, we know that it will also be helpful for family members, service providers, business leaders and anyone who is helping someone with autism find and keep a job.

The Employment Tool Kit is divided into the following sections:

- Introduction
- Self-Advocacy
- What Job is Right For You?
- Benefits and Funding
- Employment Models: What Option is Best For You?
- Your Job Search
- Transportation Options
- Resumes, Cover Letters and Applications
- The Job Interview
- Accommodations and Disclosure
- Soft Skills: Understanding the Social Elements of Your Job
- Success Stories and Lessons Learned



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Need Personalized Support?  
Our Autism Response Team (ART) is

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### Autism After Age 21

What happens when my child is no longer in school?  
Where will he live when he no longer wants to live with me?  
What is going to happen to my child when I'm no longer around, or able to care for him?

These are just a few questions that Easterseals hears from concerned parents of kids with autism. Most children with autism are eligible to receive special education services through the school system until age 21. As the nation's largest provider of services and support for

Explore Resources

Living With Autism

[State Autism Profiles](#)[Autism Signs and Symptoms](#)[Autism Resources](#)[Autism After Age 21](#)

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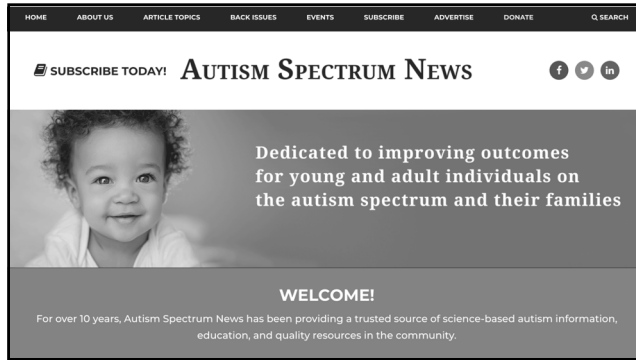
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### The “Prime Directive” is Independence

- Reduce reliance on prompts.
- Help individual's predict and control. environment and behavior.
- Increase self-esteem and self-efficacy.
- Develop independence through a “learning to swim” mindset.

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### Theater as a Medium to Develop Social Skills

- Theater arts offer an opportunity for individuals with ASD to venture into the community in a win-win relationship.
- EPIC's performances help the general community better understand the nature of having ASD.
- At the same time, actors with ASD have the opportunity to interact in a medium that we believe will foster not only the development of self-esteem, but appropriate social interaction—the latter very clearly being the primary hurdle to successful adult transition for those with ASD.
- EPIC hopes to quantify our initial experiences of the benefits of theater for those with ASD through a long-term, qualitative study measuring the associative effects of theater arts, training on social skills, sense of purpose and independence in daily life activities.

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## EPIC Players



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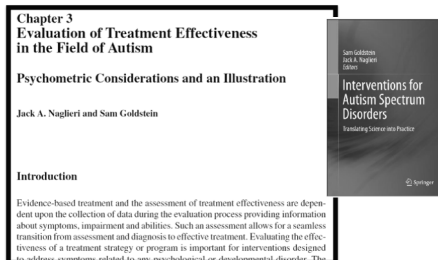
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## Treatment Evaluation with ASRS



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## Treatment Evaluation with ASRS

- Step 1: Identify specific area or areas of need based on ASRS T-scores of 60 or more
- Which indicates many characteristics similar to individuals diagnosed with an ASD.
  - Examine ASRS Total Score
- The Total Score is, however, insufficient for treatment planning because it is too general.
- Step 2: Look at the separate treatment scales

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## Treatment Evaluation with ASRS

- Total Score of 73 by Parent & Teacher
- Social Communication scores are high for both raters meaning he has problems with appropriate use of verbal and non-verbal communication requiring him to initiate, engage in, and maintain social contact (Social Communication T-scores of 77 and 78)

Table 3.3 Case of Donny: parent and teacher ASRS T-scores, differences values needed for significance

	Parent	Teacher	Difference
Total score	73	73	0
Social communication	77	78	1
Unusual behavior	60	53	-7
Self-regulation	70	74	4
DSM-IV scale	69	68	-1
Treatment scales			
Peer socialization	70	73	3
Adult socialization	58	63	5
Social/emotional reciprocity	77	76	-1
Atypical language	52	44	-8
Stereotypy	49	54	5
Behavioral rigidity	72	48	-24
Sensory sensitivity	44	48	4
Attention	71	73	2

T-scores greater than 59 appear in *italic text*

\*Note Differences needed for significance when comparing Parent and Teacher Table 4.5 of the ASRS Manual

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## Treatment Evaluation with ASRS

- ... and he struggles with maintaining control over his behavior (i.e., he is very argumentative) and attending in complex settings (Self-Regulation score of 70)

Table 3.3 Case of Donny: parent and teacher ASRS T-scores, differences values needed for significance

	Parent	Teacher	Difference
Total score	73	73	0
Social communication	77	78	1
Unusual behavior	60	53	-7
Self-regulation	70	74	4
DSM-IV scale	69	68	-1
Treatment scales			
Peer socialization	70	73	3
Adult socialization	58	63	5
Social/emotional reciprocity	77	76	-1
Atypical language	52	44	-8
Stereotypy	49	54	5
Behavioral rigidity	72	48	-24
Sensory sensitivity	44	48	4
Attention	71	73	2

T-scores greater than 59 appear in *italic text*

\*Note Differences needed for significance when comparing Parent and Teacher Table 4.5 of the ASRS Manual

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## Treatment Evaluation with ASRS

- Raters agree except for Unusual Behavior and Behavioral Rigidity scales.

	Parent	Teacher	Difference	Difference needed <sup>a</sup>
Total score	73	73	0	5 NS
Social communication	77	78	1	6 NS
Unusual behavior	60	53	-7	6 Sig ←
Self-regulation	70	74	4	7 NS
DSM-IV scale	69	68	-1	6 NS
Treatment scales				
Peer socialization	70	73	3	9 NS
Adult socialization	58	63	5	12 NS
Social/emotional reciprocity	77	76	-1	8 NS
Atypical language	52	44	-8	11 NS
Stereotypy	49	54	5	13 NS
Behavioral rigidity	72	48	-24	8 Sig ←
Sensory sensitivity	44	48	4	12 NS
Attention	71	73	2	7 NS

T-scores greater than 59 appear in *italic text*

\*Note Differences needed for significance when comparing Parent and Teacher ratings are found in Table 4.5 of the ASRS Manual

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## Treatment Evaluation with ASRS

- The difference between Donny's Unusual Behavior scores as rated by his mother (60) and teacher (51) suggests that behaviors in the home and the classroom are different; which implies that the exploration of the environmental impact on his odd behaviors could lead to good intervention options.
- The significant difference between Donny's Behavioral Rigidity scores as rated by his mother (72) and teacher (48), which also warrants further exploration.

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## Treatment Evaluation with ASRS

- Consistently high scores on Peer Socialization, Social/Emotional Reciprocity and Attention

	Parent	Teacher	Difference	Difference needed <sup>a</sup>	
Total score	73	73	0	5	NS
Social communication	77	78	1	6	NS
Unusual behavior	60	53	-7	6	Sig
Self-regulation	70	74	4	7	NS
DSM-IV scale	60	68	-1	6	NS
Treatment scales					
Peer socialization	70	73	3	9	NS
Adult socialization	58	63	5	12	NS
Social/emotional reciprocity	77	76	-1	8	NS
Atypical language	52	44	-8	11	NS
Stereotypy	49	54	5	13	NS
Behavioral rigidity	72	48	-24	8	Sig
Sensory sensitivity	44	48	4	12	NS
Attention	71	73	2	7	NS

T-scores greater than 59 appear in italic text

<sup>a</sup>Note Differences needed for significance when comparing Parent and Teacher ratings are found in Table 4.5 of the ASRS Manual

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## Treatment Evaluation with ASRS

- Item level analysis within Peer Socialization helps clarify the exact nature of the behaviors that led to the high score

3 Evaluation of Treatment Effectiveness in the Field of Autism

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Fig. A.7 Item level analysis from ASRS interpretive report (shaded items indicate scores that are more than 1 SD from the normative mean)

Peer Socialization	
Item	Score
13. seek the company of other children? (R)	1
14. have trouble talking with other children?	3
19. have social problems with children of the same age?	2
31. play with others? (R)	1
45. understand age-appropriate humor or jokes? (R)	0
50. talk too much about things that other children don't care about?	4
64. choose to play alone?	3
69. show good peer interactions? (R)	2
70. respond when spoken to by other children? (R)	1
Peer Socialization Raw Score = 17	

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111

## Treatment Evaluation with ASRS

## Quick Solution Finder

## Peer Socialization

Increase ability to seek out other children	51
Initiate conversation with other children	51
Increase ability to play appropriately with other children	51
Increase ability to understand humor	227
Improve ability to carry on normal conversation with peers	174
Respond appropriately when other children initiate	159

Item	Score
14. have trouble talking with other children?	3 NS
50. talk too much about things that other children don't care about?	4
64. choose to play alone?	3
69. show good peer interactions? (R)	2

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## Treatment Evaluation with ASRS

- The Quick Solution Guide provides the correspondence of behaviors associated with ASD and specific interventions provided by authors in the chapters that appear in the book.
- For example, Donny had a high ASRS T-score on the Social/Emotional Reciprocity scale and one of the items that addressed "looking at others when spoken to" was very high. Interventions for this behavior can be found on pages

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## Treatment Evaluation with ASRS

Table 3.4 Parent T-scores for ASRS scales obtained over three time periods

	Time 1	Time 2	Time 3	Progress monitoring (Time 2 – 1)	Progress monitoring (Time 3 – 1)
Total score	73	70	63	-3 NS	10 Sig
Social communication	77	77	66	0 NS	11 Sig
Unusual behavior	60	58	58	-2 NS	2 NS
Self-regulation	70	67	62	-3 NS	8 NS
DSM-IV scale	69	68	63	-1 NS	6 NS
Treatment scales					
Peer socialization	70	69	68	-1 NS	2 NS
Adult socialization	58	58	58	0 NS	0 NS
Social/emotional reciprocity	77	77	63	0 NS	14 Sig
Atypical language	52	52	52	0 NS	0 NS
Stereotypy	49	49	49	0 NS	0 NS
Behavioral rigidity	72	67	67	-5 NS	5 NS
Sensory sensitivity	44	44	44	0 NS	0 NS
Attention	71	68	58	-3 NS	13 Sig

T-scores greater than 59 appear in *italic text*  
 Note Differences needed for significance when comparing scores over time for Parent and Teacher ratings are found in Table 4.11 of the ASRS Manual ( $p = 0.10$  with Bonferroni correction)

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## Conclusions



- The determination of eligibility and the integration of specialized educational programs as part of comprehensive treatment and transition for students with ASD continues to evolve.
- It is still the case that there is at times a confusing relationship between clinical/medical diagnosis and care, and eligibility determination and specialized educational processes.
- Over the last twenty years school psychologists have become very knowledgeable about the evaluation and treatment of ASD. The process by which eligibility as Autism under IDEIA is determined continues to vary significantly between states and school districts.
- We are just beginning to understand the skills, behavior and mindset of students with ASD making a successful transition into adult life.
- We need to adopt a reasoned and reasonable set of guidelines for school psychologists charged not only with determining eligibility under IDEIA for a student to be served as OHI/Autism but also gather statistically viable information about a student's cognitive, neuropsychological, social, emotional, academic and behavioral presentation and competence so as to seamlessly integrate assessment data into measurable IEP goals and transition plans.

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## Continuing Education

**CEFI®** (Manual Quiz: 3 CE Credits)  
The Comprehensive Executive Function Inventory™ is a comprehensive evaluation of executive function strengths and weaknesses in youth aged 5 to 18 years.

**ASRS®** (Manual Quiz: 4 CE Credits)  
The Autism Spectrum Rating Scales™ identifies symptoms, behaviors, and associated features of Autism Spectrum Disorders in youth.

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www.samgoldstein.com

Dr. Sam Goldstein

HOME RESOURCES CALENDAR ABOUT CONTACT

**DR. SAM GOLDSTEIN**  
Neuropsychologist - Author -  
Test Developer - Educator

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Devin Teichert  
 Song of Myself  
 December 16, 2008


Were They but There at Night

There is a bolder field where every stone  
 Is a glazed, glittering gem, like stars fallen from the sky  
 All except one, a plain grey rock alone in the center  
 Feeling excluded and shunned

People come, tourists, painters, photographers, collectors  
 To view each shining boulder, a pleasure to the beholder  
 Ooh! Ahh! Look at this one! Come quick!  
 Pedestals bulge with fingernails and paint once run dry

But the grey rock remains ignored  
 An ugly blotch on a sweeping mural

The sun sets, everyone leaves  
 And they miss the outcrop of the field  
 For when night falls, the grey rock in the center  
 It glows in the dark



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## Questions?


[www.samgoldstein.com](http://www.samgoldstein.com)


[info@samgoldstein.com](mailto:info@samgoldstein.com)


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TEDx: <https://www.youtube.com/watch?v=isfw8JJ-eWM>

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