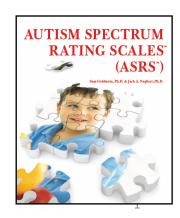
#### The Changing Face of Autism: Understanding, Evaluating and Treating Autism Spectrum Disorders: New Data, New Ideas, and the ASRS



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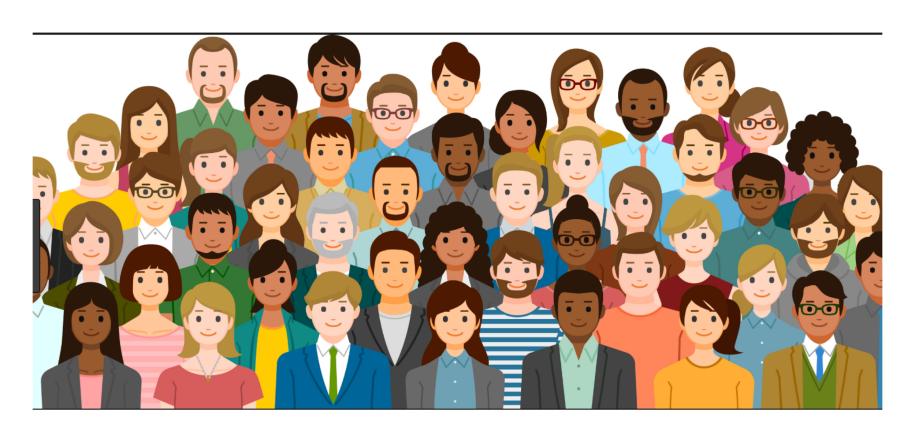
#### Relevant Disclosure

- Co-author of the Autism Spectrum Rating Scales (MHS, 2009).
- Co-author of Assessment of Autism Spectrum Disorders text (Guilford, 2009).
- 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.

#### Goals

- Briefly discuss the historical theories of Autism Spectrum Disorders (ASD).
- Define ASD and DSM 5 criteria.
- Briefly discuss symptoms of ASD by age.
- Briefly discuss a core theory of ASD.
- Briefly review hypothesized causes.
- Discuss data from the ASRS, the largest epidemiological/standardization sample collected of normal children and those with ASD.
- Present cases through the lifespan
- Discuss the ASRS and other methods for assessment, diagnosis and treatment of autism.
- Discuss issues of diagnosis versus eligibility

# We are social beings.



# What Benefits Do We Derive From Socialization?



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

The social development of autistic children is qualitatively different from other children.

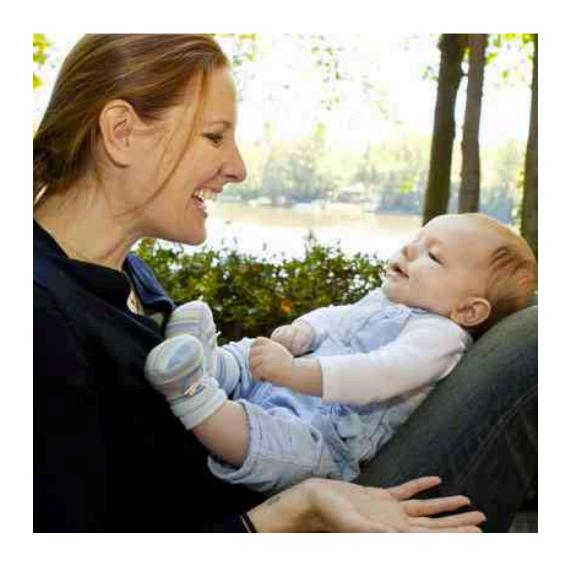


In normal children perceptual, affective and neuroregulatory mechanisms predispose young infants to engage in social interaction from very early on in their lives.

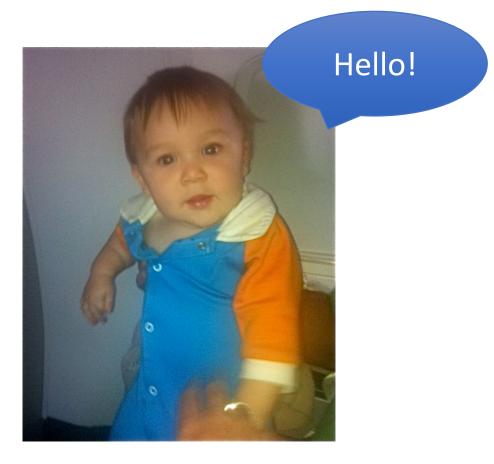


#### Socialization Begins Early Reina and Her Mother





Adrian, my seatmate on a recent flight.



# Adrian

You look like an interesting guy.



# Adrian

See what I can do! Wanna take me home?







#### Where are Autism's Roots?

- In the bible?
- In ancient cultures?
- In history?
- In religion?
- Portrayed in art?

# Les âges de l'ouvrier



Léon FRÉDÉRIC 1895

Les âges de l'ouvrier



Léon FRÉDÉRIC 1895



Is this child portrayed as autistic?



Which woman is her mother?

### Kanner's Description (1943)

- first physician in the world to be identified as a child psychiatrist
- founder of the first child psychiatry department at Johns Hopkins University Hospital
- Wrote Child Psychiatry (1935), the first English language textbook to focus on the psychiatric problems of children.



Leo Kanner who introduced the label *early infantile autism* in 1943 in his paper: Kanner, L. (1943). Autistic disturbances of affective contact. Nervous Child, 2, 217-250.

## Kanner's Description (1943)

- His seminal 1943 paper, "Autistic Disturbances of Affective Contact", together with the work of Hans Asperger, forms the basis of the modern study of autism.
- Leo Kanner was the Editor for Journal of Autism and Developmental Disorders, then called Journal of Autism and Childhood Schizophrenia



Leo Kanner who introduced the label early infantile autism in 1943 in his paper: Kanner, L. (1943). Autistic disturbances of affective contact. Nervous Child, 2, 217-250.

### Kanner's Description (1943)

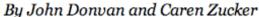
- Inability to relate to others
- Disinterest in parents and people
- Language difficulties
- Fascination with inanimate objects
- Resistance to change in routine
- Purposeless repetitive movements
- A wide range of cognitive skills
- Where they possess an innate inability for emotional contact



Leo Kanner who introduced the label early infantile autism in 1943 in his paper: Kanner, L. (1943). Autistic disturbances of affective contact. Nervous Child, 2, 217-250.

#### **Autism's First Child**

AS NEW CASES OF AUTISM HAVE EXPLODED IN RECENT YEARS—SOME FORM OF THE CONDITION AFFECTS ABOUT ONE IN 110 CHILDREN TODAY—EFFORTS HAVE MULTIPLIED TO UNDERSTAND AND ACCOMMODATE THE CONDITION IN CHILDHOOD. BUT CHILDREN WITH AUTISM WILL BECOME ADULTS WITH AUTISM, SOME 500,000 OF THEM IN THIS DECADE ALONE. WHAT THEN? MEET DONALD GRAY TRIPLETT, 77, OF FOREST, MISSISSIPPI. HE WAS THE FIRST PERSON EVER DIAGNOSED WITH AUTISM. AND HIS LONG, HAPPY, SURPRISING LIFE MAY HOLD SOME ANSWERS.





- Kyle reported that he has been told he was evaluated at three years of age and was delayed in development.
- As a preschooler he was fearful of tornadoes and sirens. He often talked excessively with peers to the point of annoyance and was bullied both verbally and physically for poor hygiene and disheveled appearance.
- He reported that he had temper tantrums as a youth and excessive bouts of anxiety and frustration.
- He would strike out at objects.
- As a youth he reported problems with language delay.
- His kindergarten teacher thought he had odd eccentricities.
- Kyle recalled being anxious, worried and inattentive as a youth.
- He described having few friends, being withdrawn, restless, irritable and difficulty concentrating. His medical history has been generally unremarkable.

- Kyle reported he was confused by social dynamics in middle school and as a youth often alone.
- He noted, however, he had one or two friends.
- He disliked school. His best areas were in math, English, research and writing. He struggled with physics and making presentations.
- He graduated from Champagne Central High School in 2001 with a strong grade point average.
- He dated some in high school but was generally socially isolated.
- He wanted to go on an LDS mission but did not. He expressed concern that it appeared that he was never "worthy" to enter the missionary service.
- Kyle is not active in the LDS Church. He resigned his membership.

- Kyle noted difficult engaging in small talk with others.
- He reported that others often mistake his comments for negative intentions.
- Nonetheless, as a youth he was able to engage in imaginative play.
- He rarely initiated interactions.
- He acknowledged that he has had interests that at times are excessive.
- He reported that he can become angry easily but internalizes it.
- He was evaluated by a psychologist over twenty years ago and briefly participated in counseling.
- Kyle noted problems with sadness, depression, anxiety, nervousness, stress, sleep problems and getting angry quickly.
- Kyle worked with a child psychologist at age twelve.
- He saw a psychiatrist and was treated with Prozac and Klonopin.

- Kyle is single and has never married.
- He does not have ongoing relationships and spends most of his free time alone.
- Kyle reported, however, that he has girlfriend whom he sees once a week. She is a single mother. They text daily but rarely talk. They met about a year ago. She is ten years older than Kyle.

- Kyle noted that it is difficult for him to figure out how to do new things, problem solve, plan ahead, change a plan and think quickly when needed.
- He has a hard time doing things in the right order.
- He has difficulty with word finding and expressing his thoughts. Kyle reported problems being unaware of time, distractible, losing his train of thought easily and difficulty doing more than one thing at a time.
- He reported difficulty making decisions and problems with short term memory.
- He tends to lose and misplace things daily.
- He noted problems being easily frustrated and at times not caring.
- He noted headaches from caffeine ingestion.

- Kyle is an assistant librarian at Stevens Henneger College.
- He noted it is stressful for him to deal with people.
- He enjoys the work.
- He also works as a shelver and customer service specialist for the Salt Lake County Library.
- Kyle enjoys role playing games.
- He spends quite a bit of time online with a gaming group.

- Kyle tended to sit stiffly in the chair.
- No habitual mannerisms were noted.
- Activity level was normal. Kyle was not distracted.
- He appeared moderately confident in his abilities.
- Comprehension was good.
- Kyle related adequately with the examiner.
- He smiled appropriately.
- His thoughts appeared logical, focused and generally relevant.

- Eye contact was generally average.
- Kyle maintained and initiated conversation, although conversation often was one sided. Receptive and expressive language appeared adequate.
- Kyle was neither anxious or sad. Overall his affect was generally neutral.
   Kyle was emotionally stable.
- Kyle was alert, attentive and concentrated well.
- He shared joint attention. Body and object use as well as visual and listening response were normal.
- No atypical sensory behaviors were observed. Instrumental and informative gestures at times were excessive.
- Quality of social overture and social response were somewhat limited as was reciprocal, social communication.

#### **Autism Diagnostic Observation Schedule - 2 (Module 4)**

Communication		
Stereotyped/idiosyncratic Use of Words or Phrases		1
Conversation		2
Descriptive, Conventional, Instrumental or Informational Gestures		0
Emphatic or Emotional Gestures		2
Reciprocal Social Interaction		
Unusual Eye Contact	0	
Facial Expression Directed to Others	1	
Comments on Others' Emotions/Empathy	0	
Responsibility	0	
Quality of Social Overtures	2	
Quality of Social Response	1	
Amount of Reciprocal Social Communication	2	
Stereotyped Behaviors and Restricted Interests		
Unusual Sensory interest in Play Material/Person	0	
Hand and Finger and Other Complex Mannerisms	1	
Excessive Interest in Unusual or Highly Specific Topics/Objects		
or Repetitive Behaviors	1	
Compulsions or Rituals	1	
Communication Total	5	
Social Interactions Total	6	
Communication + Social Interaction Total	11	
Stereotyped Behaviors and Restricted Interests Total	3	
Autism Cutoff	10	
Autism Spectrum	7	

#### **Woodcock-Johnson IV: Tests of Cognitive Abilities**

# Sandard Scores (mean = 100; s.d = 15) Oral Vocabulary Number Series Verbal Attention VOCABULARY Sandard Scores (mean = 100; s.d = 15)

#### **Woodcock-Johnson IV: Tests of Oral Language**

	<b>\$</b> andard Scores (mean = 100; s.d = 15)
Picture Vocabulary	121
Oral Comprehension	97
Understanding Directions	98
ORAL LANGUAGE	110
BROAD ORAL LANGUAGE	107
LISTENING COMPREHENSION	97
VOCABULARY	128

# Test of Memory and Learning - 2

#### (mean = 100; s.d. = 15)

77
82
76
76
97
78
97
91
73

- Kyle is able to engage in nearly all activities of every day living without significant problems.
- He struggles to handle unexpected changes and interact with people.
- Kyle reports challenges with behaviors related to executive functioning involving flexibility, self-monitoring and working memory.
- He notes symptoms of depression, anxiety and inattention.
- Kyle demonstrates superior vocabulary with above average oral language.
- Memory, however, was assessed as well below average, primarily due to marked variability in subtest scores.
- Kyle also experienced mild difficulty on a task of sustained attention.
- His personality profile is characteristic of individuals who struggle with social and personal attainments, characteristic of social pragmatic communication problems accompanied by anxiety.

- On the ADOS he struggled with conversation and empathic gestures.
- He had a difficult time with social overture and reciprocal social communication.
- His presentation is characteristic of an Autism Spectrum Disorder in an adult.
- Kyle meets the DSM-5 diagnostic criteria for:

Autism Spectrum Disorder, w/o intellectual deficits Unspecified Anxiety Disorder Unspecified Attention Deficit Hyperactivity Disorder

- Lydia noted that she has always had difficulty interacting with people.
- Her medical history is noted by a compressed skull fracture at age eighteen. She is uncertain if this adversely affected her cognitive functioning.
- She had her thyroid removed in 2017. She currently takes thyroid medication.
- Lydia has tried multiple psychiatric medications but has disliked the side effects. She notes that St. John's Wort is beneficial.
- Lydia is single and has never married.
- She has not dated in twenty years.
- She described herself as a "rabid feminist" and noted that "no one ever asked me to marry them."
- Lydia noted that she has always been argumentative in relationships.
- Most relationships have not worked out.
- Lydia indicated seven years ago she had a few dates from "a website."
- Lydia has no close friends or family

- As a youth, Lydia described herself as clumsy.
- She has always had trouble with small talk.
- She is blunt in relationships.
- She does not have a "clue" about her earlier childhood communication.
- She recalled that as a child she believed she joined in games.
- She is still friendly with some of her childhood friends but is rarely visited by friends.
- She reported that she has not been emotionally stable until she moved to to her current city.
- She noted that she has difficulty keeping her apartment clean.

- Lydia recalled a troubled childhood, including a mother with chronic mental health problems and abusive treatment at home.
- Nonetheless, she graduated successfully from college and has been able to work at multiple jobs throughout the world.
- For the last eleven years she has worked at a job that is consistent and predictable but below her capabilities.
- Lydia does not report significant challenges with activities of every day living other than interacting with others and socializing.
- She acknowledges she has become increasingly more socially withdrawn.

- Lydia was alert, attentive and concentrated reasonably well.
- Her ability to share joint attention was adequate.
- Reciprocal social communication was generally appropriate.
- No muscular tension nor habitual mannerisms were noted.
- Lydia's thought processes appeared focused and relevant.
- She was teary multiple times during the history session when retelling her life story.

## Autism Diagnostic Observation Scale - 2 (Module 4)

Communication	
Stereotyped/idiosyncratic Use of Words or Phrases	(
Conversation	1
Descriptive, Conventional, Instrumental or Informational Gestures	(
Emphatic or Emotional Gestures	1
Communication Total	2
Reciprocal Social Interaction	
Unusual Eye Contact	(
Facial Expression Directed to Others	1
Comments on Others' Emotions/Empathy	(
Responsibility	(
Quality of Social Overtures	
Quality of Social Response	-
Amount of Reciprocal Social Communication	]
Social Interaction Total	4
Stereotyped Behaviors and Restricted Interests	
Unusual Sensory interest in Play Material/Person	(
Hand and Finger and Other Complex Mannerisms	(
Excessive Interest in Unusual or Highly Specific Topics/Objects	1
or Repetitive Behaviors	
Compulsions or Rituals	
Stereotyped Behaviors and Restricted Interests Total	2
Overall Total	8
Autism Cutoff	10
Autism Spectrum	7
-	

- Lydia's TOVA results are not within normal limits and are suggestive of attentional problems. Omission errors and response variability were below expected for typical individuals.
- Beck Depression Inventory II Total Score 3 (minimal symptoms)
- Beck Anxiety Inventory II Total Score 1 (minimal symptoms)

- The Millon profile is characteristic of someone who may be apprehensive and distancing from others. Individuals with this profile often markedly deprecate their self-worth.
- They are generally socially shy and awkward. They often want closeness and affection from others but fear abandonment and experience a recurrent pervasive despondency, a general state of sadness and mood disharmony.
- Deprecation of aptitudes and sporadic avoidance of independent behavior are noted by individuals with this personality profile. They are often conciliatory and submissive to others.
- Their self-image is often weak, fragile, anxious and depressive. They typically seek a passive life style. They are often apathetic and indifferent.
- Such individuals are very conscientious, abiding by what they view as social propriety and decorum. They often attend closely to the behavior of others. This pattern of presentation is characteristic of a schizoid personality.

- Current assessment suggests that her presentation, while just below the autism cutoff on a screening measure for adult autism is above the threshold for consideration of Autism Spectrum Disorder.
- Further, current testing suggests Lydia experiences problems with sustained attention, an issue that is characteristic of some individuals with Autism, as well as individuals with the Inattentive Type of Attention Deficit Hyperactivity Disorder.
- Lydia reports minimal symptoms of depression and anxiety.
- Her current personality profile is characteristic of a somewhat schizoid pattern.
   Such individuals are often apprehensive and distancing from others. They deprecate their self-worth. They tend to be generally shy and awkward.
- Lydia meets the DSM-5 diagnostic criteria for Autism Spectrum Disorder with average intellect and minimal support needs.

# A Brief Current Research Update of ASD and Transition to Adulthood

# Epidemiology of Autism Spectrum Disorders in Adults in the Community in England

Traolach S. Brugha, MD(NUI), FRCPsych; Sally McManus, MSc; John Bankart, MSc, PhD; Fiona Scott, PhD, CPsychol; Susan Purdon, MSc, PhD; Jane Smith, BSc; Paul Bebbington, PhD, FRCPsych; Rachel Jenkins, MD, FRCPsych; Howard Meltzer, PhD

**Context:** To our knowledge, there is no published information on the epidemiology of autism spectrum disorders (ASDs) in adults. If the prevalence of autism is increasing, rates in older adults would be expected to be lower than rates among younger adults.

**Objective:** To estimate the prevalence and characteristics of adults with ASD living in the community in England.

**Design:** A stratified, multiphase random sample was used in the third national survey of psychiatric morbidity in adults in England in 2007. Survey data were weighted to take account of study design and nonresponse so that the results were representative of the household population.

**Setting:** General community (ie, private households) in England.

**Participants:** Adults (people 16 years or older).

**Main Outcome Measures:** Autism Diagnostic Observation Schedule, Module 4 in phase 2 validated against the Autism Diagnostic Interview—Revised and Diagnostic Interview for Social and Communication Disorders in phase 3. A 20-item subset of the Autism-Spectrum Quo-

tient self-completion questionnaire was used in phase 1 to select respondents for phase 2. Respondents also provided information on sociodemographics and their use of mental health services.

**Results:** Of 7461 adult participants who provided a complete phase 1 interview, 618 completed phase 2 diagnostic assessments. The weighted prevalence of ASD in adults was estimated to be 9.8 per 1000 (95% confidence interval, 3.0-16.5). Prevalence was not related to the respondent's age. Rates were higher in men, those without educational qualifications, and those living in rented social (government-financed) housing. There was no evidence of increased use of services for mental health problems.

**Conclusions:** Conducting epidemiologic research on ASD in adults is feasible. The prevalence of ASD in this population is similar to that found in children. The lack of an association with age is consistent with there having been no increase in prevalence and with its causes being temporally constant. Adults with ASD living in the community are socially disadvantaged and tend to be unrecognized.

Arch Gen Psychiatry. 2011;68(5):459-466

# Epidemiology of autism in adults across age groups and ability levels\*

Traolach S. Brugha, Nicola Spiers, John Bankart, Sally-Ann Cooper, Sally McManus, Fiona J. Scott, Jane Smith and Freya Tyrer

## **Background**

The epidemiology of autism in adults has relied on untested projections using childhood research.

### Aims

To derive representative estimates of the prevalence of autism and key associations in adults of all ages and ability levels.

### Method

Comparable clinical diagnostic assessments of 7274 Adult Psychiatric Morbidity Survey participants combined with a population case-register survey of 290 adults with intellectual disability.

### **Results**

The combined prevalence of autism in adults of all ages in England was 11/1000 (95% CI 3–19/1000). It was higher in

those with moderate to profound intellectual disability (odds ratio (OR) = 63.5, 95% CI 27.4–147.2). Male gender was a strong predictor of autism only in those with no or mild intellectual disability (adjusted OR = 8.5, 95% CI 2.0–34.9; interaction with gender, P = 0.03).

### **Conclusions**

Few adults with autism have intellectual disability; however, autism is more prevalent in this population. Autism measures may miss more women with autism.

### **Declaration of interest**

None.

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## Access

# Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis

Matthew J Hollocks (a1), Jian Wei Lerh (a2), Iliana Magiati (a2), Richard Meiser-Stedman (a1) ... 🛨

DOI: https://doi.org/10.1017/S0033291718002283 Published online: 04 September 2018

## Abstract

Adults with autism spectrum disorder (ASD) are thought to be at disproportionate risk of developing mental health comorbidities, with anxiety and depression being considered most prominent amongst these. Yet, no systematic review has been carried out to date to examine rates of both anxiety and depression focusing specifically on adults with ASD. This systematic review and meta-analysis examined the rates of anxiety and depression in adults with ASD and the impact of factors such as assessment methods and presence of comorbid intellectual disability (ID) diagnosis on estimated prevalence rates. Electronic database searches for studies published between January 2000 and September 2017 identified a total of 35 studies, including 30 studies measuring anxiety ( $n = 26\,070$ ; mean age = 30.9, s.p. = 6.2 years) and 29 studies measuring depression ( $n = 26\,117$ ; mean age = 31.1, s.p. = 6.8 years). The pooled estimation of current and lifetime prevalence for adults with ASD were 27% and 42% for any anxiety disorder, and 23% and 37% for depressive disorder. Further analyses revealed that the use of questionnaire measures and the presence of ID may significantly influence estimates of prevalence. The current literature suffers from a high degree of heterogeneity in study method and an overreliance on clinical samples. These results highlight the importance of community-based studies and the identification and inclusion of well-characterized samples to reduce heterogeneity and bias in estimates of prevalence for comorbidity in adults with ASD and other populations with complex psychiatric presentations.

# Psychometric Evaluation of Social Cognitive Measures for Adults with Autism

Kerrianne E. Morrison <sup>10</sup>, Amy E. Pinkham, Skylar Kelsven, <sup>†</sup> Kelsey Ludwig, David L. Penn, and Noah J. Sasson

Although social cognition is frequently identified as a target in clinical trials and psychosocial interventions for adults with autism spectrum disorder (ASD), these efforts are hampered by a lack of consensus and validation of social cognitive measures. The current study provides psychometric evaluation of 11 frequently used measures encompassing different subdomains of social cognition. Adults with autism (N = 103) and typically developing controls (N = 95) completed 11 commonly used social cognitive tasks spanning the domains of emotion processing, social perception, and mentalizing/theory of mind. We examined each measure's internal reliability and sensitivity to group differences, how performance related to general intellectual ability, and alignment of measures with a proposed two-factor structure of social cognition in ASD. Controls outperformed the ASD group on 8 of the 11 social cognitive tasks, with the largest group differences occurring on two mentalizing measures, The awareness of social inference task (TASIT) and hinting task. In ASD, all tasks demonstrated strong internal consistency and avoided ceiling and floor effects. Social cognitive performance was also related to, but not redundant with, intellectual functioning. We also found support for a two-factor structure of social cognition, with basic social perception and emotional processing aligning into a lower-order social perception factor, while mentalizing tasks aligned into a higher-order social appraisal factor. In sum, eight tasks showed adequate to strong psychometric properties. The psychometric data, effect size estimates, and correlations between measures reported here can be used for study planning for social cognitive interventions in autism. Autism Res 2019, 12: 766–778. © 2019 The Authors. Autism Research published by International Society for Autism Research published by Wiley Periodicals, Inc.

Lay Summary: We examined 11 tasks that measure how adults with autism perceive and interpret social information. Eight of the tasks were reliable and showed lower performance in adults with autism compared to typically-developing controls. Task performance was related to but distinguishable from IQ. These measures evaluated here may be useful in assessing the effectiveness of interventions and treatments to improve social abilities in adults with autism.

Keywords: autism spectrum disorder; adults; reliability; social social cognition; validity

JOURNAL OF APPLIED BEHAVIOR ANALYSIS

2019, **52,** 150–172

NUMBER 1 (WINTER)

## ASSESSING AND TEACHING JOB-RELATED SOCIAL SKILLS TO ADULTS WITH AUTISM SPECTRUM DISORDER

CAROLYN M. GROB, DOROTHEA C. LERMAN, CHANNING A. LANGLINAIS AND NATALIE K. VILLANTE

UNIVERSITY OF HOUSTON-CLEAR LAKE

Few studies have evaluated interventions to improve the job-related social skills of adults with autism spectrum disorder. In this study, we examined the efficacy of a treatment package for teaching several social skills that are critical to job success, such as responding appropriately to feedback and asking for a task model from the supervisor. Three adults, aged 19 to 27 years, participated. Initial training of each skill consisted of verbal explanations, modeling, and role-play with feedback, along with stimulus prompts to promote generalization to a different setting. The trainer introduced additional intervention components as needed. We also evaluated generalization across different social skills and evocative situations. Results indicated that the treatment package was generally effective in improving the targeted social skills, and that stimulus prompts may be necessary for generalization to a job setting. However, generalized responding across social skills rarely emerged. These findings have important implications for preparing individuals with autism to function successfully on the job.

Key words: job skills, social skills, behavioral skills training, stimulus prompts, multiple exemplar training

# The costs of services and employment outcomes achieved by adults with autism in the US

autism © 2009 SAGE Publications and The National Autistic Society Vol 13(3) 285–302; 103791 1362-3613(200905)13:3

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RICHARD J. COWAN Kent State University, USA

ABSTRACT This article examines the cost of services and employment outcomes obtained by adults with autism within the United States vocational rehabilitation (VR) system. It found that the number of such individuals has increased by more than 121 percent from 2002 to 2006. Moreover, though adults with autism were employed at higher rates than most disability groups investigated, they tended to work far fewer hours and earn less in wages per week. The study also found that adults with autism were among the most costly individuals to serve.

adults; autism; employment; service costs; vocational rehabilitation

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Autism. Author manuscript; available in PMC 2016 Oct 1.

Published in final edited form as:

Autism. 2015 Oct; 19(7): 785-793.

Published online 2015 May 27. doi: <u>10.1177/1362361315585643</u>

PMCID: PMC4581899 NIHMSID: NIHMS684593 PMID: 26019306

## Longitudinal patterns of employment and postsecondary education for adults with autism and average-range IQ

Julie Lounds Taylor, Natalie A. Henninger, and Marsha R. Mailick

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The publisher's final edited version of this article is available at <u>Autism</u> See other articles in PMC that <u>cite</u> the published article.

### **Associated Data**

Supplementary Materials

Abstract Go to: ♥

This study examined correlates of participation in postsecondary education (PSE) and employment over 12 years for 73 adults with autism spectrum disorders (ASD) and average-range IQ whose families were part of a larger, longitudinal study. Correlates included demographic (sex, maternal education, paternal education), behavioral (activities of daily living, maladaptive behaviors, autism symptoms) and family (size of maternal social network; maternal depressive symptoms, anxiety, and pessimism) factors. Although two-thirds of adults with ASD participated in competitive employment/PSE during the study, fewer than 25% maintained these activities over the study period. Behavioral characteristics distinguished those who never had competitive employment/PSE from those who sometimes or consistently participated in these activities. Women were considerably less likely than men to maintain employment/PSE over time.

Keywords: Autism spectrum disorder, adult, employment, postsecondary education, longitudinal

# Employment and adults with autism spectrum disorders: Challenges and strategies for success

### Dawn Hendricks

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Accepted: August 2009

Abstract. Individuals with autism spectrum disorder (ASD) have the ability and desire to work, but there are still several obstructions. Research overwhelmingly demonstrates disappointing employment outcomes for this group. The vast majority is unemployed and for those who do have gainful employment, underemployment is common. The increased prevalence of ASD coupled with unique social, communication, and behavioral characteristics translate into the need for services to help them achieve employment success. Consideration of individual characteristics including strengths, needs, as well as specific interests, coupled with implementation of proper supports can result in successful and ongoing employment. This paper provides a review of evidence based research related to employment for individuals with ASD. Specific areas addressed include benefits of employment, state of employment, obstacles to employment, current service options, and an in depth review of supports needed for success. These supports focus not only on job tasks, but also the interpersonal skills needed to foster a positive work experience.

Keywords: Autism, ASD, employment for adults with autism

J Autism Dev Disord. Author manuscript; available in PMC 2012 May 1.

Published in final edited form as:

J Autism Dev Disord. 2011 May; 41(5): 566-574.

doi: <u>10.1007/s10803-010-1070-3</u>

PMCID: PMC3033449 NIHMSID: NIHMS233259

PMID: 20640591

# Employment and Post-Secondary Educational Activities for Young Adults with Autism Spectrum Disorders During the Transition to Adulthood

Julie Lounds Taylor<sup>™</sup> and Marsha Mailick Seltzer

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The publisher's final edited version of this article is available at <u>J Autism Dev Disord</u> See other articles in PMC that <u>cite</u> the published article.

Abstract Go to: ✓

This report describes the post-high school educational and occupational activities for 66 young adults with autism spectrum disorders who had recently exited the secondary school system. Analyses indicated low rates of employment in the community, with the majority of young adults (56%) spending time in sheltered workshops or day activity centers. Young adults with ASD without an intellectual disability were three times more likely to have no daytime activities compared to adults with ASD who had an intellectual disability. Differences in behavioral functioning were observed by employment/day activity group. Our findings suggest that the current service system may be inadequate to accommodate the needs of youths with ASD who do not have intellectual disabilities during the transition to adulthood.

Keywords: Transition to adulthood, Employment, Post-secondary education, Autism spectrum disorders



## Postsecondary Education and Employment Among Youth With an Autism Spectrum Disorder

Paul T. Shattuck, PhD,<sup>®</sup>a Sarah Carter Narendorf, MSW,<sup>a</sup> Benjamin Cooper, MPH,<sup>a</sup> Paul R. Sterzing, MSSW,<sup>a</sup> Mary Wagner, PhD,<sup>b</sup> and Julie Lounds Taylor, PhD<sup>c</sup>

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Abstract Go to: ♥

#### **OBJECTIVES:**

We examined the prevalence and correlates of postsecondary education and employment among youth with an autism spectrum disorder (ASD).

#### **METHODS:**

Data were from a nationally representative survey of parents, guardians, and young adults with an ASD. Participation in postsecondary employment, college, or vocational education and lack of participation in any of these activities were examined. Rates were compared with those of youth in 3 other eligibility categories: speech/language impairment, learning disability, and mental retardation. Logistic regression was used to examine correlates of each outcome.

### **RESULTS:**

For youth with an ASD, 34.7% had attended college and 55.1% had held paid employment during the first 6 years after high school. More than 50% of youth who had left high school in the past 2 years had no participation in employment or education. Youth with an ASD had the lowest rates of participation in employment and the highest rates of no participation compared with youth in other disability categories. Higher income and higher functional ability were associated with higher adjusted odds of participation in postsecondary employment and education.

#### **CONCLUSIONS:**

Youth with an ASD have poor postsecondary employment and education outcomes, especially in the first 2 years after high school. Those from lower-income families and those with greater functional impairments are at heightened risk for poor outcomes. Further research is needed to understand how transition planning before high school exit can facilitate a better connection to productive postsecondary activities.

## PEDIATRICS

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRIC

Pediatrics. 2012 Jun; 129(6): 1042–1049.

doi: 10.1542/peds.2011-2864

PMCID: PMC3362908





### **ORIGINAL PAPER**



# Success Factors Enabling Employment for Adults on the Autism Spectrum from Employers' Perspective

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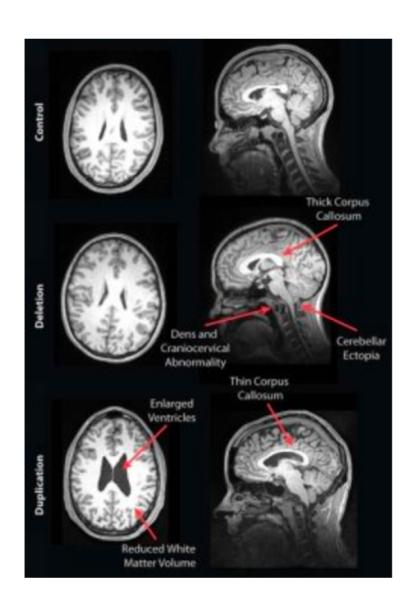
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### Abstract

Employment outcomes for individuals with autism spectrum disorder (ASD) are poor and there is limited understanding on how best to support individuals with ASD in the workplace. Stakeholders involved in the employment of adults with ASD, including employers and employment service providers have unique insights into the factors influencing employment for this population. Organisational and individual factors facilitating successful employment for adults with ASD across Australia and Sweden were explored, including the supports and strategies underpinning employment success from an employers' perspective. Three themes including *Knowledge and Understanding of ASD*, *Work Environment* and *Job Match* emerged, suggesting that a holistic approach was key to supporting success, with employer knowledge and understanding of ASD underpinning their ability to facilitate employment.

 $\textbf{Keywords} \ \ \text{Autism} \cdot \text{Competitive employment} \cdot \text{Employment outcomes} \cdot \text{Vocational support}$ 





Some people with autism have abnormalities at a specific site on the 16th chromosome known as 16p11.2. Deletion or duplication of a small piece of chromosome at this site is one of the most common identified genetic causes of autism spectrum disorder.

MRI reveals striking brain differences in people with genetic autism. August 8, 2017. Radiological Society of North America

## Assessment of ASD

- High levels of co-morbidity require a comprehensive assessment including: intellect, neuropsychological abilities, achievement, emotional status, personality and protective factors.
- A careful history is essential.
- Well developed, reliable and valid measures must be used to the extent they are available.
- DSM 5 or ICD 10 criteria must be met.

# Making the Diagnosis of ASD

- Meets DSM 5 Criteria.
- Coping behaviors assessed.
- Co-morbid behaviors and disorders assessed.
- Corroborating data obtained about child and adulthood.
- Intellectual, achievement and neuropsychological data collected if warranted.

# Determining IDIEA Eligibility of Autism

- Autism, as defined by <u>Individuals with Disabilities Education Act (IDEA)</u>, refers to "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."
- This federal definition then proceeds to name traits commonly related to the condition: "Other characteristics often associated with autism are engaging in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.
- The term autism does not apply if the child's educational performance is adversely affected primarily because the child has an emotional disturbance, as defined in [IDEA]."
- IDEA rounds out its definition by noting that a child who shows the characteristics of autism after age three could be diagnosed as having autism if the criteria above are satisfied. This enables a child to receive special education services under this classification if he or she develops signs of autism after his or her third birthday.
- Typically a psychiatrist, clinical psychologist, physician or other highly qualified professional makes the diagnosis. It would not be uncommon for the evaluation team to suspect Autism, then ask the parent to see a psychiatrist, clinical psychologist or appropriately trained pediatrician.

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).

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.

## Core DSM and ICD Core ASD Symptoms in All Ages

- Impaired social relations.
- Impaired communication skills.
- Impaired behavior.



## Symptoms Present Before 24 Months

## Children with ASD Struggle to:

- Orient to name
- Attend to human voice
- Look at face and eyes of others
- Imitate
- Show objects
- Point
- Demonstrate
   interest in other children



## Symptoms Present Before 36 Months

## Children with ASD:

- Use of other's body to communicate or as a tool
- Stereotyped hand/finger/body mannerisms
- Ritualistic behavior
- Failure to demonstrate pretend play
- Failure to demonstrate joint attention



Autism is now referred to as a spectrum disorder in which individuals can present problems ranging from total impairment to near reasonable functioning.

In a Spectrum Disorder genetic and phenotypic factors predispose certain individuals to express certain Central Nervous System vulnerabilities leading to poorly adapted variations in development and behavior.

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.

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

# DSM 5 Autism Spectrum Disorder

- Combined social and communication categories.
- Tightened required criteria reducing the number of symptom combinations leading to a diagnosis.
- Omitted Retts and Childhood Disintegrative Disorders.
- Clarifies co-morbidity issues.
- Eliminated PDD NOS and Aspergers in favor of Autism Spectrum Disorder.
- Created Social Pragmatic Communication Disorder.
- Still no specified profile for adults, just guidelines.

## DSM 5 Autism Spectrum Disorder

- 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.

## DSM 5 ASD Criteria A

Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text):

- 1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
- 2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
- 3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

### DSM 5 ASD Criteria B

Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

- 1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
- 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
- 3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
- 4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

### **DSM 5** Autism Spectrum Disorder

#### • Specify if:

With or without accompanying intellectual impairment.

With or without accompanying language impairment.

Associated with a known medical or genetic condition or environmental factor.

Associated with another neurodevelopmental, mental, or behavioral disorder.

With catatonia.

### DSM 5 ASD Criteria C, D, E.

- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life)
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make co-morbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

#### The Three Functional Levels of Autism

ASD Level 1
Requiring Support



difficulty initiating social interactions

organization and planning problems can hamper independence

**ASD Level 2** 

Requiring
Substantial Support



social interactions limited to narrow special interests

frequent restricted/ repetitive behaviors **ASD Level 3** 

Requiring Very Substantial Support



severe deficits in verbal and nonverbal social communication skills

great distress/difficulty changing actions or focus

### Applying DSM 5 With Adults (page 54)

- "Many adults with ASD without intellectual or language disabilities learn to suppress repetitive behavior in public."
- "Special interests may be a source of pleasure and motivation and provide avenues for education and vocation later in life."
- "Diagnostic criteria may be met when restricted, repetitive patterns of behavior, interests or activities were clearly present during childhood. . . even if symptoms are no longer present."
- "Among adults with ASD with fluent language, the difficulty in coordinating non-verbal communication with speech may give the impression of add, wooden or exaggerated body language."

### Applying DSM 5 With Adults (page 56-57)

- Symptoms are "clear in the developmental period."
- "In later life interventions or compensations, as well as current supports, may mask these difficulties in at least some contexts."
- "However **symptoms remain sufficient** to cause current impairment in social, occupational or other important areas of functioning."
- "ASD is diagnosed four times more often in males than females."
- "Girls without accompanying intellectual impairment or language delays may go unrecognized."

# DSM IV TR Autism and Asperger Syndrome

Data from the Autism Spectrum Rating Scales Epidemiologic Sample (2009)

### Lorna Wing: Godmother of Autism

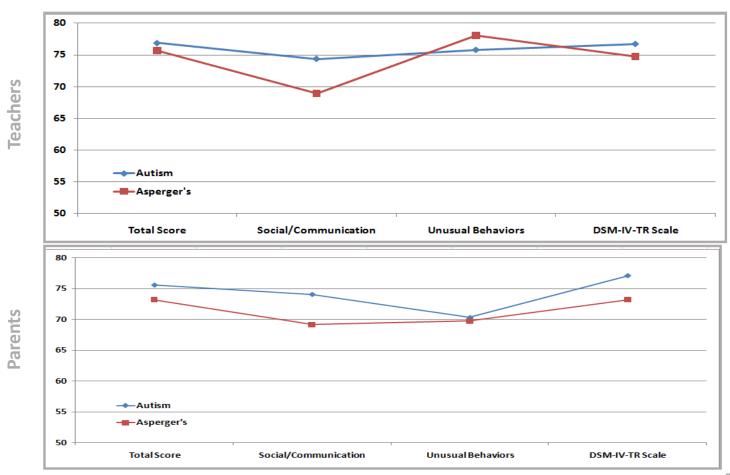




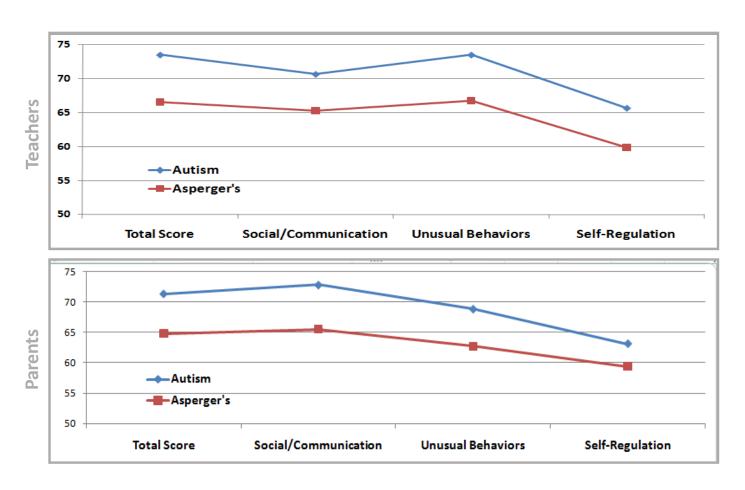
### Autism vs. Asperger

- 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.

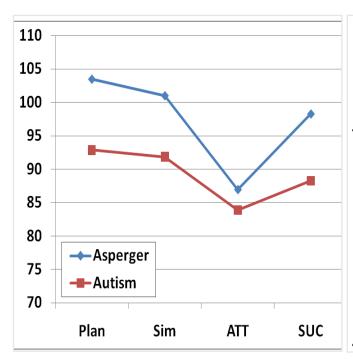
### Autism vs Asperger (2-5 years)



### Autism vs Asperger (6-18 Years)



### Autism vs Asperger (6-18 years)



Descriptive Statistics and Comparisons Between Individuals with Autism (n = 20) and Asperger Syndrome (n = 23).

		Mn	SD	F	Sig	d-ratio
PLAN	Asperger	103.5	31.6	1.71	.20	0.40
	Autism	92.9	19.2			
SIM	Asperger	101.0	15.3	3.33	.08	0.54
	Autism	91.9	17.5			
ATT	Asperger	86.9	17.7	0.30	.59	0.17
	Autism	83.9	18.8			
SUC	Asperger	98.3	15.7	2.46	.12	0.47
	Autism	88.3	25.6			

## 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:

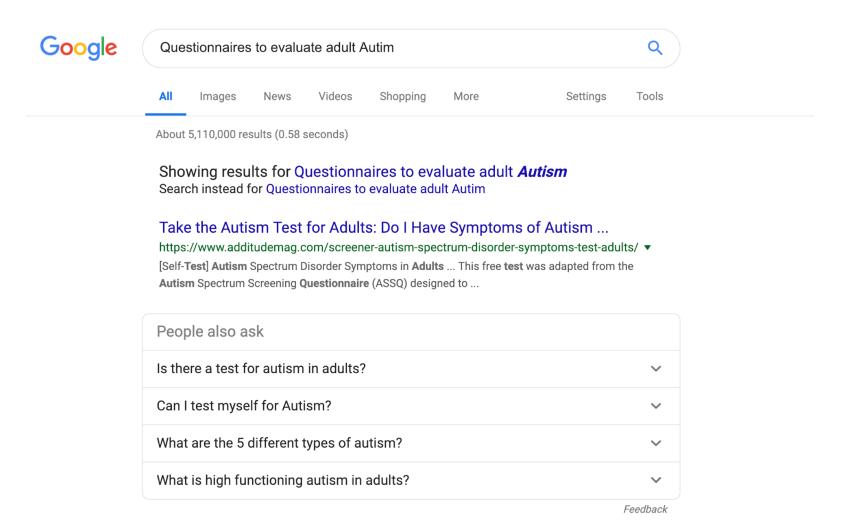
- Deficits in using communication for social purposes, such as greeting and sharing information, in a manner that is appropriate for the social context.
- Impairment of the ability to change communication to match context or the needs of the listener, such as speaking differently in a classroom than 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).

### 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!

### Google It! Conducting an Evaluation for ASD



### Google It! Conducting an Evaluation for ASD

#### ARC Tests - Autism Research Centre

https://www.autismresearchcentre.com/arc\_tests •

Adult Asperger Assessment (AAA) Click to view ..... Childhood Autism Spectrum Test (CAST) Click to view ..... Social Stories Questionnaire (SSQ) Click to view.

#### Assessing Autism in Adults: An Evaluation of the Developmental ...

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5807495/ ▼

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### https://www.autismresearchcentre.com/arc\_tests

#### **Downloadable Tests**

Various tests have been devised by ARC for use in the course of our research. Some of these tests are made available here for download.

You are welcome to download these tests provided that they are used for genuine research purposes, and provided due acknowledgement of ARC as the source is given.

#### Please note

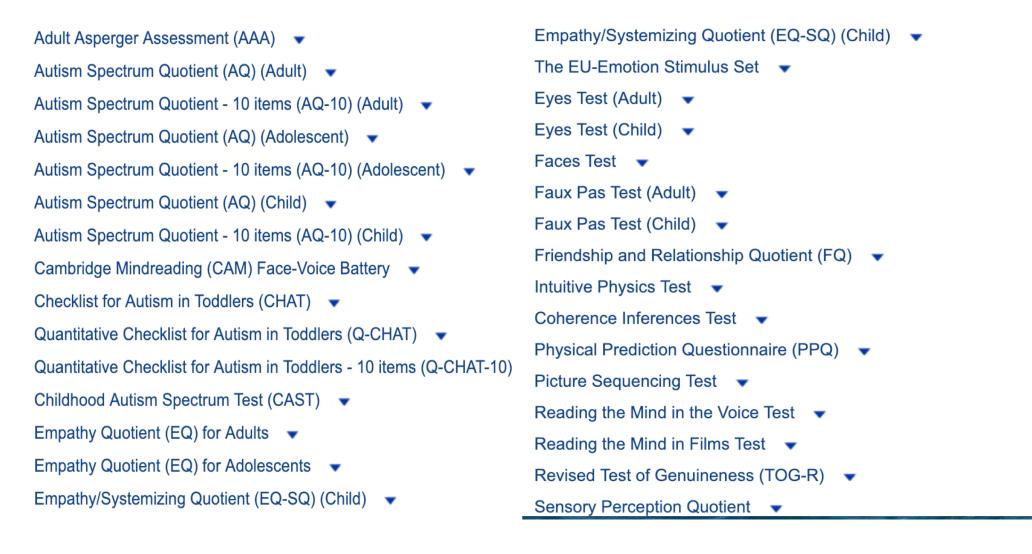
Our tests are posted on our website to enable free access to academic researchers. None of them are diagnostic: No single score on any of our tests or questionnaires indicates that an individual has an Autism Spectrum Condition (ASC). If you are concerned that you, or a friend or relative, may have ASC, please discuss these concerns with your GP or family doctor or ask the **National Autistic Society** (NAS) or equivalent charity in your country, for advice.

#### **Translations**

If you have translated any of the ARC tests, and are happy to be contacted by other researchers to obtain a copy of your translation, please contact the **webmaster**.

Please see our **Terms and Conditions for translations.** 

### https://www.autismresearchcentre.com/arc\_tests



### Cambridge Behavioural Scale

I can easily tell if someone else wants to enter a conversation.	strongly	slightly	slightly	strongly
	agree	agree	disagree	disagree
2. I prefer animals to humans.	strongly	slightly	slightly	strongly
	agree	agree	disagree	disagree
3. I try to keep up with the current trends and fashions.	strongly	slightly	slightly	strongly
	agree	agree	disagree	disagree
4. I find it difficult to explain to others things that I understand easily, when they don't understand it first time.	strongly	slightly	slightly	strongly
	agree	agree	disagree	disagree
5. I dream most nights.	strongly	slightly	slightly	strongly
	agree	agree	disagree	disagree
6. I really enjoy caring for other people.	strongly	slightly	slightly	strongly
	agree	agree	disagree	disagree
7. I try to solve my own problems rather than discussing them with others.	strongly agree	slightly agree	slightly disagree	strongly disagree
8. I find it hard to know what to do in a social situation.	strongly	slightly	slightly	strongly
	agree	agree	disagree	disagree
9. I am at my best first thing in the morning.	strongly	slightly	slightly	strongly
	agree	agree	disagree	disagree

Autism Spectrum Disorder as Reflected in the Autism Spectrum Rating Scales (Goldstein and Naglieri, 2009) Exploratory and Confirmatory Factor Analyses

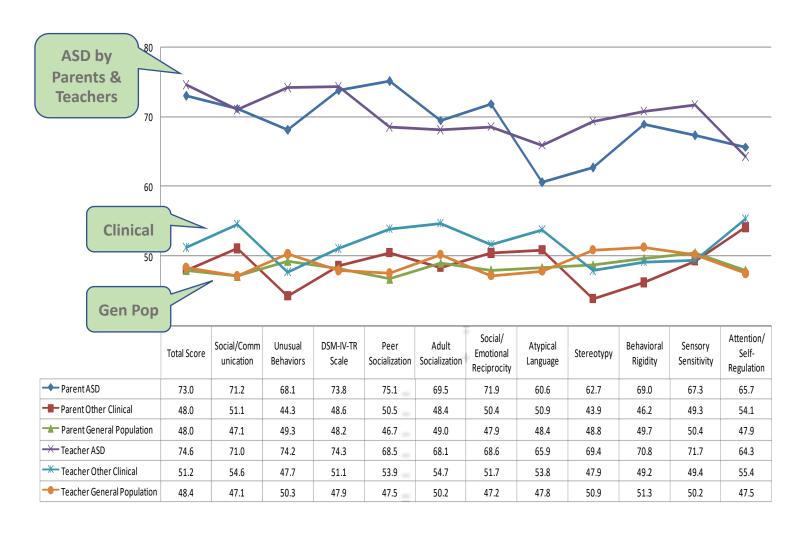
### Validity of the Factors

- Factor analysis is a valuable tool to understand how items group.
- But we also need to know if the items have validity, that is do they measure what they purport to measure?
- Discriminating individuals with ASD from the regular population is important.
- Discriminating individuals with ASD from those who are not in the regular population (e.g. they suffer from other conditions) but not ASD is equally important.

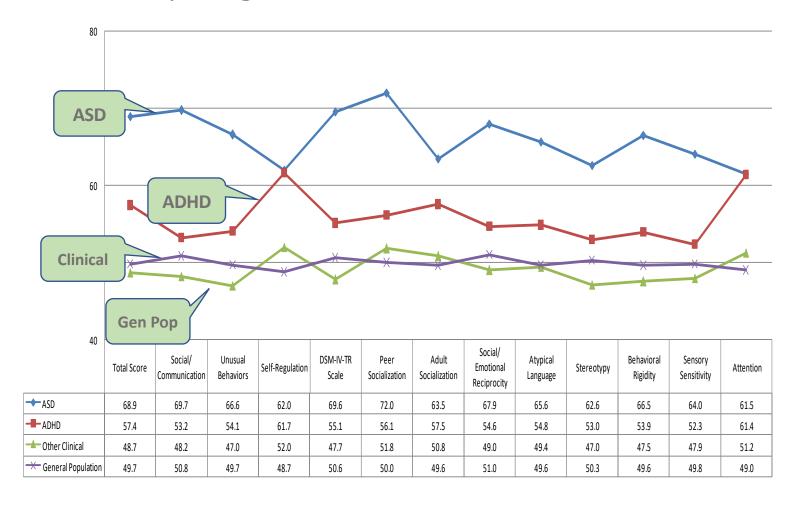
### **ASRS** Profiles

- A scale like the ASRS should differentiate adults with ASD from the normal population.
- Comparison to regular individuals should demonstrate that those with ASD have high scores.
- Comparisons to other clinical groups should also show differences from those with ASD.
- Comparisons of the ASD to regular and other clinical samples provides an essential examination of validity.

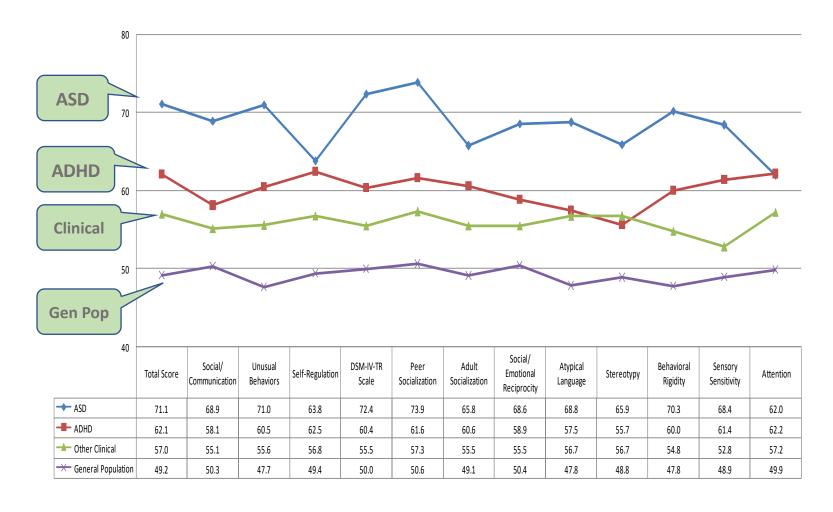
### ASRS Validity for ages 2-5



### ASRS Validity: Ages 6-18 Parents

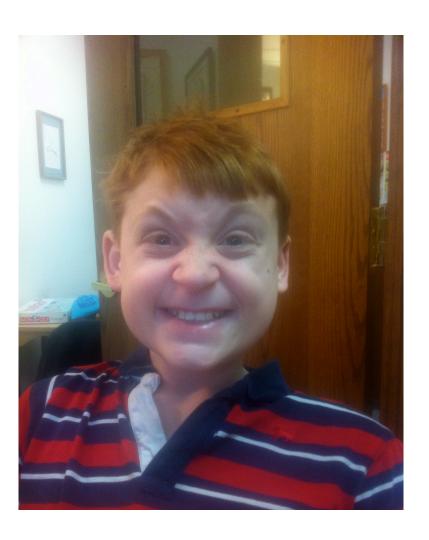


### ASRS Validity: Ages 6-18 Teachers

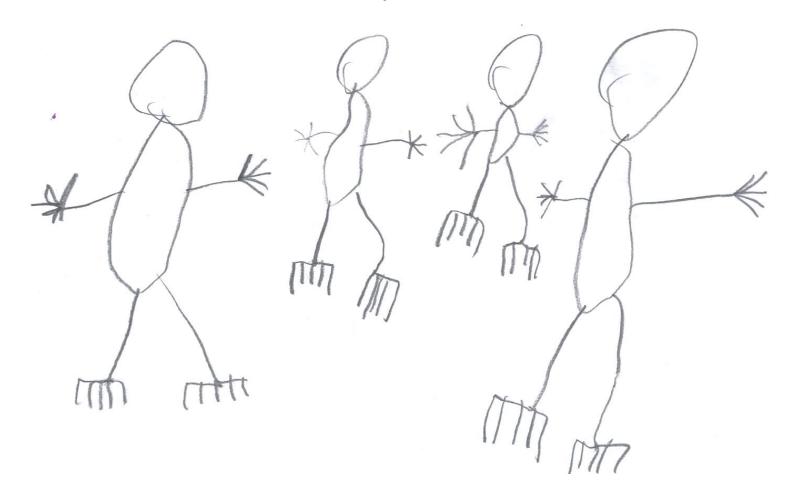


The ASRS now has a DSM 5 scale as well as scoring options for non-verbal children.

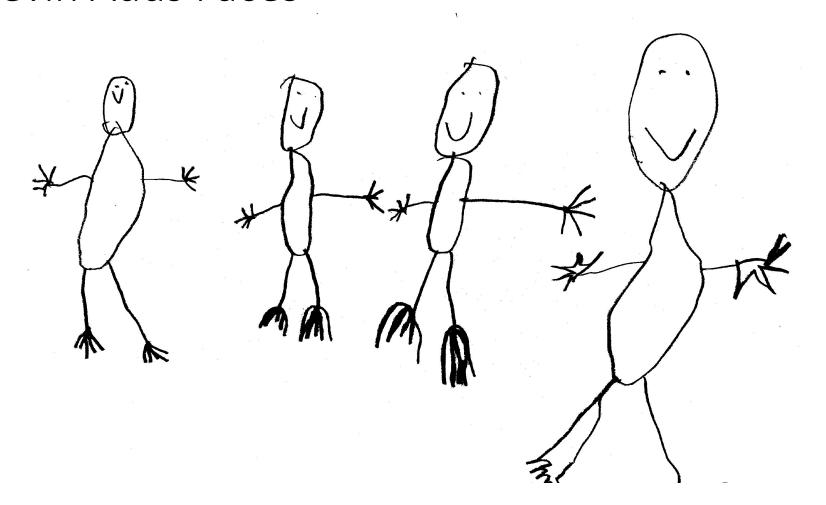
### Meet Kevin



### Kevin Draws His Family



### Kevin Adds Faces



### Pretend Play in Autism

- Limited, often absent
- When present usually characterized by: repetitive themes, rigidity, isolated acts, one-sided play, limited imagination.

# 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.

### 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.

### 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 the gap between how a person with ASD mediates their internal autistic status and their overt behavior (external autistic presentation)?

### 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.

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.

### 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.

## 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.

## **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

## 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.

## 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.

## 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.

## Importance of a National Norm

- Sample was stratified by
  - Sex, age, race/ethnicity, parental education level (PEL; for cases rated by parents), geographic region
  - Race/ethnicity of the child (Asian/Pacific Islander, Black/African
     American/African Canadian, Hispanic, White/Caucasian, Multi-racial by the rater
  - Parents provided PEL of both parents
    - the higher of the two levels was used to classify the parental education level of the child
  - All raters completed the ASRS via the paper-and-pencil or online methods.

### Importance of a National Norm

ASRS Standardization Samples by Age and Rater						
Age Groups	<b>Parent Raters</b>	Teacher Raters				
2 - 5 Years	320	320				
6 - 11 Years	480	480				
12 - 18 Years	480	480				
Sub Total n	1,280	1,280				
TOTAL N	2,560					

Note: at ages 2-16 years there were 80 subjects (40 girls and 40 boys) per one year age group. At ages 17-18 there were 80 subjects (40 girls and 40 boys) across this two year interval.

## Importance of a National Norm

- Validity samples were collected
  - a single primary diagnosis was indicated
  - a qualified professional (e.g., psychiatrist, psychologist) had made the diagnosis
  - Criteria were made using DSM-IV-TR or ICD-10
  - Clinical samples include:
    - ASD (N = 580)
    - ADHD (N = 250)
    - Communication Delay (N = 180)
    - Developmental Delay (N = 140)
    - Anxiety / Depression (N = 100)

## **ASRS** Reliability

## ASRS Reliability Ages 2-5 Parents & Teachers (or caregivers)

		Pa	rent Rating	s	Teacher Ratings		
Scale		Normative Sample (N = 320)	Clinical Sample (N = 243)	Average	Normative Sample (N = 320)	Clinical Sample (N = 249)	Average
Total Score		.95	.98	.97	.94	.99	.97
ASRS	Social/ Communication	.94	.98	.96	.95	.98	.97
Scales	Unusual Behaviors	.91	.96	.94	.85	.97	.92
DSM-IV-TR	Scale	.91	.97	.94	.91	.98	.95
	Peer Socialization	.77	.96	.89	.85	.95	.91
	Adult Socialization	.67	.85	.76	.78	.85	.81
	Social/Emotional Reciprocity	.83	.96	.91	.88	.96	.93
Treatment Scales	Atypical Language	.71	.77	.74	.59	.79	.69
Scales	Stereotypy	.75	.86	.80	.67	.86	.77
	Behavioral Rigidity	.85	.94	.90	.82	.95	.90
	Sensory Sensitivity	.71	.89	.81	.59	.90	.77
	Attention/Self-Regulation	.83	.88	.85	.83	.89	.86

### ASRS Reliability Ages 6-18 : Parents

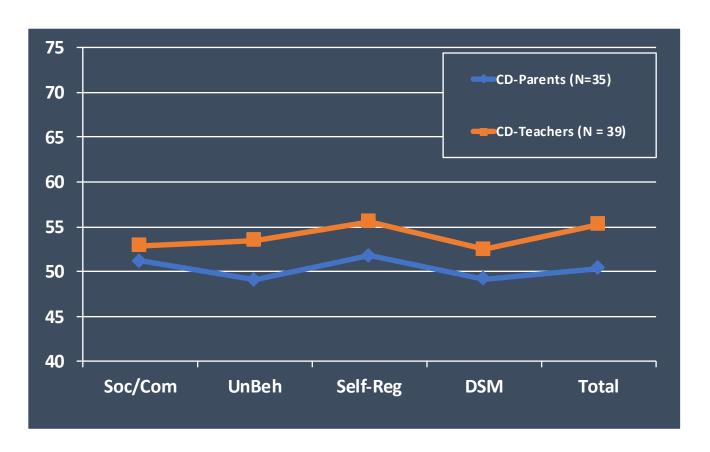
	·	6	to 11 Years		12 to 18 Years			
Scale		Normative Sample (N = 480)	Clinical Sample (N = 230)	Average	Normative Sample (N = 480)	Clinical Sample (N = 185)	Average	
Total Score		.97	.98	.97	.97	.97	.97	
ASRS	Social/ Communication	.91	.97	.94	.92	.95	.93	
Scales	Unusual Behaviors	.94	.95	.94	.93	.95	.94	
	Self-Regulation	.92	.92	.92	.93	.93	.93	
DSM-IV-TR	DSM-IV-TR Scale		.96	.95	.94	.96	.95	
	Peer Socialization	.84	.92	.87	.84	.91	.86	
	Adult Socialization	.77	.77	.77	.79	.77	.78	
	Social/Emotional Reciprocity	.85	.94	.89	.88	.91	.89	
Treatment	Atypical Language	.81	.85	.82	.82	.85	.83	
Scales	Stereotypy	.79	.78	.79	.77	.79	.78	
	Behavioral Rigidity	.89	.92	.90	.86	.94	.89	
	Sensory Sensitivity	.79	.85	.81	.77	.82	.79	
	Attention	.90	.91	.90	.89	.91	.90	

## ASRS Reliability Ages 6-18 : Teachers

Scale		6	to 11 Years		12 to 18 Years			
		Normative Sample (N = 480)	Clinical Sample (N = 167)	Average	Normative Sample (N = 480)	Clinical Sample (N = 325)	Average	
Total Score	1	.97	.98	.97	.97	.97	.97	
	Social/ Communication	.93	.96	.94	.92	.96	.94	
ASRS Scales	Unusual Behaviors	.93	.95	.94	.94	.95	.94	
Scales	Self-Regulation	.94	.93	.94	.93	.91	.92	
DSM-IV-TR	SM-IV-TR Scale		.96	.95	.94	.96	.95	
	Peer Socialization	.84	.90	.86	.83	.90	.86	
	Adult Socialization	.80	.81	.80	.77	.77	.77	
T	Social/Emotional Reciprocity	.89	.92	.90	.89	.92	.90	
Treatment Scales	Atypical Language	.75	.87	.79	.80	.85	.82	
Scales	Stereotypy	.69	.77	.71	.72	.81	.76	
	Behavioral Rigidity	.90	.93	.91	.90	.94	.92	
	Sensory Sensitivity	.77	.87	.80	.84	.87	.85	
	Attention	.92	.92	.92	.91	.92	.91	

# ASD vs Communication Disorders

### ASD vs Communication Disorders



## Race / Ethnic Differences

## ASRS Race Ethnic Differences

Table 8.26. Differences between Race/Ethnic Groups: ASRS (6-18 Years) Parent Ratings

					<i>d</i> -ratio		
Scale			African American	Hispanic	White	White - African American	White- Hispanic
		M	50.9	45.7	49.3		
<b>Total Score</b>		SE	0.9	1.0	0.5	0.14	0.31
		N	122	128	536		
	Social/ Communication	M	50.8	46.4	49.1		0.24
		SE	0.9	0.9	0.5	0.15	
		N	122	128	536		
	Unusual Behaviors	M	50.6	45.6	49.4	0.11	0.33
ASRS Scales		SE	0.9	0.9	0.5		
		N	122	128	536		
		M	50.3	46.1	49.1	0.10	0.26
	Self-Regulation	SE	0.9	1.0	0.5		
		N	122	128	536		
		M	51.0	45.6	49.7		
DSM-IV-TR Scale SE		0.9	0.9	0.5	0.13	0.37	
		N	128	131	549		

## Race Ethnic Differences Short Form

Table 9.12. Effect of Race/Ethnicity: ASRS Short Forms

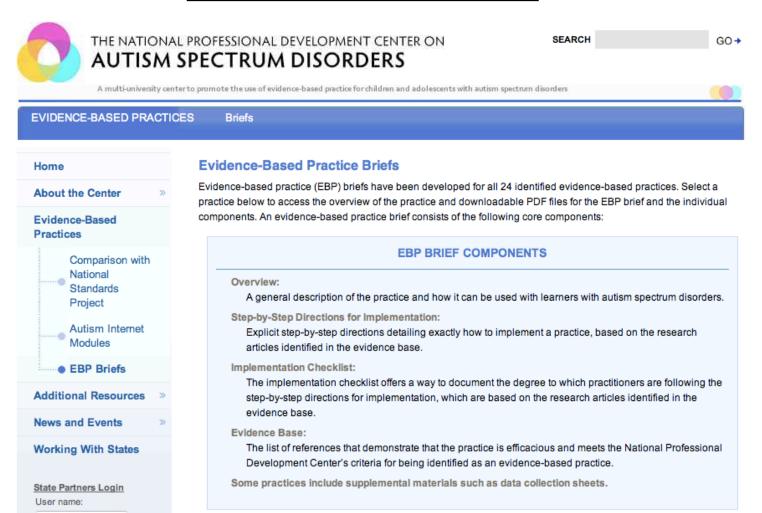
Ago	Rater			ш	NAZII	<i>d</i> -ratio	
Age			AA	нт	HI WH		WH-HI
		M	46.5	49.2	49.9		0.06
	Parent	SE	1.4	1.7	0.8	-0.34	
2-5		N	52	57	172		
Years	Teacher/Childcare Provider	M	48.0	45.6	50.7		0.34
		SE	1.7	1.9	1.1	-0.18	
		N	47	48	195		
	Parent	M	50.6	46.2	49.6	0.09	0.29
		SE	0.9	0.9	0.5		
6-18		N	133	135	560		
Years	Teacher	M	50.7	51.9	49.8	0.07	
		SE	0.9	0.9	0.6		-0.16
		N	132	152	521		

### Intervention

- Despite strong claims no curative treatment has been studied vigorously.
- "In the absence of a definitive cure there are a thousand treatments" (Klin).

 Behavior modification, educational intervention and pharmacology have been studied.

#### http://autismpdc.fpg.unc.edu/content/briefs



#### http://autismpdc.fpg.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

## 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.

## Components of an Effective Treatment Program

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

### Medications

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



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 Hessl<sup>2</sup>, Barbara Rathmell<sup>3</sup>, Peter Zarevics<sup>3</sup>, Maryann Cherubini<sup>3</sup>, Karen Walton-Bowen<sup>3</sup>, Yi Mu<sup>4</sup>, Danh V. Nguyen<sup>4</sup>, Joseph Gonzalez-Heydrich<sup>5</sup>, Paul P. Wang<sup>3</sup>,\*, Randall L. Carpenter<sup>3</sup>, Mark F. Bear<sup>6</sup> and Randi J. Hagerman<sup>7</sup>

+ Author Affiliations

4\*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 (GABAB) 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 male), 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 8% 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 GABAB agonists have potential to improve social function and behavior in patients with **fragile X** syndrome.

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New Drug May Treat ASD Psychostimulants for ADHD-like symptoms in individuals with autism spectrum disorders.

Cortese S, Castelnau P, Morcillo C, Roux S, Bonnet-Brilhault F.

Institute for Pediatric Neuroscience, NYU Child Study Center, Langone Medical Center, 215 Lexington Avenue, 14th Floor, 10016 NY, USA. <a href="mailto:samuele.cortese@gmail.com">samuele.cortese@gmail.com</a>.

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 CINHAL were searched through 3 January 2012. From a pool of 348 potentially relevant references, 12 citations (11 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.

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).

## 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.

## Oxytocin May Have Many Effects



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

MICHAELG. AMAN, PH.D., CHRISTOPHERJ. MCDOUGLE, 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 2009J.

### 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.

## 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.

#### Autism Spectrum Disorder (ASD)

#### **ASD** Homepage











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Research & Tracking

Articles & Key Findings

Frequently Asked Questions

Materials & Multimedia +

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### Links to Other Websites

#### **Families**

#### 100 Days Kit, Autism Speaks 🖸

This kit provides information to help families get through the first steps of an autism diagnosis.

#### A Parent's Guide to Evidence-Based Practice and Autism 🔼 🏻

This manual from the National Autism Center aims to assist parents as they make difficult decisions about how best to help their children with autism spectrum disorders reach their full potential.

#### Autism Source, Autism Society of America (ASA)

ASA's Autism Source is a database of resources in local communities. It includes contact information for ASA chapters and other local supports.

#### Autism NOW [2]

Autism Now is an initiative of The Arc and The Administration on

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**Healthcare Providers** 

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- Child and Adolescent Psychiatrist Finder

#### **Autism Resource Center**

This Resource Center was made possible by a grant from the American Academy of Child and Adolescent Psychiatry's Campaign for America's Kids (CFAK).

Last updated August 2018

#### **About**

Autism is a condition which is usually diagnosed before a child is three. Autistic children have delayed speech or no speech at all, problems interacting socially, limited interests and odd or repetitive behaviors. Autism is a neurodevelopmental disorder caused by abnormal brain development and functioning. Many children with autism also have an intellectual disability.

Finding the right treatment plan can be challenging because every child is unique and has different strengths and weaknesses. Often parents have their child tested for hearing problems because their child does not respond to conversation or commands. They may also show strange or difficult to manage behaviors. Early detection and getting the right educational, medical, behavioral, and supportive services can improve the functioning and long-term outlook of children with autism.

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#### **Resource Materials**

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Important: The documents are in PDF format and you will need Adobe Reader to open and/or print them. You can download Adobe Reader for free at <a href="http://www.adobe.com/">http://www.adobe.com/</a>. Our Print on Demand service is currently unavailable. If you are interested in having any of the PDFs below printed you can download the document free of charge and take to a local printer or contact us for more information.

In 2006 the Autism Society launched Living with Autism which presents user-friendly information within four eye-catching pages. The series was developed to provide easy-to-understand, practical information related to the autism spectrum for a broad audience on a wide range of topics. The series will continually evolve, adding new pieces on a regular basis, and address topics across the spectrum and lifespan. Emphasis of all pieces in the series is on living successfully with autism, so articles will provide useful information, helpful tips and additional resources provided by those with expertise on the particular topic. The Living with Autism series is designed for individuals on the autism spectrum, their families, friends and concerned professionals.

#### **Living With Autism**





## Strategies for Teaching Based on Autism Research

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#### STAR Autism Program: A Research-Based ABA Curriculum

Joel Arick, Lauren Loos, Ruth Falco , Dave Krug, with contributions by John Gill.

STAR Program Order Form

The STAR Autism Program teaches children with autism the critical skills identified by the 2001 National Research Council. The ABA (Applied Behavior Analysis) instructional methods of discrete trial training, pivotal response training and functional routines form the instructional base of this comprehensive program for children with autism.

The STAR Program includes detailed lesson plans, teaching materials, data systems and a curriculum-based assessment for teaching in the six curricular areas of receptive language, expressive language, spontaneous language, functional routines, academics, and play & social skills.

Continue to read about the many benefits of this research based program....



The first randomized, controlled trial for comprehensive autism treatment for children as young as 18 months old.

While certainly not a cure for the condition, the study did find that intense early treatment yields major improvements in IQ scores, language processing, and in the ability to manage everyday tasks essential for early childhood development and education.

Published in *Pediatrics* the University of Washington study was funded by the National Institute of Mental Health. It involved 48 children ages 18 to 30 months, half of whom were randomly assigned to receive the Early Start Denver Model, an intensive autism therapy protocol. The other half were assigned to a control group and received less intensive therapy.

After two years, those who participated in the Denver Model group had average IQ scores 17.6 points higher than the control group, putting them within the range of normal intelligence, while those in the other group gained just seven points, remaining in the zone of intellectual disability.



### Division TEACCH

Treatment and Education of Autistic and related Communication-handicapped CHildren

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**TEACCH Autism Program** 

A Division of the UNC Department of Psychiatry



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#### **Introduction to TEACCH**

TEACCH is an evidence-based service, training, and research program for individuals of all ages and skill levels with autism spectrum disorders. Established in the early 1970s by **Eric Schopler** and colleagues, the TEACCH program has worked with thousands of individuals with autism spectrum disorders and their families. TEACCH provides **clinical** services such as diagnostic evaluations, parent training and parent support groups, social play and recreation groups, individual counseling for higher-functioning clients, and supported employment. In addition, TEACCH conducts **training** nationally and internationally and provides consultation for teachers, residential care providers, and other professionals from a variety of disciplines. **Research** activities include psychological, educational, and biomedical studies.

The administrative headquarters of the TEACCH program are in Chapel Hill, North Carolina, and there are nine regional TEACCH Centers around the state of North Carolina. Most clinical services from the TEACCH centers are free to citizens of North Carolina.

**Training Spotlight** 

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#### The SCERTS<sup>®</sup> Model

(Prizant, Wetherby, Rubin & Laurent, 2007)

#### What is SCERTS?

SCERTS<sup>®</sup> is an innovative educational model for working with children with autism spectrum disorder (ASD) and their families. It provides specific guidelines for helping a child become a competent and confident social communicator, while preventing problem behaviors that interfere with learning and the development of relationships. It also is designed to help families, educators and therapists work cooperatively as a team, in a carefully coordinated manner, to maximize progress in supporting a child.



#### The acronym "SCERTS" refers to the focus on:

"SC" - Social Communication – the development of spontaneous, functional communication, emotional expression, and secure and trusting relationships with children and adults;

"ER" - Emotional Regulation - the development of the ability to maintain a well-regulated emotional state to cope with everyday stress, and to be most available for learning and interacting;

"TS" – Transactional Support – the development and implementation of supports to help partners respond to the child's needs and interests, modify and adapt the environment, and provide tools to enhance learning (e.g., picture communication, written schedules, and sensory supports). Specific plans are also developed to provide educational and emotional support to families, and to foster teamwork among professionals.

The SCERTS model targets the most significant challenges faced by children with ASD and their families. This is accomplished through family-professional partnerships (family-centered care), and by prioritizing the abilities and supports that will lead to the most positive long-term outcomes as indicated by the <u>National Research Council (2001; Educating Children with Autism)</u>. As such, it



#### Learn Floortime from Dr. Stanley Greenspan

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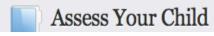
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#### Floortime-Registration

Registration for the Greenspan Floortime Approach and workshops is now closed. The Assessment will continue to be available for sign up. (See the first column on the home page.) If you would like information regarding future courses, please fill out the contact information at the bottom of our home page under "Free Guide: Discover Your Child's Learning Style."...

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#### **REACHING BEYOND AUTISM**













All children have within them the potential to be great kids.

It's our job to create a great world where this potential can flourish.

Stanley Greenspan, MD - Great Kids, 2007.

# 3

Tributes to DIR®Floortime™

Floortime has brought my child out of himself and into a bright and sweet world of adventure. (Parent) Read More

#### DIR®, FLOORTIME™, AND DIRFLOORTIME™

The <u>Developmental</u>, <u>Individual Difference</u>, <u>Relationship-based (*DIR*®) Model is a framework that helps clinicians, parents and educators conduct a comprehensive assessment and develop an intervention program tailored to the unique challenges and strengths of children with Autism Spectrum Disorders (ASD) and other developmental challenges. The objectives of the *DIR*® Model are to build healthy foundations for social, emotional, and intellectual capacities rather than focusing on skills and isolated behaviors. For a detailed overview, download 2 page flyer.</u>

■ The <u>D</u> (Developmental) part of the Model describes the building blocks of this foundation. Understanding where the child is developmentally is critical to planning a treatment program. The <u>Six Developmental Milestones</u> describes the developmental milestones that every child

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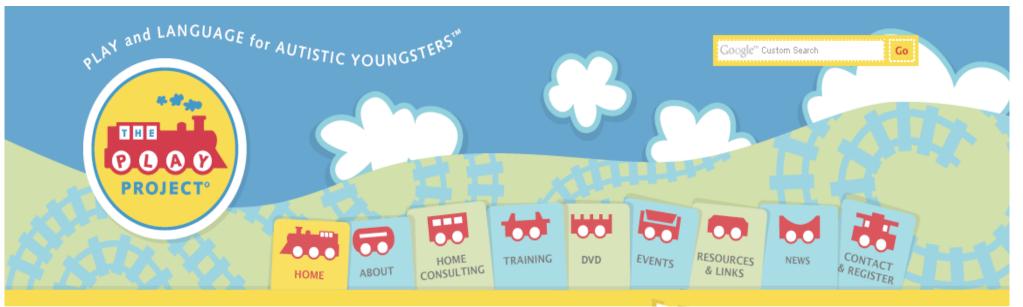
#### Welcome, Parents

Learning that your child is not developing as expected can be devastating. As you begin the search for information and guidance, you may get the discouraging message that there's not much you can do to help your child connect with the world around him. But there's much you can do. With the right treatment, your child can learn to relate, love others very deeply, and begin climbing the developmental ladder to communicate and think creatively and logically.

Get Started

#### Quick Links

- Find workshops and presentations close to your home
- Find DIRFloortime™ Professionals
- DIR® Schools and Summer Programs
- Dr. Greenspan's Web Radio Show
- Boront Bosouroon



Welcome! The P.L.A.Y. Project is a proven therapy program for children with autism. PLAY Project therapists train parents to help children connect, communicate and build relationships with others.





66 By doing what your child loves,

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### Adults (22+)

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TOOL KIT







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### Challenging Behaviors Tool Kit

Sometimes, people with autism display behaviors that are challenging to understand and address.

The Challenging Behaviors Tool Kit will provide you with strategies and resources to address these behaviors and help support you during difficult situations.

The kit is broken into different sections. You may want to read the kit in its entirety or work through a section at a time:

- Why is Autism Associated with Aggressive and Challenging Behaviors?
- Why is it Important to Do Something about Challenging Behaviors?
- Who Can Help? What is this Idea of a Team?
- What are the Things to Consider?
- What are the Positive Strategies for Supporting Behavior Implementation?
- What Might I Need to Know about Managing a Crisis Situation?
- What are Long Term Solutions and Where Can We Learn More?
- Challenging Behaviors Glossary

We sat down with 2 experts to help answer your frequently asked questions: Gary S. Mayerson, Founding Attorney at Mayerson and Associates, and Nicole Weidenbaum, Executive Director of Nassau Suffolk Services for Autism.

Check out the videos below to hear what they had to say!



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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

For additional information about the transition process, check out the Autism Speaks Transition Tool



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### **Employment Tool Kit**

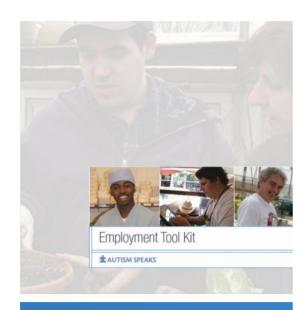
Autism Speaks would like to help you find the right job by providing you with tools and resources, including our Employment Tool Kit.

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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#### **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

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Autism After Age 21

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For over 10 years, Autism Spectrum News has been providing a trusted source of science-based autism information, education, and quality resources in the community.

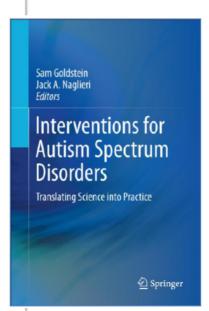
# Chapter 3 Evaluation of Treatment Effectiveness in the Field of Autism

**Psychometric Considerations and an Illustration** 

Jack A. Naglieri and Sam Goldstein

#### Introduction

Evidence-based treatment and the assessment of treatment effectiveness are dependent upon the collection of data during the evaluation process providing information about symptoms, impairment and abilities. Such an assessment allows for a seamless transition from assessment and diagnosis to effective treatment. Evaluating the effectiveness of a treatment strategy or program is important for interventions designed to address symptoms related to any psychological or developmental disorder. The



- 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

- 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	<i>7</i> 8	1
Unusual behavior	60	53	<b>-7</b>
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	<i>76</i>	-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

<sup>&</sup>lt;sup>a</sup>Note Differences needed for significance when comparing Parent and Teacher Table 4.5 of the ASRS Manual

 ... 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)

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<sup>&</sup>lt;sup>a</sup>Note Differences needed for significance when comparing Parent and Teacher Table 4.5 of the ASRS Manual

 Raters agree except for Unusual Behavior and Behavioral Rigidity scales.

	Parent	Teacher	Difference	Difference neededa		
Total score	73	73	0	5	NS	
Social communication	<i>77</i>	<i>7</i> 8	1	6	NS	
Unusual behavior	60	53	<b>-7</b>	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	<i>77</i>	<i>76</i>	-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>&</sup>lt;sup>a</sup>Note Differences needed for significance when comparing Parent and Teacher ratings are found in Table 4.5 of the ASRS Manual

- 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.

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

	Parent	Teacher	Difference n		rence neededa
Total score	73	73	0	5	NS
Social communication	<i>77</i>	<i>7</i> 8	1	6	NS
Unusual behavior	60	53	<b>-7</b>	6	Sig
Self-regulation	70	74	4	7	NS
DSM-IV scale	69	68	-1	6	NS
Treatment scales					
Peer socialization	70	<i>73</i>	3	9	NS
Adult socialization	58	63	5	12	NS
Social/emotional reciprocity	<i>77</i>	<i>76</i>	-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	<i>73</i>	2	7	NS

T-scores greater than 59 appear in italic text

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

 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. 3.7 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
3. 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

# 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	27
Improve ability to carry on normal conversation with peers	74
Respond appropriately when other children initiate	59

Peer Socialization	
Item	Score
14. have trouble talking with other children?	3 4
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

- 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

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

	Time 1	Time 2	Time 3	_	gress monitoring ne 2 – 1)		gress monitoring me $3-1$ )
Total score	73	70	63	-3	NS	10	Sig
Social communication	<i>77</i>	<i>77</i>	66	0	NS	11	Sig
Unusual behavior	60	58	58	-2	NS	2	NS
Self-regulation	<i>70</i>	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)

### 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.

### 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 selfesteem, 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.

### **EPIC Players**

### ABOUTUS

EPIC Players is a nonprofit, neuro-inclusive theatre company dedicated to creating professional performing arts opportunities and supportive social communities through the arts for person living with developmental disabilities.

Through neuro-inclusive mainstage productions, musical cabarets, original showcases, skills based classes and career resources, we hope to breakdown social stigmas surrounding neuro-diverse communities, increase critical employment opportunities and pioneer increased inclusion in the arts.

TICKETS

AUDITION



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 bolder, a pleasure to the beholder

Ooh! Ahh! Look at this one! Come quick!

Pockets bulge with fragments and paint cans run dry

But the grey rock remains ignored

An ugly blotch on a sweeping mural

The sun sets, everyone leaves

And they miss the centerpiece of the field

For when night falls, the grey rock in the center

T4 -1----- !-- 41-- 4--1-



### 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.



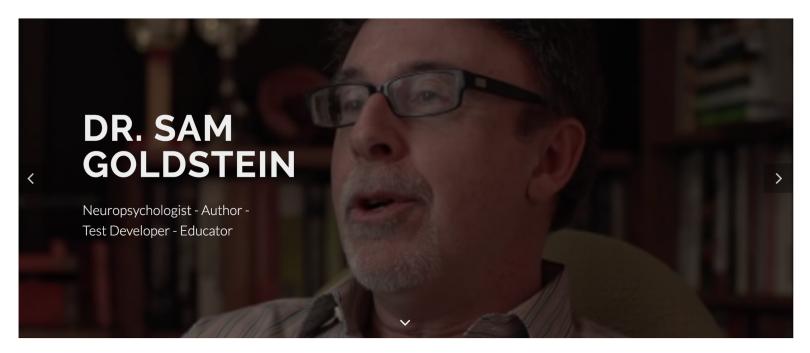
ASRS® [Manual Quiz: 4 CE Credits]

The Autism Spectrum Rating Scales<sup>™</sup> identifies symptoms, behaviors, and associated features of Autism Spectrum Disorders in youth

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