

Autism Spectrum Disorders: Transition of Children to Adulthood

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Objectives and Disclosure

- illustrate the various clinical features of adults with autism
- Review genetic and imaging studies which reveal clues about etiology and pathophysiology
- Discuss outcome data for adults with autism
- Review treatment approaches
- Review local delivery of care issues
- Disclosures to report: GW Pharma grants for CBD studies



How Matt Harvey Became the Most Exciting Pitcher in Baseball

Go Ahead, Throw That *Gatsby* Bash

The Curious Story of Zhu Ling, Poison Victim

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OCTOBER 2010

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.

JOHN DONVAN and CAREN ZUCKER | AUG 30 2010, 2:31 PM ET

VIDEO



A Video Letter From the Editor

Highlights from the May 2013 issue

The Atlantic, "Autism's First Child"



copy, follow-up
report Neur. Ch. 2: 217-250, 194

INTERPERSONAL

PATHOLOGY

a list of

To understand and measure emotional qualities is very difficult. Psychologists and educators have been struggling with that problem for years but we are still unable to measure emotional and personality traits with the exactness with which we can measure intelligence.
—ROSE ZELIGS in *Glimpses into Child Life**

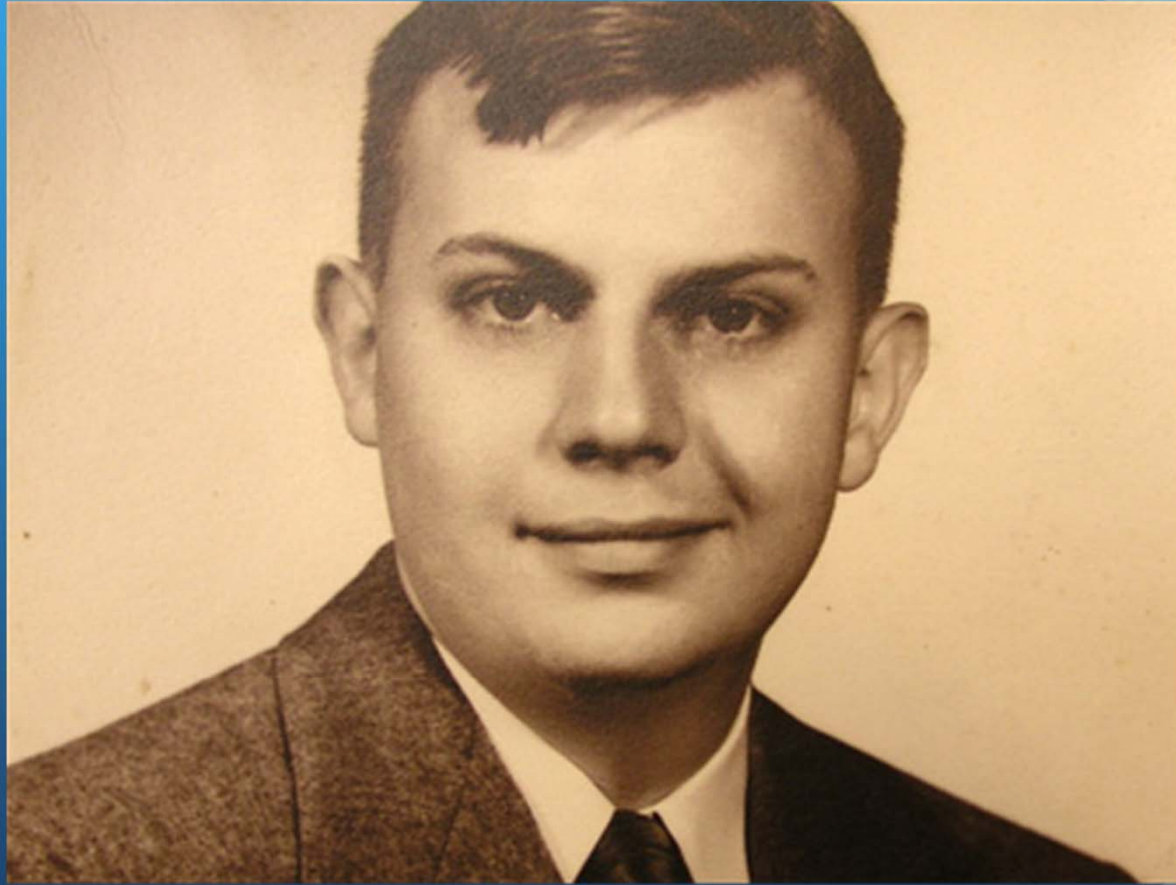
AUTISTIC DISTURBANCES OF AFFECTIVE CONTACT

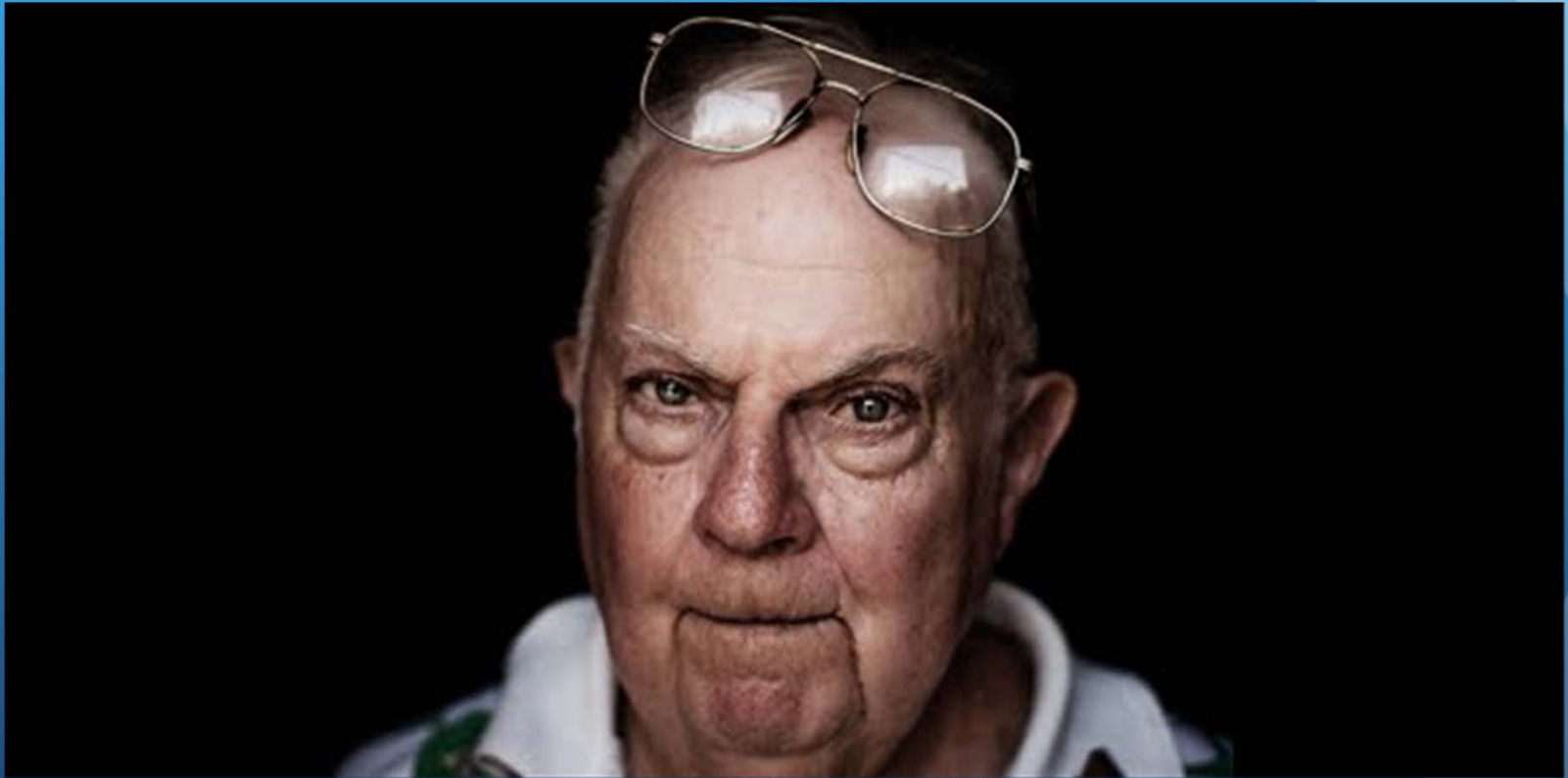
stress in Intuition By LEO KANNER
not on Language.

SINCE 1938, there have come to our attention a number of children whose condition differs so markedly and uniquely from anything reported so far, that each case merits—and, I hope, will eventually receive—a detailed consideration of its fascinating peculiarities. In this place, the limitations necessarily imposed by space call for a condensed presentation of the case material. For the same reason, photographs have also been omitted. Since none of the children of this group has as yet attained an age beyond 11 years, this must be considered a preliminary report, to be enlarged upon as the patients grow older and further observation of their development is made.

Case 1. Donald T. was first seen in October, 1938, at the age of 5 years, 1 month. Before the family's arrival from their home town, the father sent a thirty-three-page typewritten history that, though filled with much obsessive







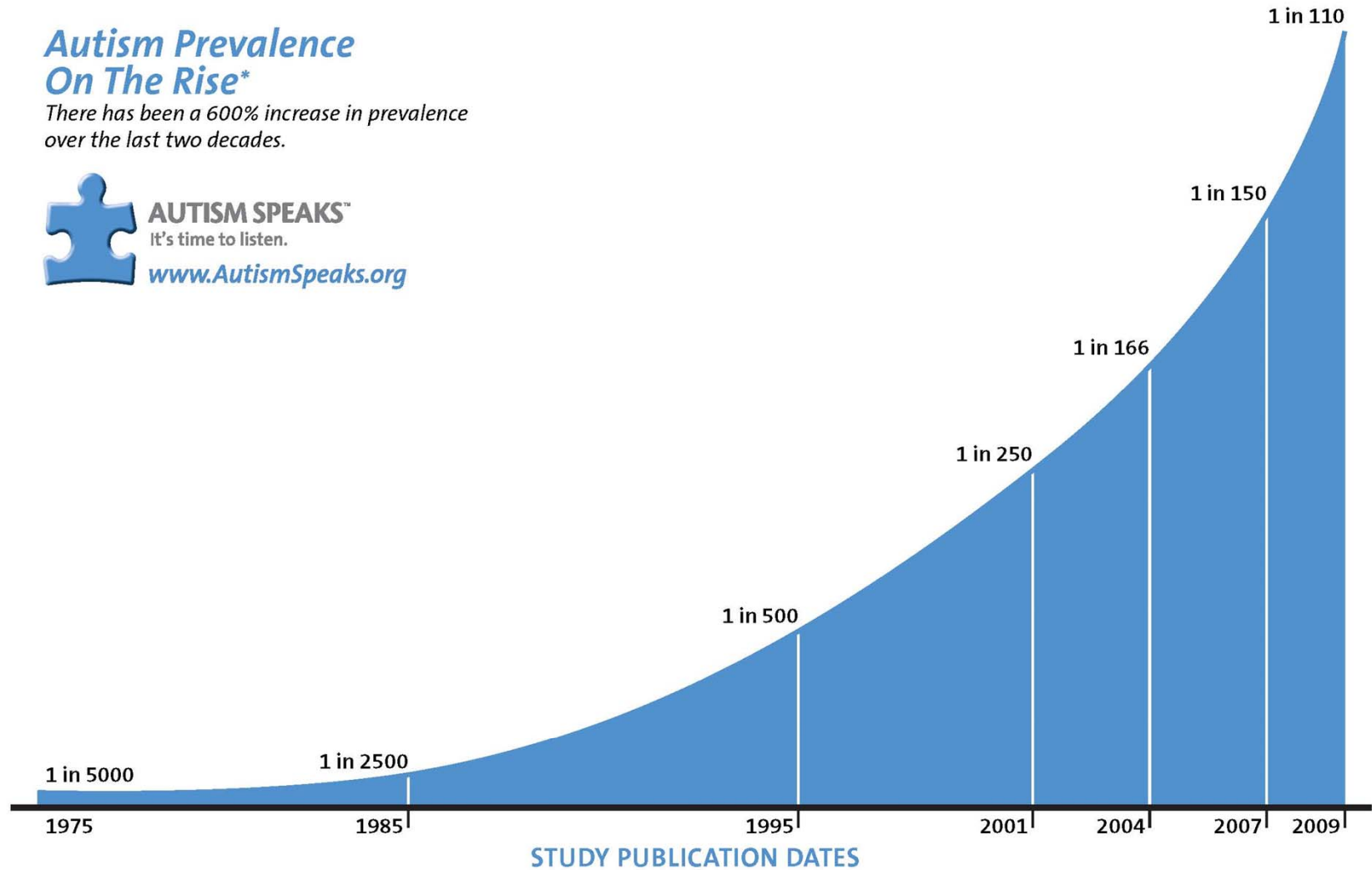
Autism Prevalence On The Rise*

There has been a 600% increase in prevalence
over the last two decades.



AUTISM SPEAKS™
It's time to listen.

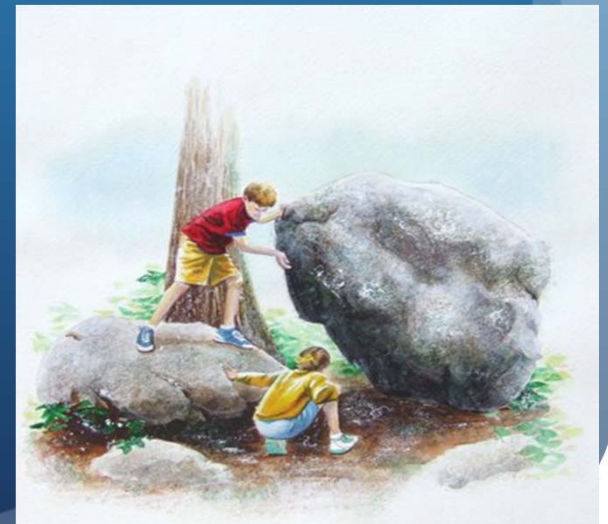
www.AutismSpeaks.org



*Recent research has indicated that changes in diagnostic practices may account for at least 25% of the increase in prevalence over time, however much of the increase is still unaccounted for and may be influenced by environmental factors.

Prevalence continues to grow

- Current CDC estimates 1 in 88 children aged 8 years have an autism spectrum disorder
 - 1 in 54 boys
 - 1 in 252 girls
- (March 30 issue of CDC publication Morbidity and Mortality Weekly Report). MMWR 2012; 61:1-24.

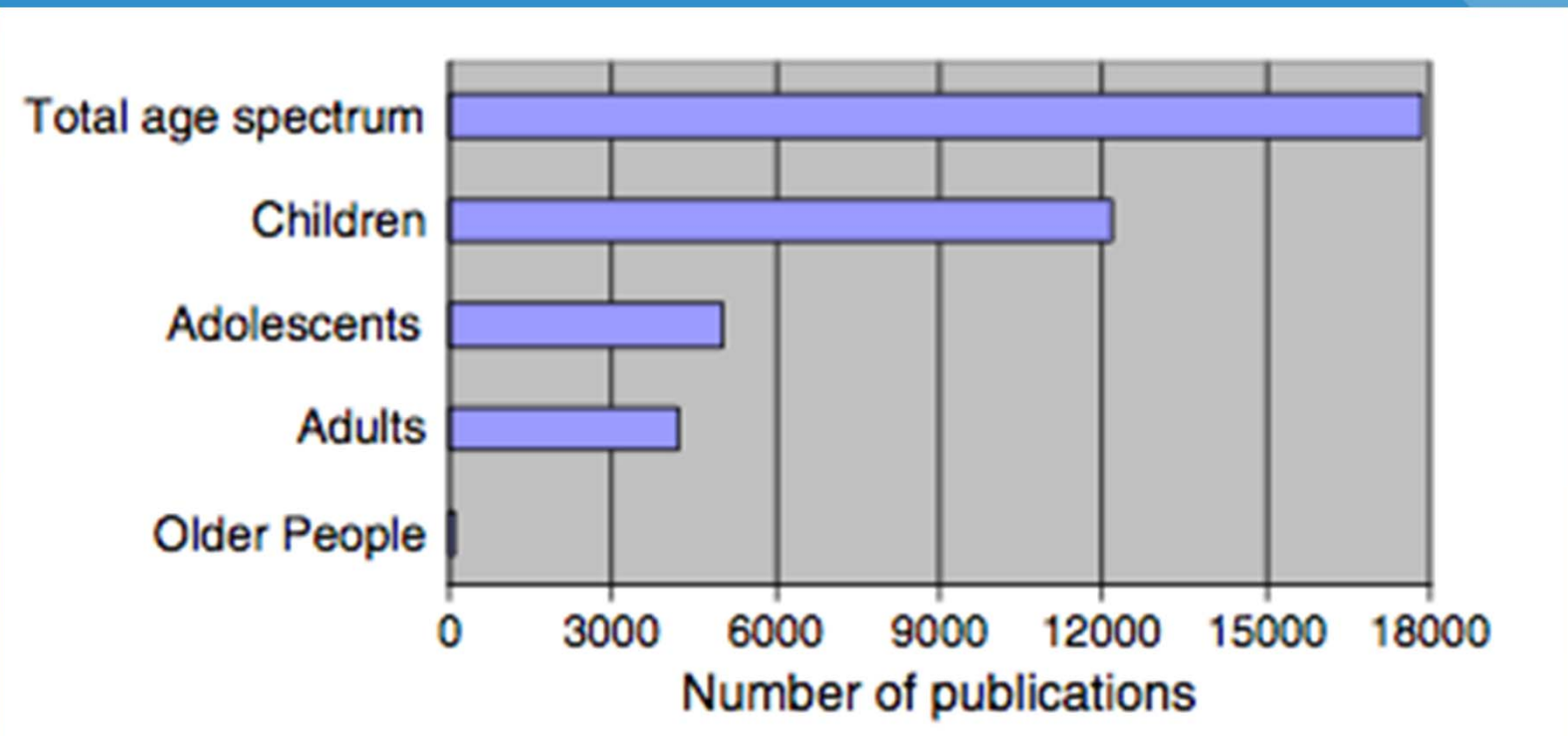


CDC National Health Statistics Report

- Parent-reported ASD among children aged 6 to 17 years is 1 in 50.
 - Greatest increase among boys aged 14 to 17 years
 - Telephone survey
- Reasons for increase
 - Public awareness
 - Newer community studies
 - Diagnostic practices
 - Environmental-genetic interactions
- BLUMBERG, et al., 2013 U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, NATIONAL CENTER FOR HEALTH STATISTICS (ed.).

Number of publications on ASD according to age.

Mukaetova-Ladinska, E. B., et al. (2012). Int J Geriatr Psychiatry 27(2): 109-118.

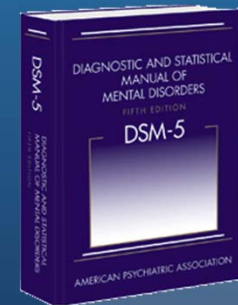


NHS NICE clinical guideline for adults with ASD

- Identification of clinical symptoms
 - Quick screen and comprehensive evaluation
- Evidence based interventions including those for challenging behavior
- Assessment and interventions for families
- Organization and delivery of care
 - Local care pathways, clinical teams
- <http://www.nice.org.uk/nicemedia/live/13774/59685/59685.pdf>

DSM-5 criteria for Autism Spectrum Disorder

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifest by the following, currently or by history:
 - 1. Deficits in social-emotional reciprocity
 - 2. Deficits in nonverbal communicative behaviors used for social interaction
 - 3. Deficits in developing and maintaining, and understanding relationships

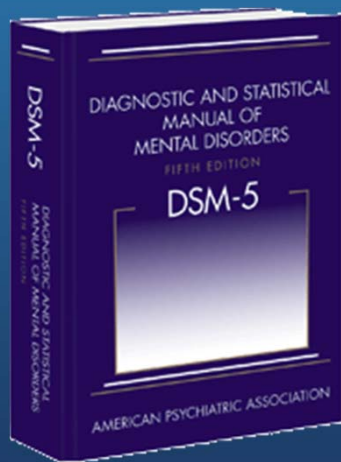


DSM-5 criteria for Autism Spectrum Disorder

- B. Restricted, repetitive patterns of behavior, interests, or activities, as manifest by at least two of the following, currently or by history.
 - 1. Stereotyped or repetitive motor movements, use of objects, or speech
 - 2. insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior
 - 3. Highly restricted, fixated interests that are abnormal in intensity or focus
 - 4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment

DSM-5 criteria for Autism Spectrum Disorder revised

- C. Symptoms must be present in early developmental period childhood (but may not become fully manifest until social demands exceed limited capacities)
- D. Symptoms cause clinical significant impairment in function



Severity level for ASD	Social communication	Restricted interests and repetitive behavior
Level 3 (requiring very substantial support)	Severe deficits with very limited initiation of social interactions and minimal response to social overtures from others.	markedly interfere with functioning in all spheres. Marked distress, very difficult to redirect.
Level 2 (requiring substantial support)	Marked deficits with limited initiation of social interactions and reduced or abnormal response to social overtures from others.	obvious interference with functioning , Distress or frustration is apparent, difficult to redirect
Level 1 (requiring support)	Without supports in place, deficits in social communication cause noticeable impairments.	significant interference with functioning in one or more contexts. Resists interruption or

TABLE 4.

Studies Comparing Diagnosis of ASD in *DSM-IV* and *DSM-5*

Study / year	Number of Subjects	Type of Sample	Instruments Used	Results	Limitations
Mattila et al ¹⁹ / 2011	82	Screened epidemiological sample diagnosed with <i>DSM-IV</i> criteria	ADI-R, ADOS, early <i>DSM-5</i> criteria	<i>DSM-5</i> was less sensitive than <i>DSM-IV</i> for ASD, (0.46)	Early <i>DSM-5</i> criteria, prevalence for PDD-NOS was not examined
Mandy et al ²⁰ / 2012	708	Consecutive referrals to an autism specialty clinic	3Di	<i>DSM-5</i> model was superior to <i>DSM-IV</i>	Higher functioning sample, 3Di is a <i>DSM-IV</i> derived tool
Frazier et al ²¹ / 2012	14,744 siblings (8,911 with autism)	Family-selected internet registry	Mapped caregiver rated SRS and SCQ to <i>DSM-5</i> criteria	<i>DSM-5</i> had lower sensitivity, (0.81 vs. 0.95) but greater specificity, (0.97 vs. 0.86) than <i>DSM-IV</i>	Early <i>DSM-5</i> criteria, self-selected sample, reliance on caregiver reports only
McPartland et al ⁴ / 2012	933 (657 diagnosed with ASD)	Multicenter <i>DSM-IV</i> field trial database, with clear reliability data	Algorithm of items from <i>DSM-IV</i> mapped to match <i>DSM-5</i> criteria	60.6% of cases with ASD met <i>DSM-5</i> criteria with a specificity of 94.9%	Included only 48 <i>DSM-IV</i> subjects with Asperger's disorder, modified a historical data set to new criteria
Matson et al ^{22,23} / 2012	2,721 toddlers aged 17-36 months	EarlySteps participants	Clinical judgment using diagnostic algorithms	52.2% of toddlers were diagnosed with ASD by <i>DSM-5</i>	Single author review of evaluations based on <i>DSM-IV</i>
Gibbs et al ¹³ / 2012	132 youth	Referred to tertiary autism clinic for initial evaluation	ADOS, ADI-R	76.5% of participants were diagnosed with ASD by <i>DSM-5</i>	ADOS and ADI-R are <i>DSM-IV</i> based tools
Taheri and Perry ³³ / 2012	131 children aged 2-12 years	Retrospective file review	CARS, <i>DSM-IV</i> checklist	62.6% of total sample met diagnosis of ASD by <i>DSM-5</i>	No Asperger's disorder patients, <i>DSM-5</i> criteria were evaluated by checklist
Huerta et al ²⁴ / 2012	5,143 subjects, 4453 had PDD	Data sets from family genetics study, university and autism center databases	ADI-R and ADOS matched to <i>DSM-IV</i> and <i>DSM-5</i> criteria. Included parent report and/or direct observation	<i>DSM-5</i> identified 91% of children with PDD diagnoses. Overall specificity was low, (0.53) but improved over <i>DSM-IV</i>	More severe clinical sample, retrospective data analysis

3Di = Developmental, Dimensional, and Diagnostic Interview; ADI-R = Autism Diagnostic Interview; ADOS = Autism Diagnostic Observation Schedule; ASD = autism spectrum disorder; CARS = Childhood Autism Rating Scale; NOS = not otherwise specified; PDD = pervasive developmental disorder; Revised; SCQ = Social Communication Questionnaire; SRS = Social Responsiveness Scale.

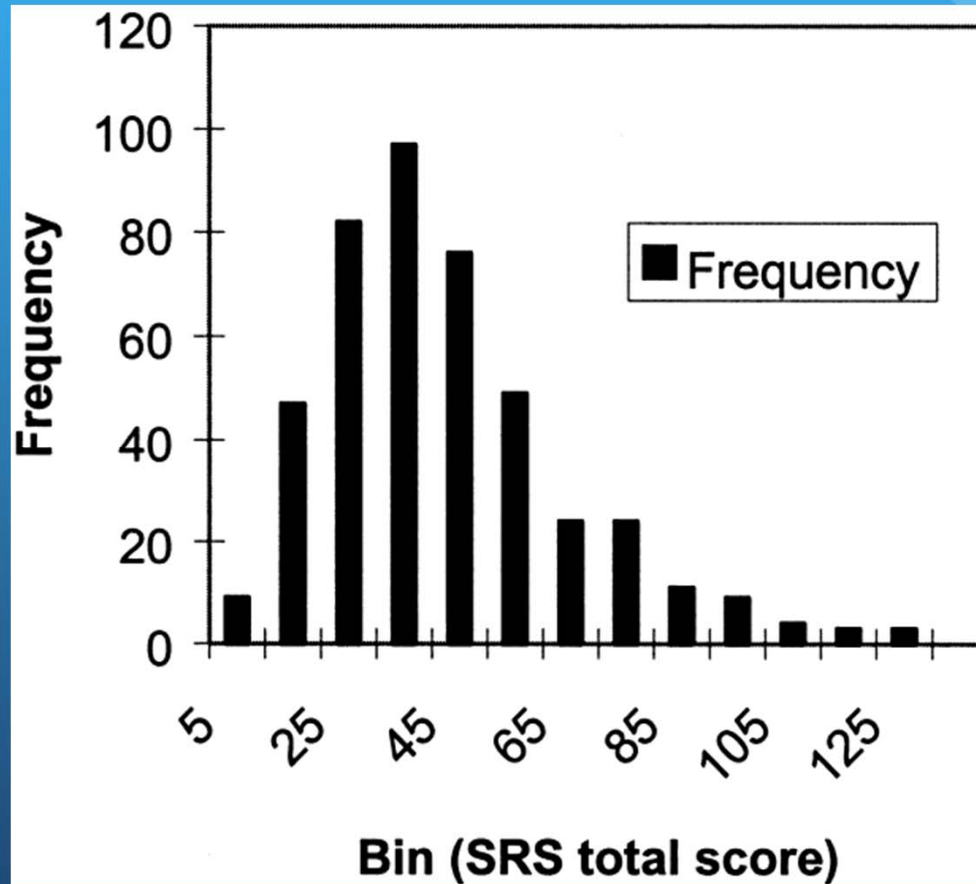
DSM-5 and adults with autism

- 150 adults referred to a ASD diagnostic clinic.,
 - N=113 (75%) met criteria for ASD from ICD-10R.
 - N=80 (52%) met diagnosis for autism/Asperger's Disorder using DSM-IV-TR
 - N=63 (42 %) met ASD criteria with DSM-5
- Compared to ICD-10R and DSM-IV
 - Lower sensitivity, but greater specificity
- Study suggests relaxing DSM-5 criteria
- Access to services
- WILSON, C. E., et al., *J Autism Dev Disord.*, 3/16/13.

Social impairment is distributed in the population.

Constantino et al, JAACAP. 2003

Apr;42(4):458-67.



Diagnosis of ASD in adults.

- ADOS module 4 tested in adult males with ASD
 - Bastiaansen, et al. 2011, *J Autism Dev Disord*, 41(9), 1256-66.
 - Brugha, et al, 2012. *Psychol Med*, 42(3), 647-56.
- SRS-A
 - a mean total score of 78.5 in ASD sample, 63.4 in mixed psychiatric sample, and 55.5 in typically developing adults.
 - Bolte, 2012, *J Autism Dev Disord*, 42(9), 1998-9.

AQ-10

Autism Spectrum Quotient (AQ)

A quick referral guide for adults with suspected autism who do not have a learning disability.

Please tick one option per question only:

		Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
1	I often notice small sounds when others do not				
2	I usually concentrate more on the whole picture, rather than the small details				
3	I find it easy to do more than one thing at once				
4	If there is an interruption, I can switch back to what I was doing very quickly				
5	I find it easy to 'read between the lines' when someone is talking to me				
6	I know how to tell if someone listening to me is getting bored				
7	When I'm reading a story I find it difficult to work out the characters' intentions				
8	I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant etc)				
9	I find it easy to work out what someone is thinking or feeling just by looking at their face				
10	I find it difficult to work out people's intentions				

SCORING: Only 1 point can be scored for each question. Score 1 point for *Definitely or Slightly Agree* on each of items 1, 7, 8, and 10. Score 1 point for *Definitely or Slightly Disagree* on each of items 2, 3, 4, 5, 6, and 9. If the individual scores **more than 6 out of 10**, consider referring them for a specialist diagnostic assessment.

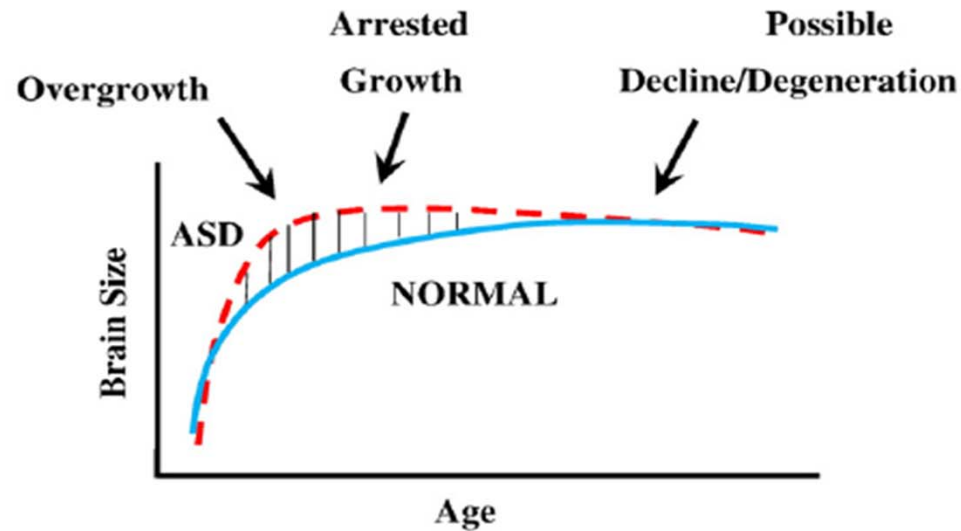
This test is recommended in 'Autism: recognition, referral, diagnosis and management of adults on the autism spectrum' (NICE clinical guideline CG142). www.nice.org.uk/CG142

Key reference: Allison C, Auyeung B, and Baron-Cohen S, (2012) *Journal of the American Academy of Child and Adolescent Psychiatry* 51(2):202-12.

Age-related brain changes in autism

- 586 MRI scans from 259 patients from age 1 year to 50 years
- Early brain overgrowth
- Accelerated decrease in brain volume in ASD
 - Neuronal loss
 - Age related degeneration, (gene expression)
 - Courchesne, E., et al. (2011). "Brain growth across the life span in autism: age-specific changes in anatomical pathology." Brain Res 1380: 138-145.

A



B

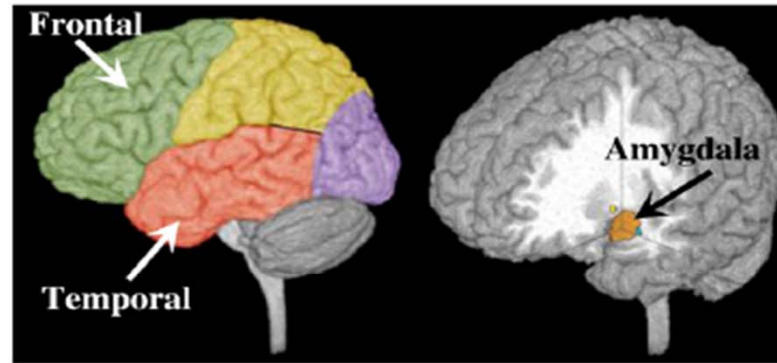


Fig. 1 – Three phases of growth pathology in autism. (A) Model of early brain overgrowth in autism that is followed by arrest of growth. Red line represents ASD, while blue line represents age-matched typically developing individuals. In some regions and individuals, the arrest of growth may be followed by degeneration, indicated by the red dashes that slope slightly downward. (B) Sites of regional overgrowth in ASD include frontal and temporal cortices and amygdala (from Courchesne et al., 2007).

Brain surface anatomy and adults with ASD.

- MRI study of 89 men with ASD and 89 controls, mean age 26-28.
- Regional differences in brain volume correlated with severity of symptoms measured by ADOS and ADI-R
- “atypical neural connectivity”
 - Ecker, C., et al. (2012). "Brain anatomy and its relationship to behavior in adults with autism spectrum disorder: a multicenter magnetic resonance imaging study." Arch Gen Psychiatry 69(2): 195-209.

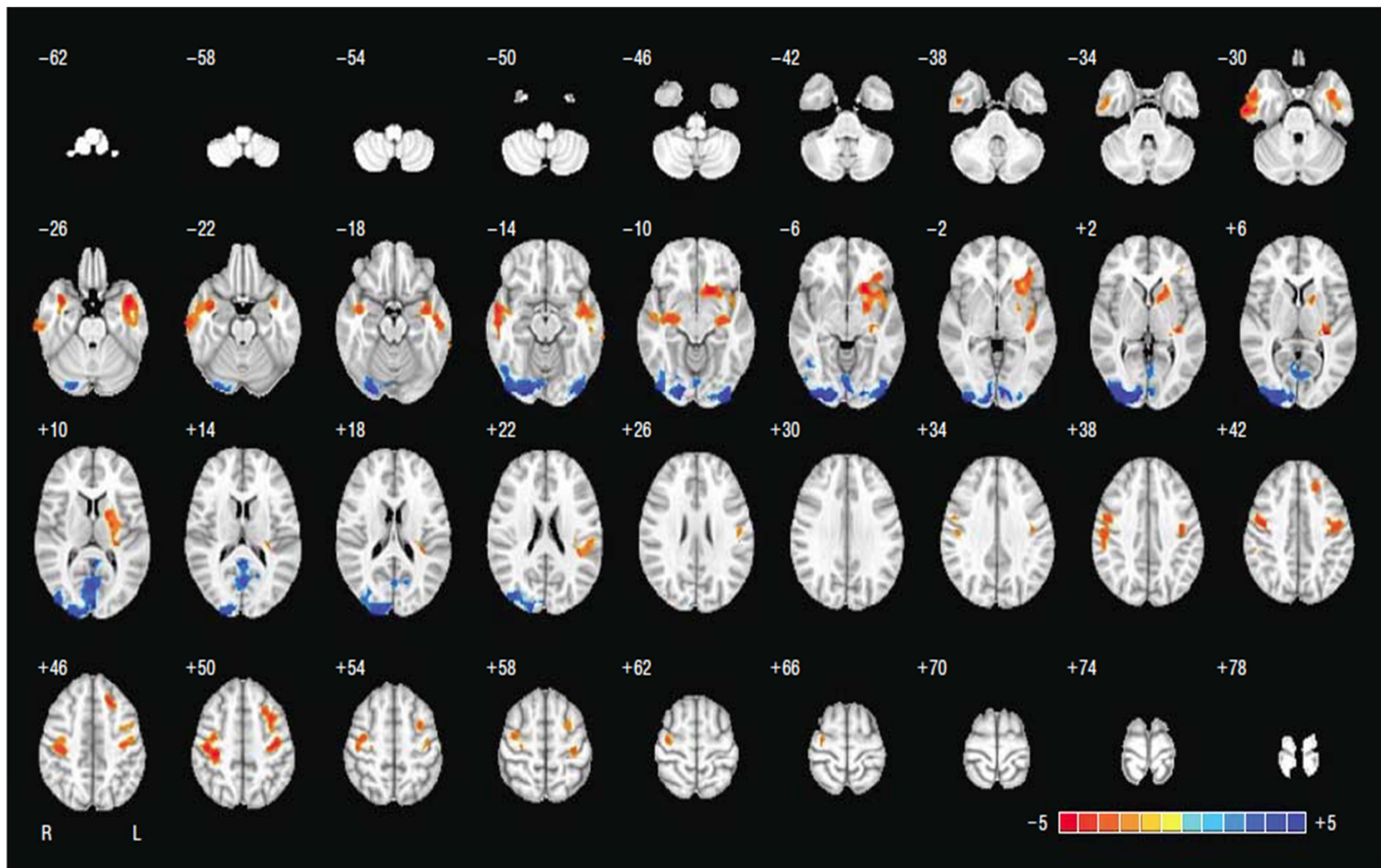


Figure 2. Brain map (voxel-based morphometry) of significant gray matter differences in autism spectrum disorder (ASD) ($P=.004$). Relative excesses in gray matter volume in adults with ASD compared with control participants are displayed in orange/red for temporal cluster and frontal cluster; deficits are displayed in blue for occipital cluster. The maps are oriented with the left side of the brain shown on the left side of each panel. The z-coordinates for each axial section in the standard space of Montreal Neurological Institute coordinates are reported in millimeters. L indicates left; R, right. The numbers at each end of the color key are given in t values.

Cortical Thickness and Surface Area in Adults with Autism

- MRI study of 84 men with ASD and 84 controls, mean age 26-28 years
- Increased cortical thickness in frontal lobe
- Reduced surface area in orbitofrontal cortex and posterior cingulum
- CT = overgrowth of cells within minicolumns,
- SA = number of columns within a region
- Ecker, C., et al. (2013). "Brain surface anatomy in adults with autism: the relationship between surface area, cortical thickness, and autistic symptoms." JAMA Psychiatry 70(1): 59-70.

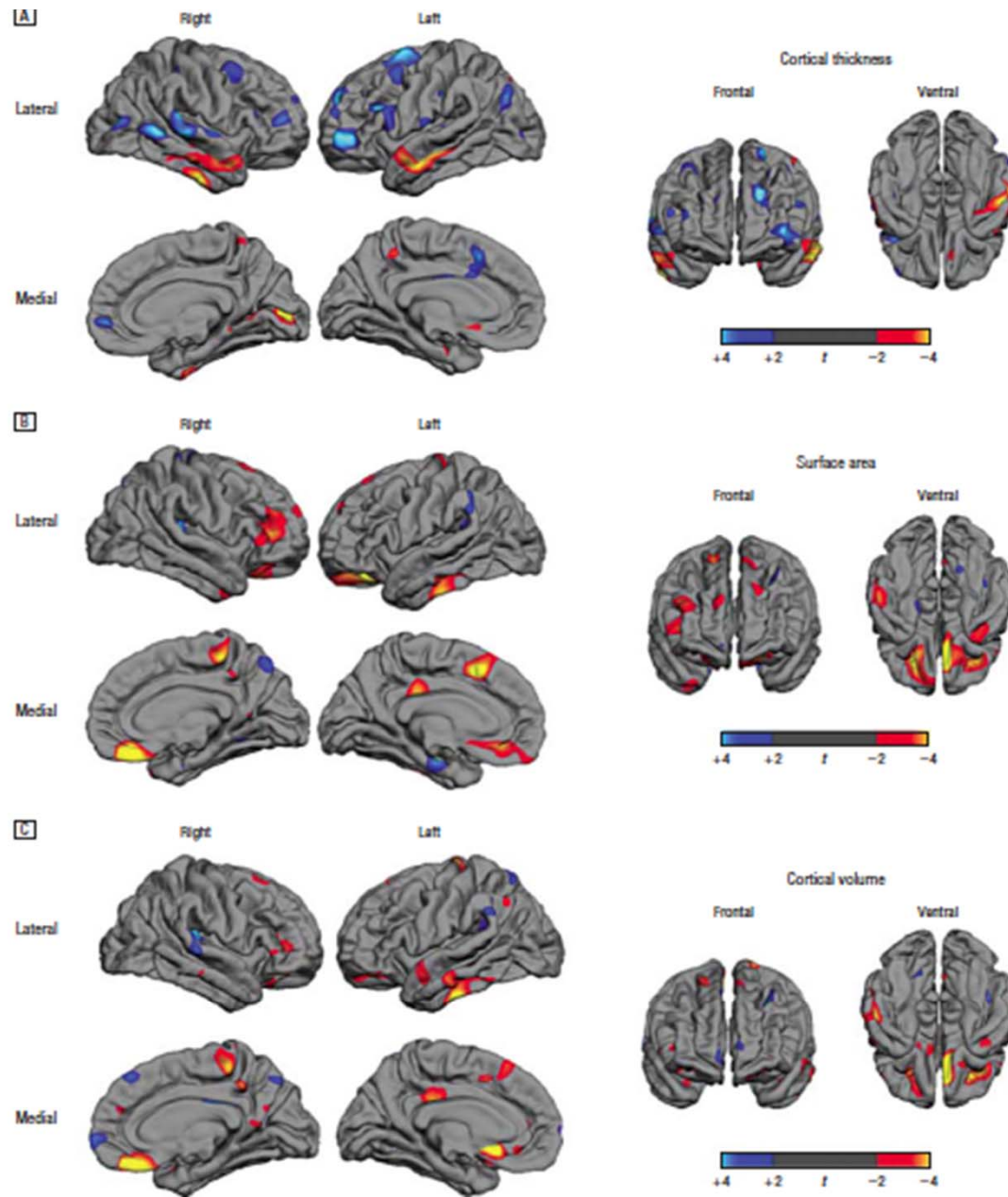


Figure 2. Spatially distributed differences in cortical thickness (A), surface area (B), and cortical volume (C) between individuals with autism spectrum disorder and controls ($P < .05$, uncorrected). Relative deficits in adults with autism spectrum disorder compared with controls are displayed in red/yellow, while excesses are displayed in blue/cyan. Surfaces are presented in lateral, medial, and frontal views for the left and right pial (outer) surface.

Table 6. Correlation Coefficients Between Cortical Thickness or Cortical Volume and Diagnostic Measures Within Clusters of Significant Between-Group Differences

Cluster	Correlation Coefficient, <i>r</i>				
	ADI-R Domain				ADOS Total (n = 82)
	Social (n = 84)	Communication (n = 84)	Repetitive Behavior (n = 84)	Total (n = 84)	
Cortical thickness					
Left frontal	0.13	0.23 ^a	0.26 ^a	0.25 ^a	-0.25 ^a
Left temporal	-0.05	0.01	0.18 ^a	0.02	-0.12
Cortical volume					
Left orbitofrontal	-0.23 ^a	-0.11	0.08	-0.16	-0.02
Right orbitofrontal	-0.22 ^a	-0.03	0.05	-0.13	-0.01

Abbreviations: ADI-R, Autism Diagnostic Interview-Revised; ADOS, Autism Diagnostic Observation Schedule.

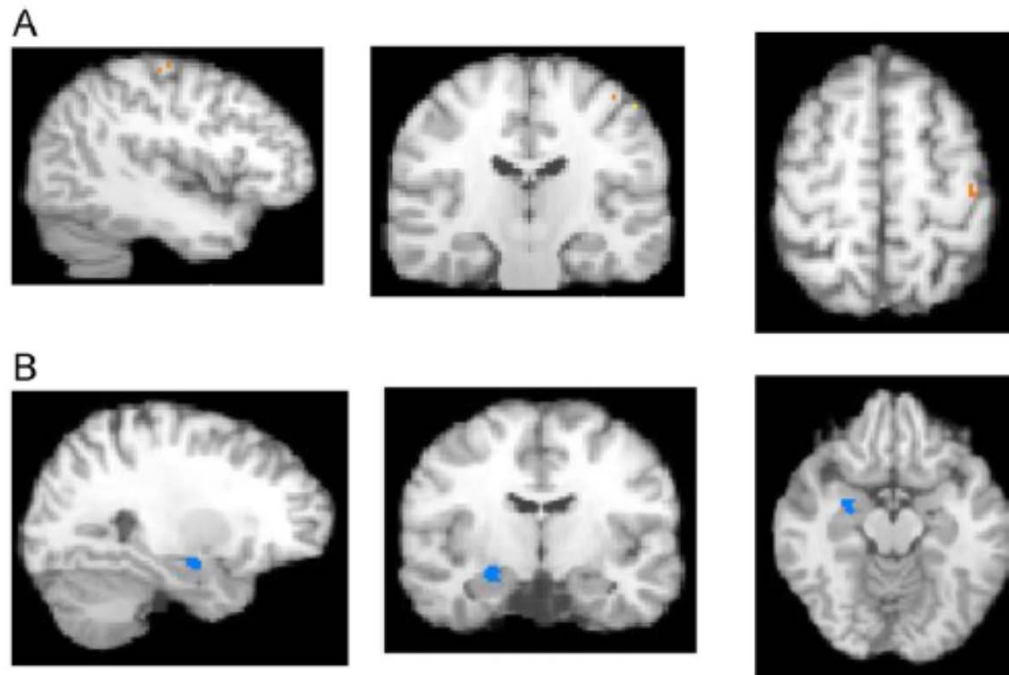
^aSignificant correlation at $P < .05$ (uncorrected).

fMRI of age related changes in autism

- Meta-analysis of child vs. adult fMRI studies: N=18 child vs. n=24 adult studies
- Neural changes are not static,
 - Frontal-temporal-parietal neurocircuitry involved in pathology of ASD
- Changes are likely well established before the current minimum age for fMRI studies, age 7.
 - Dickstein, D. P., et al. (2013). "Developmental meta-analysis of the functional neural correlates of autism spectrum disorders." [J Am Acad Child Adolesc Psychiatry 52\(3\): 279-289 e216.](#)

Social task: youth vs. adults with ASD show hyper activation of L. post-central gyrus and hypo activation in R. hippocampus and R. superior temporal gyrus

FIGURE 2 Results from activation likelihood estimation (ALE) developmental social analyses. Note: (A) Greater in autism spectrum disorder (ASD)-child versus ASD-adult ($X = -41, Y = -22, Z = 55$; Left post-central gyrus Brodmann area [BA] 3). (B) Reduced in ASD-child versus ASD-adult ($X = 26, Y = -11, Z = -14$; right para/hippocampus). TDC = typically developing controls.



Age-Dependent Brain Gene Expression and CNV in autism

- Study of 57 frozen samples of dorsolateral prefrontal cortex, compared autism cases vs. normal controls
- Abnormal gene pathways in early stages of development could lead to early brain overgrowth and later thinning
- Genes involved in cell number, genetic integrity and neural patterning are dysregulated in children < 14 years, N=102 genes
- Genes regulating signaling, cell differentiation, repair, and apoptosis are dysregulated in adults, n=730 genes
 - Chow, M. L., et al. (2012). "Age-dependent brain gene expression and copy number anomalies in autism suggest distinct pathological processes at young versus mature ages." [PLoS Genet 8\(3\): e1002592.](#)

Microglial activation in young adults with ASD

Suzuki, K., et al. (2013). "Microglial activation in young adults with autism spectrum disorder." *JAMA Psychiatry* 70(1): 49-58.

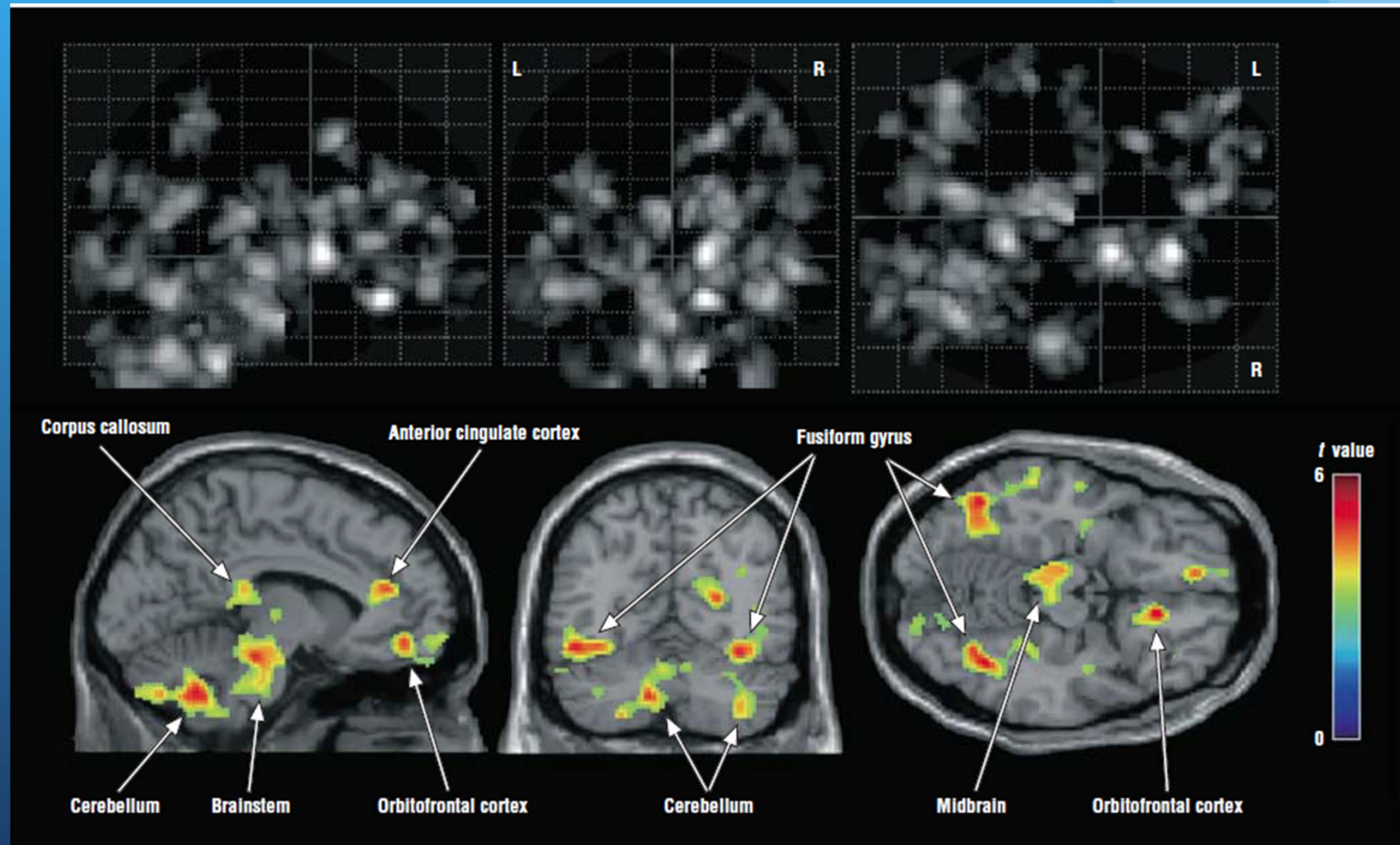


Figure 2. Results of the whole-brain voxel-based statistical parametric mapping analysis of the [¹¹C](R)-PK11195 binding potentials. Locations of clusters with significant increases in the group with autism spectrum disorder compared with the control group ($P < .05$, false discovery rate corrected) are shown on glass brain images and superimposed onto normal-template magnetic resonance images. L indicates left; and R, right.

What studies of adults may tell us about etiology of ASD

- ASD reflects an innate process beginning likely in prenatal phase and continuing throughout life.
- Early brain overgrowth followed by corrective remodeling phase - (overpruning, atrophy)
- Regional differences in brain volume may be correlated with severity of symptoms
- Age-dependent genetic expression alterations may underlie differences in anatomy and cellular pathways in ASD.
- Evidence of immune dysregulation in a subset of ASD
- ASD is a disorder of multiple causes, various phenotypes with findings of subtle differences in large-scale neural systems.

Savant skills in autism

- In n=137 individuals, mean age 24 years
- 39 (28.5%) met criteria
 - 15 had cognitive skill, e.g. Block design
 - 16 had savant skills e.g. Mathematical/calculating skill
 - Seen in 33% of males vs. 19% of females
 - Not seen with non-verbal IQ < 50 or high rates of RRB
 - HOWLIN, P., et al. 2009. *Philos Trans R Soc Lond B Biol Sci*, 364, 1359-67.

Aging and autism: Executive Function, (EF) and memory

- Neuropsychological testing in autism vs. controls, mean age 63 years
 - Various measures
- EF deteriorates in normal adults but there are some differences for adults with autism
 - Geurts, H. M. and M. E. Vissers (2012). "Elderly with autism: executive functions and memory." J Autism Dev Disord 42(5): 665-675.

Those with autism had preserved scores of verbal fluency but greater loss of visual memory

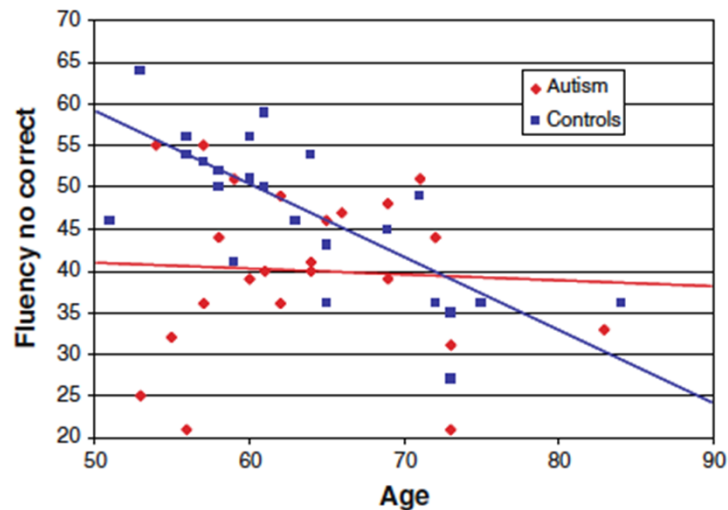


Fig. 2 Relationship between age (*x*-axis) and performance on the fluency task (*y*-axis) for the autism group (*red line*) and the control group (*blue line*). This figure illustrates that age has a more pronounced effect in the control group as compared to the autism group (Color figure online)

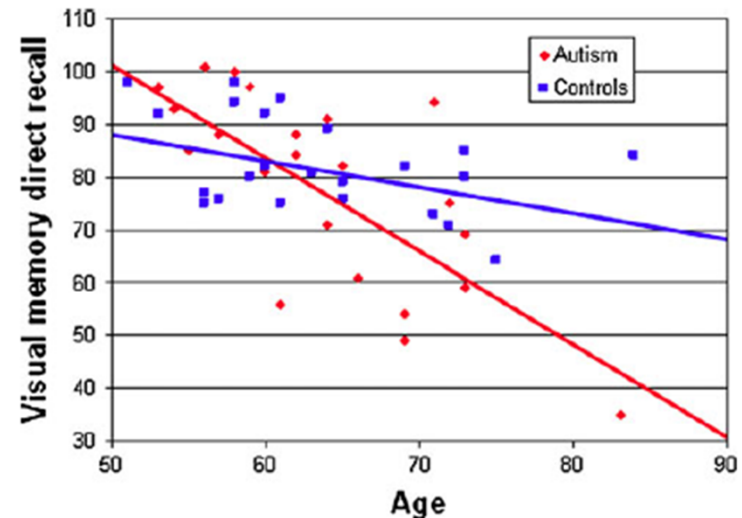


Fig. 3 Relationship between age (*x*-axis) and performance on the visual memory task (direct recall; *y*-axis) for the autism group (*red line*) and the control group (*blue line*). This figure illustrates that age has a more pronounced effect in the autism group as compared to the control group (Color figure online)

Adults with autism vs. controls have:

- Increased utilitarian judgments and decreased emotional reaction to moral dilemma Gleichgerrcht 2012
- Less social influence on donations to charity Frith 2011
- Decreased eye gaze and measures of eye contact
- Decreased attention to biologic motion Kaiser 2012 and Ohta 2012

Adults with autism vs. controls have:

- Decreased ability to detect dialect Clopper 2012
- Altered gender coherence Bejerot 2012
- Altered memory function
 - Prospective memory, working memory, autobiographical, spatial memory
- Errors in executive function Fan 2012 and use of inner speech in planning Williams 2012

Adults with autism vs. controls have:

- Decreased fMRI response to pleasant stimuli but greater response to unpleasant stimuli Cascio 2012
- Increased valence ratings for images of circumscribed interests and decreased ratings for social images Sasson 2012
- Altered scores on overall taste and bitter, sweet, and sour tastes Tavassoli 2012

Adult outcome of autism

- Less than 20% have a good or very good outcome
 - 48% live with parents
- 42% have some employment (paid, sheltered, volunteer)
- 15% in a long-term relationship
- Factors affecting outcome
 - IQ
 - early language development and good verbal IQ
 - level of autistic severity
 - mental health or medical problems
 - Level of social support
- Howlin, P. and P. Moss (2012). "Adults with autism spectrum disorders." Canadian Journal of Psychiatry - Revue Canadienne de Psychiatrie 57(5): 275-283.

Adult outcome of autism

- Psychiatric illness - 25% to 30%
 - Risks include major transitions and social isolation
- Increased mortality, esp. in women, epilepsy, severe ID
- Epilepsy in up to 39%
- Increased family stress
- Will early diagnosis and intervention efforts show an effect?
 - Howlin, P. and P. Moss (2012). "Adults with autism spectrum disorders." Canadian Journal of Psychiatry - Revue Canadienne de Psychiatrie 57(5): 275-283.

Social Outcomes in Mid- to Later Adulthood Among Individuals Diagnosed With Autism and Average Nonverbal IQ as Children

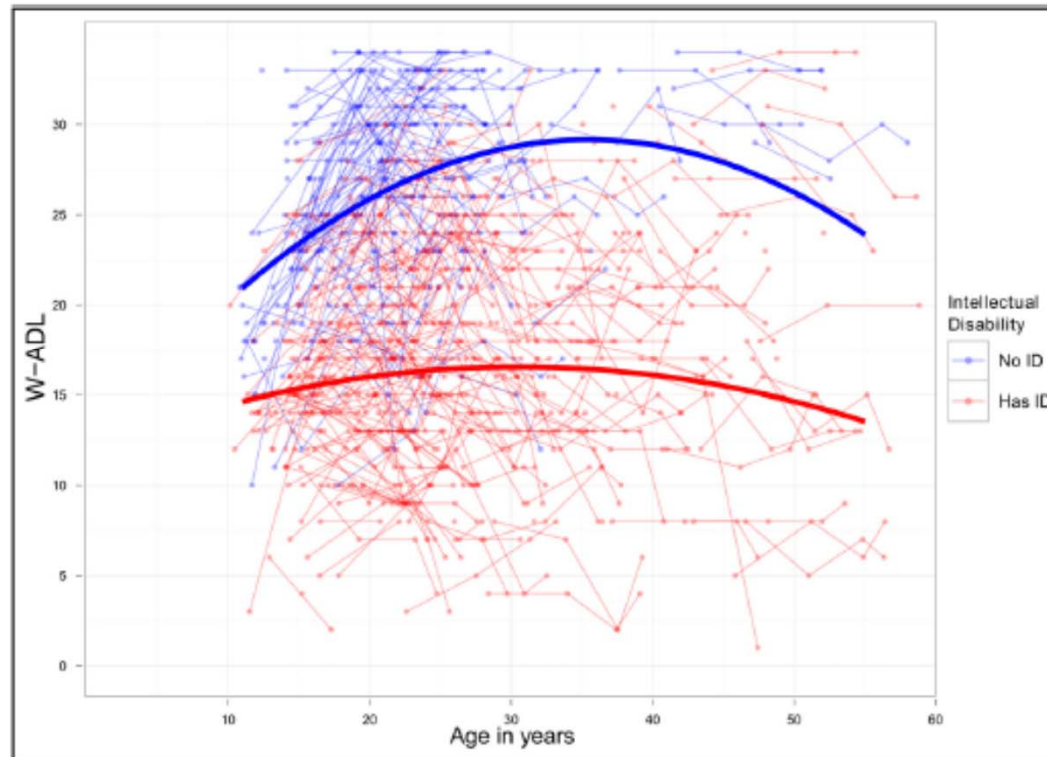
Patricia Howlin, Ph.D., Philippa Moss, Ph.D., Sarah Savage, Ph.D., Michael Rutter, M.D.

Objective: To describe current social functioning in a clinical sample of 60 adults with autism (mean age = 44 years) who were all of average nonverbal IQ (70+) when first diagnosed (mean age = 6.75 years). **Method:** Outcome measures included standardized diagnostic and cognitive assessments and questionnaires on social functioning. Child and adult variables related to current outcomes were explored. **Results:** All individuals continued to meet criteria for autism spectrum disorder (ASD) on the Autism Diagnostic Interview-Revised (ADI-R), but severity of autism symptoms declined over time. Nevertheless, only 10 individuals (17%) were rated as having a "good" or "very good" outcome; the majority (60%) were assessed as having "poor" or "very poor" outcomes. The strongest predictor of adult outcome was the Reciprocal Social Interaction domain score on the ADI at diagnostic confirmation. Change over time was further examined in a subgroup (n = 44) previously assessed 20 years ago earlier (mean age = 26 years). Although severity of autism had continued to decrease during the adult period, social outcomes were poorer than in younger adulthood. **Conclusions:** In this cohort of adults first diagnosed with autism, on average, 37 years previously, social inclusion remains very limited, despite general improvements in autism symptomatology with age. Whether these findings will be replicated in future generations of children with autism, who now have the benefits of earlier diagnosis and wider access to specialist provision, needs to be the focus of further longitudinal research. *J. Am. Acad. Child Adolesc. Psychiatry*, 2013;52(6):572-581. **Key Words:** adulthood, autism, social outcomes

Developmental trajectories daily living skills in autism

Smith et al, 2012. *JAACAP*, 51, 622-31.

FIGURE 1 Change in Waisman Activities of Daily Living (W-ADL) scores over time for autism spectrum disorder sample, individual and group trajectories. Note: Quadratic (age²) mixed-model parameterizations displayed.



Caregiver burden

- Caregiver burden was greater in ASD and explained by caregiver estimate of unmet needs
 - social contact, depression, anxiety, daytime activities, safety of self, and communication
 - Similar to estimates of those caring for those with TBI or dementia
 - Bruder, M. B., et al. (2012) J Autism Dev Disord 42(11): 2498-2504.
- Mothers of adolescents and adults with ASD
 - report more stressful events on any given days
 - Smith, et al. (2012). J Autism Dev Disord 42(9): 1836-1846.
 - have more health problems and hypo activated cortisol levels.
 - Seltzer, et al. (2010). J Autism Dev Disord 40(4): 457-469.

Health-care experiences of adults with ASD

- Online survey of n=437 subjects (209 autistic and 228 non-autistic)
 - Community-based participatory research method
- persons with autism report:
 - lower satisfaction
 - Higher odds of unmet healthcare needs
 - lower rates of preventive health measures
 - more likely to use the emergency room than non-autistic adults.
 - Nicolaidis, C., et al. (2012). "Comparison of Healthcare Experiences in Autistic and Non-Autistic Adults: A Cross-Sectional Online Survey Facilitated by an Academic-Community Partnership." J Gen Intern Med.

Physician needs in treating those with ASD

- Written survey of primary care MDs in CT
- Most common visit was annual checkup 32.1%, mental health needs were seen in 21.9%, care involved family or caretaker in 54.7% of visits
- 36% of MDs reported some training in caring for adults with ASD
 - >50% wanted more training in form of workshops or conferences
 - Bruder, M. B., et al. (2012). "Brief report: the medical care of adults with autism spectrum disorders: identifying the needs." J Autism Dev Disord 42(11): 2498-2504.

- <http://youtu.be/Td0iI59SIAc>

Treatment goals for adults with ASD

- Employment and financial stability
- Independent living skills/quality of life
- Social connection
- Medical health
- Mental health

Medication and adults with autism

- 5-year study of adolescents and adults with ASD
- 70% of adults with ASD were taking psychotropic medication
 - 38% antipsychotics, 44% antidepressants, 31% anticonvulsants
 - Mean # of meds/person = 2.9
 - Only 4.2% of those medicated at start were off medications at end of study
 - Esbensen, A. J., et al. (2009). "A longitudinal investigation of psychotropic and non-psychotropic medication use among adolescents and adults with autism spectrum disorders." J Autism Dev Disord 39(9): 1339-1349.

Systematic review of medication data in adults with autism

Dove, D., et al. (2012). "Medications for adolescents and young adults with autism spectrum disorders: a systematic review." *Pediatrics* 130(4): 717-726.

- 8 studies identified, 4 had fair quality
- Moderate evidence for aggression in risperidone but strong evidence for sedation and weight gain
- Negative study for naltrexone in mixed population of adults with ID. Willemsen-Swinkels, et al. (1995). *Arch Gen Psychiatry* 52(9): 766-773.
- RCT of fluvoxamine on repetitive behavior and aggression McDougle, et al. (1996). *Arch Gen Psychiatry* 53(11): 1001-1008.

Oxytocin

- Case for oxytocin
- RDBPC 6 week trial of intranasal oxytocin of 19 adults with ASD
 - Mean IQ 107, 24 iu oxytocin bid
 - No changes in primary outcome (social function/cognition and repetitive behaviors)
 - Some changes in secondary measures (social cognition, quality of life, and stereotypies)
 - Irritability
 - Anagnostou, E., et al. (2012). "Intranasal oxytocin versus placebo in the treatment of adults with autism spectrum disorders: a randomized controlled trial." Mol Autism 3(1): 16.

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Fluoxetine may decrease repetitive behaviors in adults

- N=37 adults with ASD, mean age 34.3 years, 92% high functioning
- Mean dose 65 mg/day, 12 week DBPC
- 35% of those in a fluoxetine group showed symptom improvement compared to 0% in the placebo group
- 50% of group showed improved measures on compulsion scale of YBOCS compared to 8% in placebo group
 - Hollander, E., et al. (2012). "A double-blind placebo-controlled trial of fluoxetine for repetitive behaviors and global severity in adult autism spectrum disorders." *Am J Psychiatry* 169(3): 292-299.

Shattuck, P. , et al. (2011). Arch Pediatr Adolesc Med 165(2): 141-146.

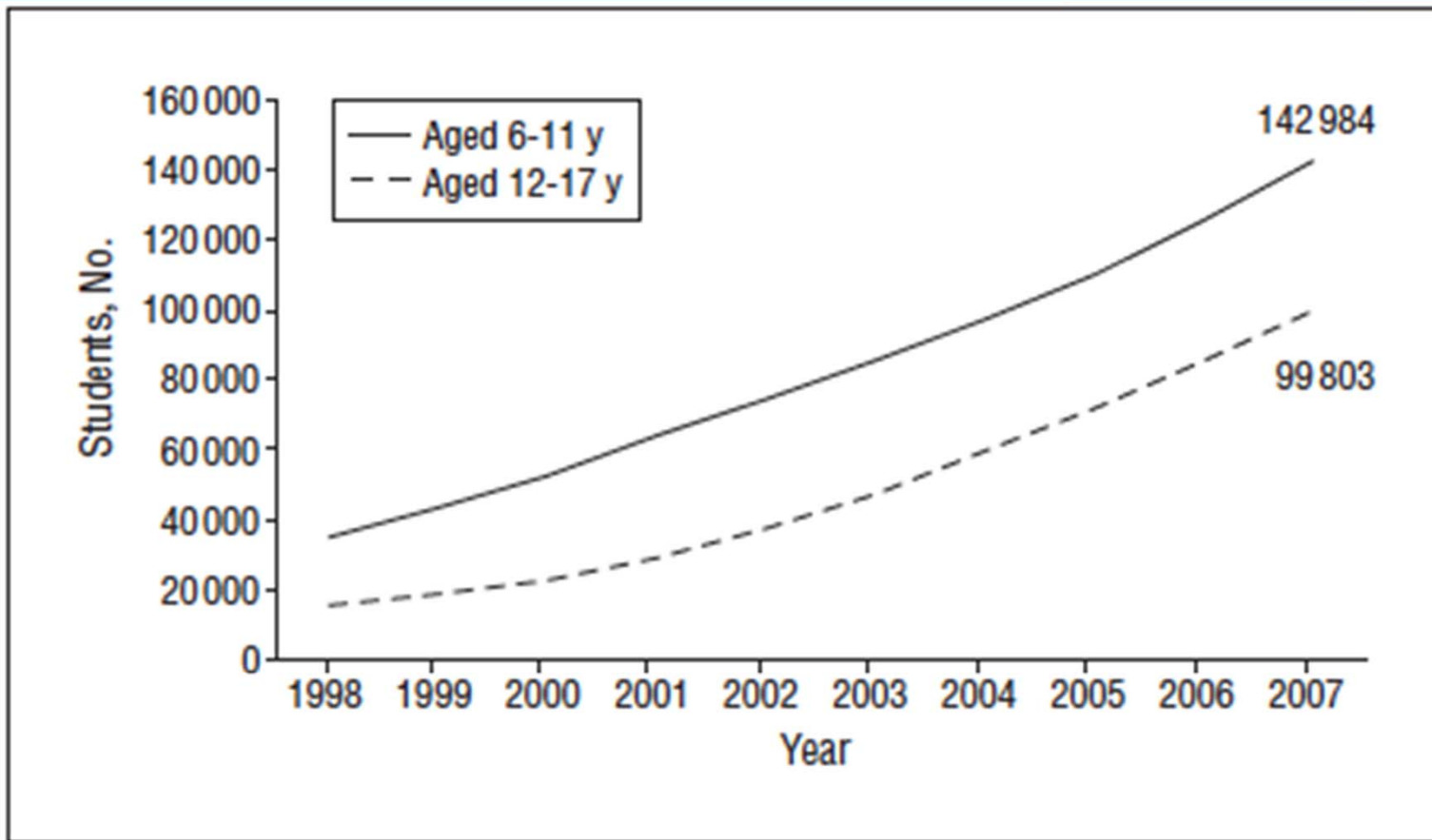


Figure. Number of students enrolled in the special education autism category by age group from 1998 to 2007.¹

Service use in young adults with ASD at transition

- National telephone survey of parents and guardians of young adults with ASD aged 19 to 23 years who had received special education, NTLS2 study
- Rate of services within 2 years of leaving high school
 - 41.9% received case management
 - Lower rates among youths with higher functional skills and low income
 - 35.0% received mental health services, 9.1% received speech therapy
 - 39.1% of youths with ASD received no services
 - More likely with African Americans and those with low income
- Shattuck, P. T., et al. (2011). "Post-high school service use among young adults with an autism spectrum disorder." [Archives of Pediatrics & Adolescent Medicine 165\(2\): 141-146.](#)

More NLTS-2 data

- 34.7% of youth with ASD will attend college and about 55% have held paid employment within 6 years of HS
 - More than 50% had no participation in employment or education.
 - 80% continue to live at home, 6% have competitive jobs
 - Higher income and functional level increases outcome
 - Shattuck, P. T., et al. (2012). "Postsecondary education and employment among youth with an autism spectrum disorder." *Pediatrics* 129(6): 1042-1049.
 - Nearly 40 percent of young adults with autism never saw friends and 28 percent had no social contact at all.
 - Orsmond, et al. (2013). *J Autism Dev Disord.*

STEM participation

- NLTS-2 data of 11,000 students with IDEA disabilities; 1,100 students with autism category
- Those with autism had highest rates of STEM (34.31%), but college rates was third lowest, (14.95% in 4-year program)
- Risks for not attending college for those with autism
 - ID, poor income, female
 - Wei, X., et al. (2012). "Science, Technology, Engineering, and Mathematics (STEM) Participation Among College Students with an Autism Spectrum Disorder." J Autism Dev Disord.

Treatment data for vocational interventions in adults with ASD

- Limited data, poor study quality, 5 studies identified
- Supported employment may improve quality of life and cognitive functioning
 - 68% remained employed at 8 years
- Need better data, impact analysis, factors affecting outcome
 - Taylor, J. L., et al. (2012). "A systematic review of vocational interventions for young adults with autism spectrum disorders." [Pediatrics 130\(3\): 531-538.](#)

Employment and Post-secondary educational activities

- Jobs were low-paid menial work at less than 30 hours/week
- 25% of young adults with ASD without ID had no daytime activities compared to 8% of those with ID
- The rate of improvement in autistic symptoms slows after exit from school system
 - Taylor, J. L. and M. M. Seltzer (2011). "Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood." J Autism Dev Disord 41(5): 566-574.



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Other treatment outcome data

- Study of 382,221 adults in the US Vocational Rehabilitation System up to 2005
 - Adults with ASD were more likely to be denied services
 - Among those served, adults with ASD had the most expensive set of services
 - Lawer, L. et al. 2009. *J Autism Dev Disord* 39(3): 487-494.

Transition services according to IDEA

- A. results-oriented process focused on improving academic and functional achievement to enable student to move to post-school activities
- B. based on individual student's needs, preferences, and skills (summary of performance)
- C. includes instruction, community experiences, development of employment, and acquisition of daily living skills and functional vocational evaluation
- IEPs for students > 16 years must include transition planning.
 - Schall, C., et al. (2012). Pediatr Clin North Am 59(1): 189-202, xii.

School transition planning

- Transition services include:
 - education after high school,
 - job training and opportunities,
 - case management,
 - training for living independently,
 - recreation and volunteer opportunities.
- Successful transitions
 - Based on needs, preferences, skills
 - Oriented to life after school
 - Starts early

KENTUCKY AUTISM TRAINING CENTER

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- [Kentucky Autism Providers and Supports](#)
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- [ASD Related Support Groups](#)
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Family Guide (2nd Edition)

Kentucky's Family Guide to Autism Spectrum Disorders (2nd Edition)

The Kentucky Autism Training Center (KATC), a part of the University of Louisville's College of Education and Human Development, is pleased to introduce Kentucky's Family Guide to Autism Spectrum Disorders. This comprehensive guide was developed by parents, professionals and individuals with autism spectrum disorders to answer the question: "When your child was first diagnosed, what information did you need most?"

The KATC honors the compassion of Dr. Pinkstaff by dedicating the second edition of the Kentucky's Family Guide to Autism Spectrum Disorders to his memory.

Dr. Thomas Pinkstaff, a longtime Lexington pediatrician, passed away April 12, 2009. During his long career in pediatrics, Dr. Pinkstaff was an active member on a wide range of associations, committees and boards, including the Kentucky Autism Training Center, and served as president of the Kentucky Chapter of American Academy of Pediatrics. He was a tireless advocate, consultant, and educator regarding children's health issues, but was especially passionate about education and support for individuals with autism.



Download the separate chapters for the [Family Guide 2nd edition \(Revised\) \[PDF\]](#). Please be aware that you may need the [Adobe Acrobat Reader](#) to view these files.

- [Chapter 1 Autism Spectrum Disorders: What is ASD, Diagnosis, and Screening \[PDF\]](#)
- [Chapter 2 Living with ASD: You Are Not Alone \[PDF\]](#)
- [Chapter 3 Interventions: A Review of Therapies, Models, and Strategies \[PDF\]](#)
- [Chapter 4 Accessing Educational Services: Navigating Through The School System in Kentucky \[PDF\]](#)
- [Chapter 5 Social Service Programs: Kentucky Resources \[PDF\]](#)
- [Chapter 6 Advocacy: Raising Awareness and Influencing Service Delivery \[PDF\]](#)
- [Chapter 7 Future Planning: Growing into Adulthood \[PDF\]](#)
- [Chapter 8 Introducing Your Child to ASD: How and When to Talk to Your Child About the Diagnosis \[PDF\]](#)

Please help us to spread the word about Kentucky's Family Guide to Autism Spectrum Disorders!

- Publish this [article \[PDF\]](#) in your next newsletter or on a message board.
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The KATC wants your feedback on Kentucky's Family Guide to Autism Spectrum Disorders

[Tell us what you think.](#)

KATC family guide

- Division of Developmental and Intellectual Disabilities (DDID) evaluation
 - Community Mental Health Center or DIDD to determine eligibility for services, including Medicaid and waiver services
 - Service and support administrator appointed as case manager
- SSI
- College disability programs
- Directive documents
- Advisory team
- Guardianship, estate planning, and trust



Autism Speaks™
FAMILY SERVICES

Transition Tool Kit

<http://www.autismspeaks.org/family-services/tool-kits/employment>

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
My Employment Rights
Glossary of Terms
Employment Resources
Step-by-Step Guide to Your Employment Search

Bridges to the Future

A Transitional Care Program

Coordinator : Jeanette Carter, RN, BSN, CPN

jeanette.carter@nortonhealthcare.org

502-629-3904

www.kosairchildrens.com/BridgesTransitionalCare

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Bridges Transitional Care Program

Medical advancements continue to improve survival rates of children with congenital abnormalities, developmental disabilities and chronic health issues. Today, more than 90 percent of kids with chronic conditions grow to lead full, productive lives; therefore, there is a growing need for transitional care from pediatric physicians to adult-service providers.

The Bridges program is designed to help facilitate the transition from pediatric to adult care in order to avoid a lapse in care, to easily communicate vital details about a patient's condition and to help make the transition more comfortable for the youth and adolescents involved.

How can Bridges help?

The Bridges program encourages parents/guardians of children as young as age 12 to begin talking about the transition in care. Bridges prepares adolescents and their parents/guardians for this transition through workshops on topics such as medications, diet, exercise, safe sex, patient rights and responsibilities, and other related topics.

Bridges also provides families with a patient care binder to easily organize important health information in order to facilitate a smooth transition. Consisting of eight sections, the Bridges patient care binder keeps all vital health information in one portable tool. This tool empowers adolescents to take control of their medical condition.

A HANDBOOK OF PROGRAM DESCRIPTIONS, ELIGIBILITY
CRITERIA, AND CONTACT INFORMATION

KENTUCKY DISABILITY
RESOURCE
MANUAL

Offered by the Human Development Institute at the University
of Kentucky for persons with disabilities, their families, and
service providers in Kentucky.

HDI HumanDevelopment
i n s t i t u t e
UNIVERSITY CENTER FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES

This manual may be also be viewed at www.hdi.uky.edu

Adults with autism face a lack of services

- There are limited facilities with programs and providers
- School services end.
- Impact and Impact Plus age out at 21 years
 - Case management
 - After school programs
 - Crisis stabilization
 - OT, PT, SLP
- Private insurance ages out at 25 years.

Support for Community Living, SCL

- Requires eligibility for ICF/MR, Long waiting list
- Residential support
- Case management
- Community supports, respite
- OT, PT, SLP
- Day programs
- Supported employment

Michelle P Waiver

- Caps at 10,000 individuals at \$40,000/year
- Similar services at SCL except residential care is not covered
- Case management
- Respite, CLS
- OT, PT, SLP
- Consumer Directed Option (CPO)
- Lack of providers

Residential supports in Louisville Metro

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Kentucky Autism Services and Supports

Filter Provider list by...

Region County

Type of service Age range served

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PROVIDER	LOCATION	PHONE	EMAIL	WEB
Blessed Assurance Community Services	Boston, KY	502-833-0210	blessednboston@umconnect.com	www.blessednboston.com
Bright Beginnings, Inc.	Louisville, KY	502-893-8812	www.information@bbeginningsinc.com	www.bbeginningsinc.com
Brooklawn Child and Family Services (Birchwood)	Louisville, KY	502-451-5177	jbrown@brooklawn.net	www.brooklawn.net
Cedar Lake Lodge	LaGrange, KY	502-222-7157		www.cedarlake.org
Community Alternatives Kentucky - Louisville	Louisville, KY	502-491-4001	alexscholtz@rescare.com	www.rescare.com
Community Choices Unlimited, Inc.	Frankfort, KY	502-223-2488	comchoices@aol.com	
Dreams With Wings	Louisville, KY	502-459-4647	soaringdreams01@aol.com	www.dreamswithwings.com
Griggs Family Care Home	Berea, KY	859-986-1207		
Harmony Habitat	Bloomfield, KY	502-252-0203	habitat321@aol.com	www.harmonyhabitat.org
Lincoln Way	Elizabethtown, KY	270-765-1877	amandamcgrew@linconwayfhp.com	
Maryhurst	Louisville, KY	502-245-1576		www.maryhurst.org
Path Forward of Kentucky	Louisville, KY	502-451-2565	alex.scholtz@pathforwardky.com	www.pathforwardky.com
Pinewood	Louisville, KY	502-451-5177	jbrown@brooklawn.net	www.brooklawn.net
Seven Counties Services Inc. Developmental Services Division	Louisville, KY	502-459-5292	gdarling@sevencounties.org	www.sevencounties.org

Please be aware that there is no implied endorsement of the listed programs in the Kentucky Autism Supports and Services Directory by the KATC. The purpose of the Kentucky Autism Services and Supports Directory is to help parents and professionals share information. It is recommended that parents speak to a representative of the program before enrolling their children, to ensure that the interests, skills, talents and needs of each child can be met in the program.

SCS Systems Strategy Committee

- Evaluates mental health care across systems in the region
- Members formed ad-hoc committee to study solutions for adults with ID in crisis
 - SCS
 - JCPS
 - DHD ID
 - UL
 - OLOP, Wellspring, The Brook

Ad-hoc committee identified gaps in services for adults with ID

- Adult CSU
- Lack of community and professional awareness of crisis support services
- Lack of access to services
 - Integrated crisis assessments and supports
 - Psychiatric services
- Supported employment opportunities
- Transition coordination from child to adult services

Seven Counties Services, (SCS), Crisis Prevention & Response

- 24 hour staffing from 502-459-5292
 - Crisis intervention, respite, behavioral treatment plans, psychiatric evaluation, community supports
- 15% to 20% of referrals for fiscal year 2012 had a diagnosis of autism
- 5% can't be stabilized due to aggression
- Increased number of MIW 202b filings but *families indicate they want short term respite*

UL adult psychiatric services

- EPS
 - Crisis evaluations, short term holds
 - Efforts to refer to ICFMR at Central State
 - “gate keeper”
- University Hospital/Norton’s
 - Adult inpatient units
 - No trained providers for autism
 - No programming - BA, OT
 - Volatile mix of patients
 - Placement issues
 - Legal issues - protection and advocacy

Needs

- Strategies to increase quality of life and improve functioning of those with ASD later in life
- Research on effective interventions in the area of supported employment, social skills interventions, medication, respite, etc.
- Transition clinical teams and interagency collaboration
- Family-based interventions to decrease the burden and connect to resources
- Parent advocacy and legislative changes to increase funding

Summary

- Studies of adults with autism offer insight into later-stages of life-long process
 - Prenatal origins
 - Genetic, neuroimaging, clinical, psychological findings
- Current services for adults with autism are inadequate
 - Effective therapies have yet to be determined
- Transition services are critical for successful adaptation



obrigado

Dank U

Merci

mahalo

Köszí

спасибо

Grazie

Thank
you

mauruuru

Takk

Gracias

Dziękuję

Děkuju

danke

Kiitos