

ASD Through the Lifespan

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Neurodevelopmental Pediatrics of the Main Line, PC  
[www.drcoplan.com](http://www.drcoplan.com)



ASD Across the Lifespan - I

- Background
  - Historical Review
  - Down, Asperger, Kanner
- The 3D Model and the Natural History of ASD
- DSM and False Dichotomies
  - “Normal” vs. “Abnormal”
  - ASD vs. “Mental Illness”

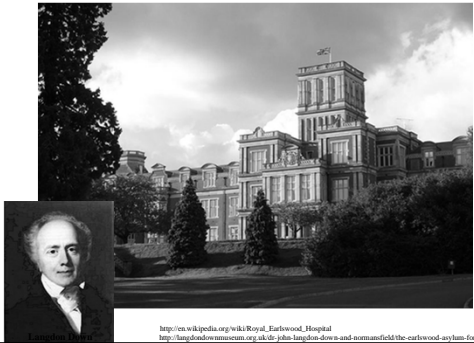
ASD Across the Lifespan - II

- Looking Forward
  - Outcome Studies: Back to the Future
- Next Steps
  - Knowledge is Power / Know what you don’t know
  - Services and Service Models
  - Advocacy

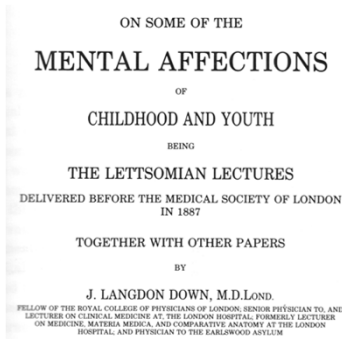
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The Royal Earlswood Asylum for Idiots (est. 1854)




[http://en.wikipedia.org/wiki/Royal\\_Earlswood\\_Hospital](http://en.wikipedia.org/wiki/Royal_Earlswood_Hospital)  
<http://langdon-downmuseum.org.uk/dr-john-langdon-down-and-normalfield-the-earlswood-asylum-for-idiot/>



ETHNIC CLASSIFICATION OF IDIOTS.  
'London Hospital Reports', 1866.

"Mongolian Idiocy" → Down Syndrome → Trisomy 21



Langdon Down, 1887

"I have alluded already to a group which I have ventured to describe as 'accidental'.... In these cases there is no outward sign of mental vacuity... no hereditary taint to mar the beauty of his visage...

"They are bright in their expression....fearless as to danger.....self-contained and self-absorbed ...they live entirely in a world of their own... Automatic movements are also very common... these may include rhythmical movements of the fingers before the eyes...

14-16

Langdon Down, 1887

"I know nothing more painful than the long motherly expectancy of speech...which never comes... [W]hen speech does exist it is often echo-like... To my question "How are you today?" came the immediate reply "Today." I ask another "Are you a good girl?" the response is simply "Girl."..... Sometimes the whole question is repeated, and the echo is not simply that of the last word.

14-16

Langdon Down, 1887

"Extraordinary memory ....with associated very great defect of reasoning power. A boy came under my observation who, having once read a book, could ever more remember it.... I discovered, however, that it was simple a process of verbal adhesion. I once gave him Gibbon's *Rise and Fall of the Roman Empire* to read. This he did, and on reading the third page he skipped a line, found out his mistake and retraced his steps; ever after, when reciting from memory the stately periods of Gibbon, he would, on coming to the third page, skip the line and go back and correct the error with as much regularity as if it had been part of the regular text....

58-60

Langdon Down, 1887

Often the memory takes the form of remembering dates and past events... One boy never fails to be able to tell the name and address of every confectioner's shop he has visited in London – and they have been numerous – and can as readily tell the date of every visit.

58-60

Why have we forgotten Langdon Down?

- Association with Eugenics?
  - "Mongolism" / Social Darwinism
- WWI – Social disruption / loss of continuity
- He didn't give it a name
- Ahead of his time?

Time Passes.....



Kristallnacht (The Night of Broken Glass): November 8, 1938



The New York Times.  
NAZIS SMASH, LOOT AND BURN  
JEWISH SHOPS AND TEMPLES



1938

Aktion T4



This poster, from around 1938, reads: "60,000 Reichsmarks is what this person suffering from a hereditary defect costs the People's community during his lifetime. Fellow citizen, that is your money too. Read *A New People*, the monthly magazine of the *Bureau for Race Politics of the NSDAP*."

[https://en.wikipedia.org/wiki/Aktion\\_T4](https://en.wikipedia.org/wiki/Aktion_T4)  
[https://en.wikipedia.org/wiki/Final\\_Solution](https://en.wikipedia.org/wiki/Final_Solution)



Leo Kanner  
1894-1981

The  
NERVOUS  
CHILD

Quarterly Journal of Psychopathology, Psychotherapy,  
Mental Hygiene, and Guidance of the Child

AUTISTIC DISTURBANCES OF AFFECTIVE CONTACT

By LEO KANNER

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.

Kanner, L. Autistic Disturbances of Affective Contact. *Nervous Child*, (2) 217-250, 1943



Johns Hopkins Hospital  
Baltimore, MD

Kanner, 1943

- N = 11 (M 8; F 3)
- Age: 2 to 8 yr.
- Symptoms in four domains:
  1. Impaired socialization
  2. Idiosyncratic language
  3. Repetitious behaviors
  4. Unusual responses to sensory stimuli

Kanner, L. Autistic Disturbances of Affective Contact. *Nervous Child*, (2) 217-250, 1943  
[www.drcoplan.com](http://www.drcoplan.com)

Impaired Socialization

- “Aloof”
- “Withdrawn”
- Limited eye contact
- Indifferent to others

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

### Idiosyncratic Language

- Echolalia
- Delayed Echolalia
- Pronoun Reversal
- Odd inflection

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

### Repetitious Behaviors

- Rigid Routines
- Stereotypes
- Lining up / spinning objects

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

### Unusual sensory responses

- “Petrified of vacuum cleaner”
- Drawn to, or afraid of, spinning objects
- Mouthing behavior
- Ingesting inedible materials
- Food selectivity

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

### Kanner, 1938 → 1943

- Gradual improvement in early childhood
  - ↑Social skills
  - ↑Language
  - ↓Cognitive rigidity
  - ↓Sensory Aversions

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

### Kanner, 1938 → 1943

“Between the ages of 5 and 6 years, they gradually abandon echolalia and learn spontaneously to use personal pronouns.

“Language becomes more communicative, at first in the sense of a question-and-answer exercise, and then in the sense of greater spontaneity of sentence formation....

Kanner, L. Autistic Disturbances of Affective Contact. Nervous Child, (2) 217-250, 1943  
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### Kanner, 1938 → 1943

“Food is accepted without difficulty. Noises and motions are tolerated more than previously. The panic tantrums subside. The repetitiousness assumes the form of obsessive preoccupations...

Kanner, L. Autistic Disturbances of Affective Contact. Nervous Child, (2) 217-250, 1943  
[www.drcoplan.com](http://www.drcoplan.com)

Kanner, 1938 → 1943

“Reading skill is acquired quickly, but the children read monotonously, and a story or a moving picture is experienced in unrelated portions rather than in its coherent totality...\*

\* “Central coherence”: the ability to see the big picture  
Kanner, L. Autistic Disturbances of Affective Contact. Nervous Child, (2) 217-250, 1943  
www.drcoplan.com

Kanner, 1938 → 1943

“Between the ages of 6 and 8, the children begin to play in a group, still never with the other members of the group, but at least on the periphery alongside the group.

Kanner, L. Autistic Disturbances of Affective Contact. Nervous Child, (2) 217-250, 1943  
www.drcoplan.com

Kanner, 1938 → 1943

“People are included in the child's world to the extent to which they satisfy his needs...

Kanner, L. Autistic Disturbances of Affective Contact. Nervous Child, (2) 217-250, 1943  
www.drcoplan.com

Kanner, 1938 → 1943

All of this makes the family feel that, in spite of recognized ‘difference’ from other children, there is progress and improvement.

Leo Kanner, 1943

Kanner, L. Autistic Disturbances of Affective Contact. Nervous Child, (2) 217-250, 1943  
www.drcoplan.com

Kanner, 1943

...[T]here is a great deal of obsessiveness in the family background...For the most part, the parents, grandparents, and collaterals are persons strongly preoccupied with abstractions of a scientific, literary, or artistic nature, and limited in genuine interest in people.... The question arises whether or to what extent this fact has contributed to the condition of the children.

Kanner, 1943

The child's aloneness from the beginning of life makes it difficult to attribute the whole picture exclusively to the type of early parental relations with our patient. We must, then, assume that these children have come into the world with innate inability to form the usual, biologically provided affective contact with people, just as other children come into the world with innate physical or intellectual handicaps.

If this assumption is correct, a further study of our children may help to furnish concrete criteria regarding the still diffuse notions about constitutional components of emotional reactivity. For here we seem to have pure-culture examples of *inborn autistic disturbances of affective contact*. [italics in the original]

Follow-up Study of Eleven Autistic Children  
Originally Reported in 1943

LEO KANNER<sup>1</sup>  
*John Hopkins University School of Medicine*  
Copyright © 1971 by Scripta Publishing Corporation.

- Deceased: 1
- Lost to follow-up: 2
- Institutionalized: 5
- Living on work farm: 1
- Living at home: 2
  - BA degree / bank teller
  - Sheltered workshop / machine operator

Kanner’s contributions

- Clinical Description
  - Social
  - Language
  - Repetitious behavior
  - Sensory aversions / attractions
- Described the *Natural History* of improvement over time (irrespective of treatment)
- Attribution
  - An “inborn disturbance of affective contact”

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“Autism’s first child”  
*The Atlantic*, 2010



<http://www.theatlantic.com/magazine/archive/2010/10/autism-8217-s-first-child/8227/>

D-Day, June 6, 1944



Archiv für Psychiatrie und Nervenkrankheiten  
3. Juni 1944, Volume 117, Issue 1, pp 76-136

Die „Autistischen Psychopathen“ im Kindesalter

Doz. Dr. Hans Asperger



- lack of empathy
- little ability to form friendships
- one-sided conversations
- special interests
- “little professors”
- clumsy movements

<http://autismus-kultur.de/wp-content/uploads/2006/06/asperger-syndrom.jpg>  
[http://en.wikipedia.org/wiki/Hans\\_Aasperger](http://en.wikipedia.org/wiki/Hans_Aasperger)  
[http://www.icn.ucl.ac.uk/dev\\_group/ufnhd/documents/Ch%201.%20Asperger%20and%20his%20his%20syndrome%20copy.pdf](http://www.icn.ucl.ac.uk/dev_group/ufnhd/documents/Ch%201.%20Asperger%20and%20his%20his%20syndrome%20copy.pdf)



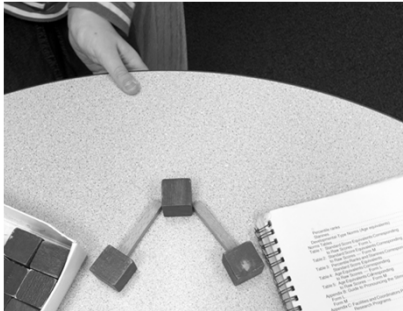
“Asperger’s syndrome: a clinical account”  
Lorna Wing. Psychological Medicine, 11(1), 1981

- Articulate yet strangely ineloquent
- Active but odd
- Specialists in unusual fields
- Speech is pedantic and often consisting of lengthy disquisitions on favourite subjects



Lorna Wing  
7 October 1928 – 6 June 2014

Image © Tina Norris, www.tinanorris.co.uk



“I made water”

MRN 13-0829



The World Turns Upside Down

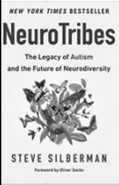
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The Nervous Child; 1943

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.

- Why does Kanner say “Since 1938”?
- Why does Kanner use the passive voice: “there have come to our attention,” rather than the active voice “I have discovered”?

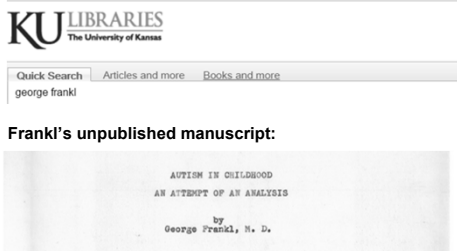
George Frankl – Unsung Hero



In 1938, Kanner hired George Frankl, a Jewish physician recently escaped from Austria. *Frankl had been Hans Asperger’s collaborator in Austria.* It was Frankl – not Kanner – who actually evaluated and wrote up Kanner’s famous “Patient #1” with autism in 1938. Frankl left Johns Hopkins in 1939 and eventually joined the faculty at the University of Kansas.

<http://www.drcoplan.com/the-world-turns-upside-down>

George Frankl – Unsung Hero



Bottom Line

- Asperger may have concealed his lower functioning patients, to protect them (and himself) from the gas chamber.
- Kanner minimized or concealed both Frankl's and Asperger's contributions to his own work.
- Asperger's Syndrome and "Kanner type" Autism have been part of the same entity from the beginning.

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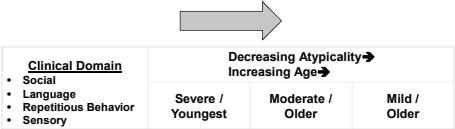
Natural History: "The temporal course  
a disease from onset to resolution"

Center for Disease Control & Prevention

ASD has a *Natural History*

www.drcoplan.com

Quantifying severity of ASD,  
and changes over time



© Coplan, J. Making Sense of Autistic Spectrum Disorders. Bantam-Dell, 2010

"Natural History" of ASD


1 - Social Interaction

"Our child is *among* us, but not *with* us."

Parent of a 4 year old with ASD


www.drcoplan.com






Clinical Domain ↓	Decreasing Atypicality / Increasing Age ⇒		
	Severe / Youngest	Moderate / Older	Mild / Older
1. Social Interaction	<ul style="list-style-type: none"><li>•No eye contact</li><li>•No physical affection</li><li>•Cannot be engaged in imitative tasks</li></ul>	<ul style="list-style-type: none"><li>•Intermittent eye contact</li><li>•Seeks affection "on his own terms"</li><li>•May invade personal space of others (not true affection)</li><li>•Engageable in imitative tasks, although with difficulty</li></ul>	<ul style="list-style-type: none"><li>•Good eye contact</li><li>•Shows interest in others, but often does not know how to join in</li><li>•Easily engaged in imitative activities</li><li>•Rigid; has difficulty if perceives that rules have been broken</li><li>•Difficulty with "Theory of Mind" tasks</li></ul>

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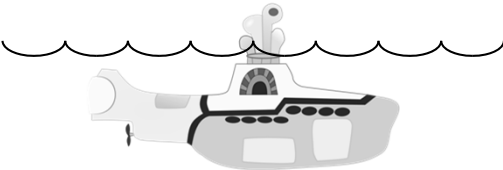
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Visible features  
(DSM III, IV, 5, IDEA, ICD10, etc.)



Underlying Neuropsychological Traits

> ♦ Theory of Mind

Theory of Mind

- Realization that other people have an internal mental & emotional state, different from one's own
- Ability to gauge the internal mental & emotional state of others
  - Able to infer motives & predict behavior of others
  - Empathy
  - Humor

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Theory of Mind

Muff

Muff is a little yellow kitten.  
She drinks milk.  
She sleeps on a chair.  
She does not like to get wet.

Q: How would Muff feel, if you gave her a bath?

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Theory of Mind

Muff

Muff is a little yellow kitten.  
She drinks milk.  
She sleeps on a chair.  
She does not like to get wet.

Q: How would Muff feel, if you gave her a bath?

A: *I don't know. We haven't read that part of the story yet.\**

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\*6 ½ y.o. boy with superior IQ  
EC: MRN 01-0938

Introspection  
Awareness of *one's own* thoughts & feelings



THE LANCET Psychiatry

Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study 25 June 2014

Dr Sarah Cassidy PhD , Paul Bradley MRCPsych B, Janine Robinson DClinPsy B, Carrie Allison PhD A, Meghan McHugh BSc B, Prof Simon Baron-Cohen PhD A B

Subjects

- 374 adults newly diagnosed with Asperger Syndrome
  - Men: 256
  - Women: 118
- Mean age at Dx: 31.5 yr (range 17-67 yr)
- 87 (23%) in full-time education at the time of study

Methods:

- Self-Report Questionnaire, lifetime experience of:
  - Suicidal thoughts
  - Suicidal plans or attempts
  - Depression

[http://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366\(14\)70248-2/fulltext](http://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(14)70248-2/fulltext)

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Results:

- Suicidal ideation: 66%
- Plans or attempts at suicide: 35%
- Depression: 31%

- Delayed Dx: Lack of treatment ➡ Poor outcome?
- ⚡ Introspection?

[http://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366\(14\)70248-2/fulltext](http://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(14)70248-2/fulltext)

2 - Language

“My child talks, but he doesn’t communicate.”  
*Mother of a 3 year old with autism*

www.drcoplan.com

Quantifying severity of ASD - 2

Clinical Domain ↓	Decreasing Atypicality / Increasing Age ⇒		
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2. Language •Pragmatics •Prosody	•Nonverbal •No response to voice; may “act deaf” •No use of gestures as a means of compensating for absence of spoken language •May use “hand-over-hand” to guide caregiver to desired objects	•Echolalia, Delayed echolalia •Verbal Perseveration •Odd Inflection (stilted, sing-song, ⬆ volume) •May use stock phrases in an attempt to communicate •Makes use of visual communication modalities (symbol cards; sign language)	•Speaks fluently, but literal; lacks understanding of verbal nuance •Difficulty with Pragmatics (framing, turn-taking, topic maintenance; conversational repair; talks “at” rather than “with” others) and Theory of Mind language tasks (fibbing; humor, verbal make-believe)

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Language Deficits in ASD:  
Literal Thinking

5 ½ year old boy with ASD and Superior IQ  
(Verbal Comprehension Index 146):

Examiner: "Which is bigger, 9 or 6?"

Child: "They are both the same size, but 9 has a loop at the top, and 6 has a loop at the bottom."

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MRN 10-0681

3 - Repetitious Behavior

"My child has over-attention deficit disorder."

Father of a 10 year old with autism and perseverative behavior



Clinical Domain ↓	Decreasing Atypicality / Increasing Age ⇒		
	Severe / Youngest	Moderate / Older	Mild / Older
3. Repetitious Behaviors  Cognitive	•Extreme distress if routines are changed or when required to transition from one task to another •Fascination with odd objects (tags, wheels, fans, etc.)	•Same, but with diminishing level of distress; able to accept verbal preparation for changes in routine •Complex repetitious play (lining up objects, memorizes numbers, letters, etc)	•May demonstrate conscious awareness of preference for routines; easier to self-modulate •Play remains repetitious, but repetitive quality is more subtle; "obsessive preoccupations" •Problems with Central Coherence
Motoric	•Frequent, intense stereotypical movements (flapping, spinning, toe-walking, finger twiddling)	•Motor stereotypies occasional; may re-emerge when excited	•Motor stereotypies rare or absent

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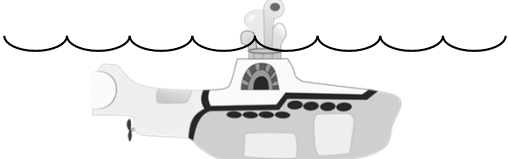
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Motoric	•Frequent, intense stereotypical movements (flapping, spinning, toe-walking, finger twiddling)	• Motor stereotypes occasional; may re-emerge when excited	• Motor stereotypes rare or absent

© Coplan, J. Making Sense of Autistic Spectrum Disorders. Bantam-Dell, 2010

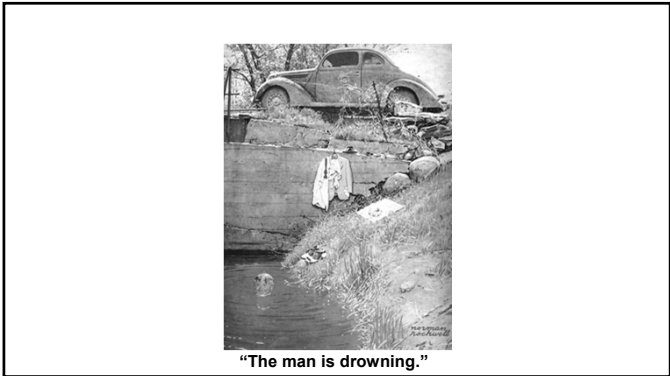
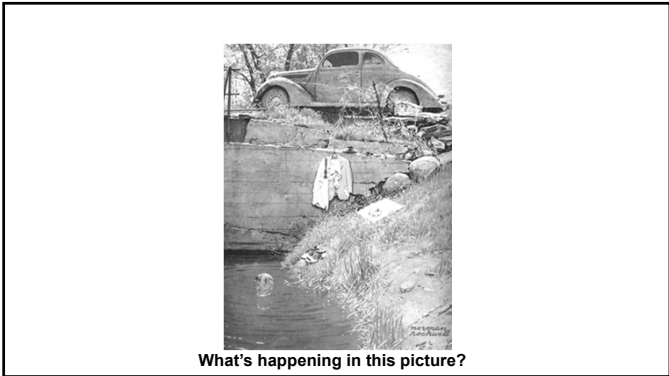
Visible features  
(DSM, IDEA, ICD, etc.)



Underlying Neuropsychological Traits

- Theory of Mind
- Central Coherence (The ability to see the big picture)

Tasks requiring Central Coherence  
(in addition to Theory of Mind)





"The man is swimming, and the car is about to fall on him."

What's happening in this picture?



What's happening in this picture?



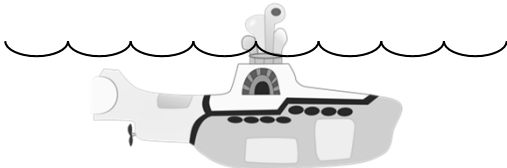
"The girl is screaming."

What's happening in this picture?



"That girl is trying to steal the other girl's book."

Visible features  
(DSM, IDEA, ICD, etc.)

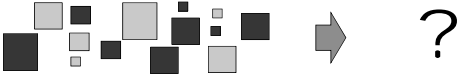


Underlying Neuropsychological Traits

- Theory of Mind
- Central Coherence
- Cognitive Rigidity

Cognitive Rigidity  
(Difficulty shifting mental sets)

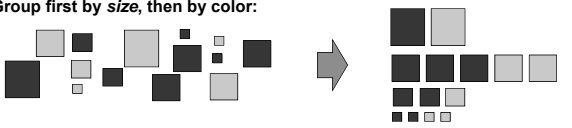
Group first by size, then by color:



### Cognitive Rigidity

(Difficulty shifting mental sets)

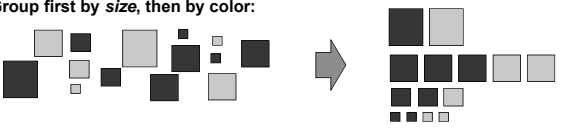
Group first by *size*, then by *color*:




### Cognitive Rigidity

(Difficulty shifting mental sets)

Group first by *size*, then by *color*:



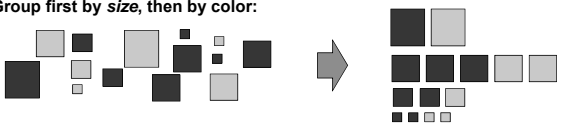
Now group first by *color*, then by *size*:



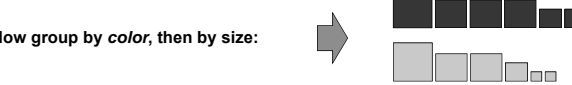
### Cognitive Rigidity

(Difficulty shifting mental sets)

Group first by *size*, then by *color*:



Now group by *color*, then by *size*:



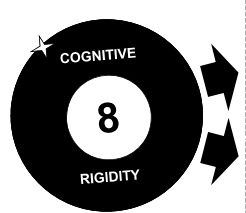


- Without a doubt
- Reply hazy, try again
- Signs point to NO
- Better not tell you now...

Mattel ©

### Cognitive Rigidity:

*The 8-Ball from Hell*




*"Externalizing Behaviors"*

- Perseveration
- *Insistently* repetitious behavior
- Difficulty with unmet expectations
- Perfectionism
- Compulsions
- (Agitation, Aggression, SIB)

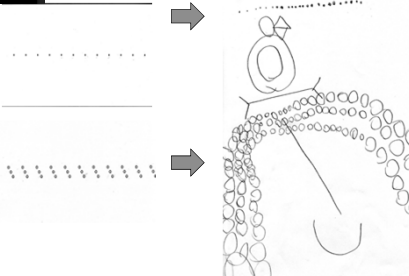
*"Internalizing Behaviors"*

- Perfectionism
- Obsessions
- (Anxiety / Depression / Suicidality)

© James Coplan MD



### Perseveration



P.

Obsessive Interests & Perseveration



"We went to Washington and stayed at a hotel."  
WW, 9 y.o. boy w. AS  
MRN: 12-0827

Repetitious Behavior with  
Insistence on Sameness

"Our son experiences extreme anxiety when what he anticipates isn't what happens...When we know a change is coming we can prepare him, but those we can't anticipate are still very upsetting for him...*The switch flips in his mind, and it's out of his control.*"

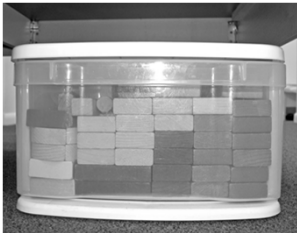
6 y.o. boy with ASD, anxiety, and normal nonverbal IQ

MRN 12-0782

Perfectionism



Perfectionism



A.



B.

Tony

8 y.o. boy with HFA, Anxiety, and Perfectionism

Teacher's Report: "Tony tries to exclude himself from any 'competition' types of games or activities, as he really dislikes being 'wrong,' 'out,' or to lose. On the times he has had tantrums after being 'out' or when his team has lost, the other children have been very empathetic towards him and he has not lashed out at them. *His frustration appears to be with himself.*"

8 yr old boy with AS  
MRN: 14-0916

Sam

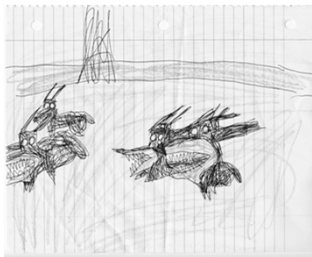
10 y.o. boy with AS, OCD, & perfectionism

"If I can't get something right I get angry with myself... Sometimes I take it out on other people"

Sam earnestly attempted the Bender-Gestalt figures, but became overwhelmed, repeatedly erasing and re-erasing.. After he had labored mightily over the first few cards, he sighed "*This is torture...*" After he had manfully struggled over a single card for several minutes, we opted to move on to another task.

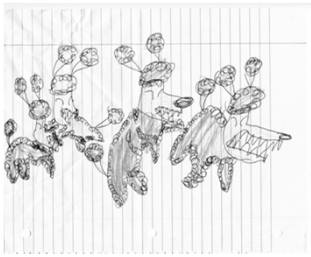


Anxiety



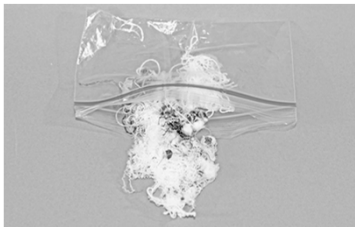
RD. 7 y.o. F, nl IQ, PDD-NOS & Anxiety. Father: GAD  
www.drcoplan.com MRN: 07-0427

Anxiety



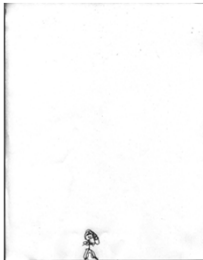
RD. 7 y.o. F, nl IQ, PDD-NOS & Anxiety. Father: GAD  
www.drcoplan.com MRN: 07-0427

Compulsions



15 y.o. boy Asperger Syndrome

Depression



www.drcoplan.com KO; 10 yr old female, PDD-NOS, normal IQ

4 - Sensory & Motor Processing

Abnormal responses to sensory stimuli



© Coplan, J. Making Sense of Autistic Spectrum Disorders. Bantam-Dell, 2010

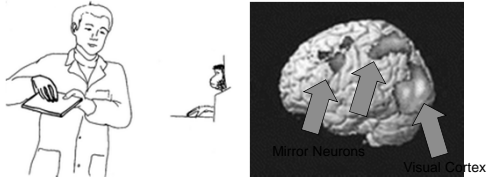


Quantifying severity of ASD - 4

Clinical Domain ↓	Decreasing Atypicality / Increasing Age ⇒		
	Severe / Youngest	Moderate / Older	Mild / Older
4.Sensorimotor: •Intense aversion or attraction to specific classes of stimuli •Clumsiness	•Auditory: Hyperacusis, covers ears, acts deaf •Visual: self-stimulation (lights/patterns); looks at objects from odd angles •Tactile: rubbing, licking, mouthing, deep pressure; averse to light touch •Olfactory: Sniffing •Extreme food selectivity •⬆ Pain threshold •Fears: Heightened / blunted	Same, but diminishing intensity	Same, but diminishing intensity

© Coplan, J. Making Sense of Autistic Spectrum Disorders. Bantam-Dell, 2010

Mirror Neurons: The Missing Link?



“The observation of actions done by another individual activates, besides visual areas, also areas that have motor properties.”

Mirror Neurons: From discovery to autism  
Rizzolatti & Fabbri-Destro, Exp Brain Res 2010



[http://en.wikipedia.org/wiki/File:Makak\\_neonatal\\_imitation.png](http://en.wikipedia.org/wiki/File:Makak_neonatal_imitation.png)



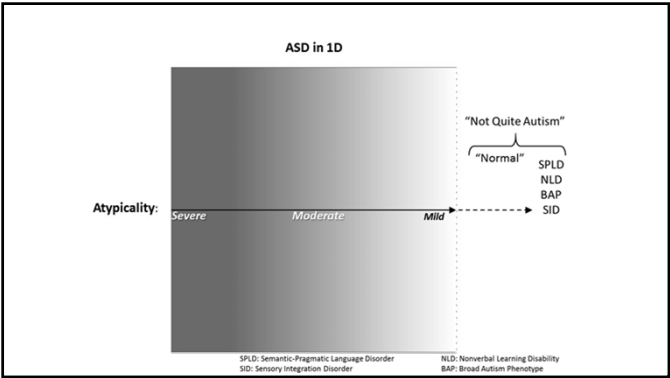
ASD Across the Lifespan - I

- Background
  - Historical Review
  - Down, Asperger, Kanner
- The 3D Model and the Natural History of ASD
  - DSM and False Dichotomies
    - “Normal” vs. “Abnormal”
    - ASD vs. “Mental Illness”

Basic Principles

1. Atypicality exists in various degrees, ranging from Severe to Mild
2. There is no clear boundary between “autistic” and “normal”

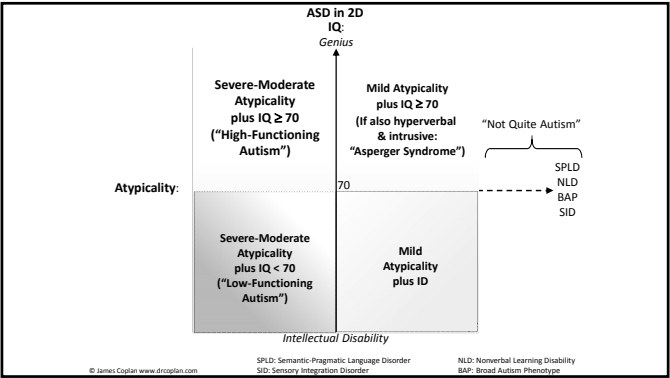
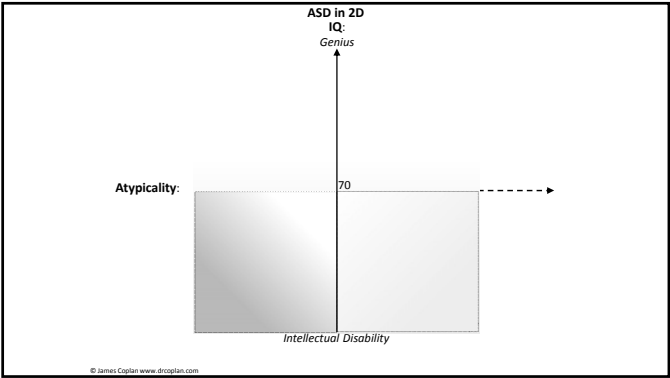
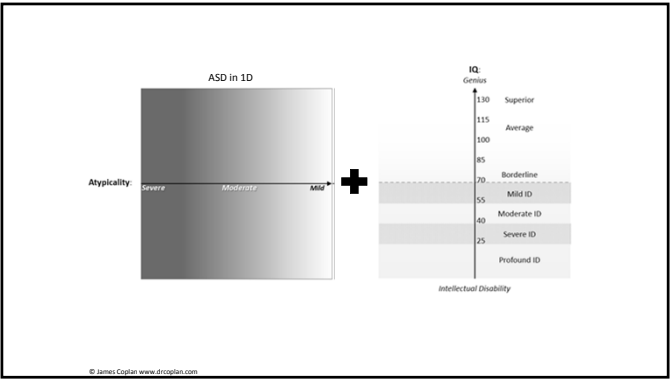
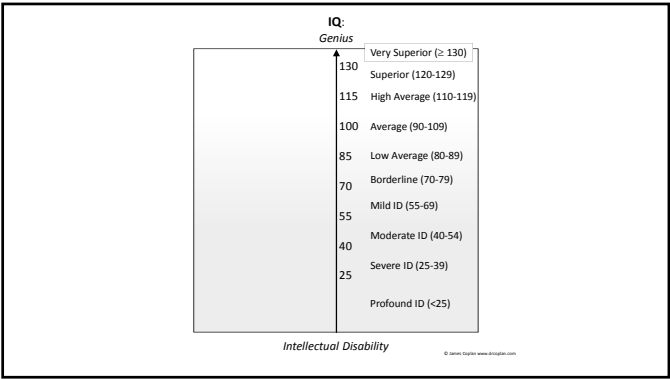
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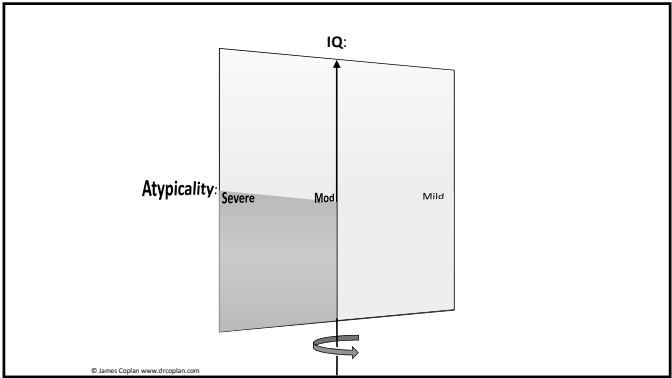
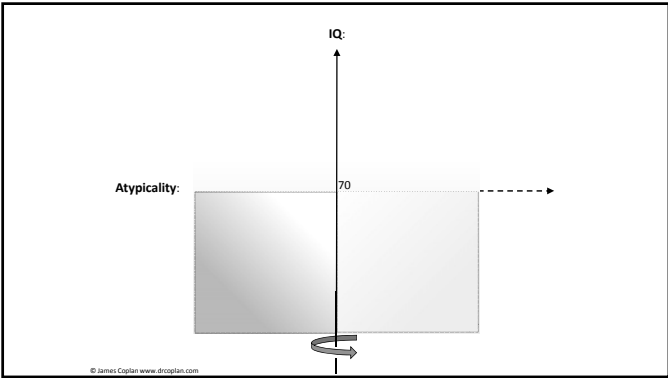


Basic Principles

1. Atypicality exists in various degrees, ranging from Severe to Mild
2. There is no clear boundary between "autistic" and "normal"
3. Intelligence (IQ) is separate from atypicality
4. Atypicality of any degree can coexist with any level of intelligence
5. The clinical picture is determined by the joint impact of the degree of atypicality and the level of intelligence

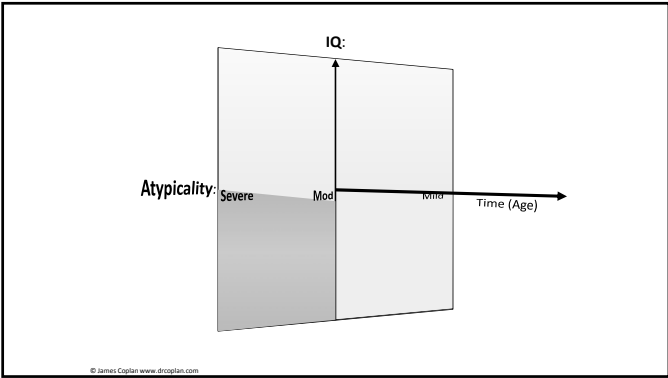
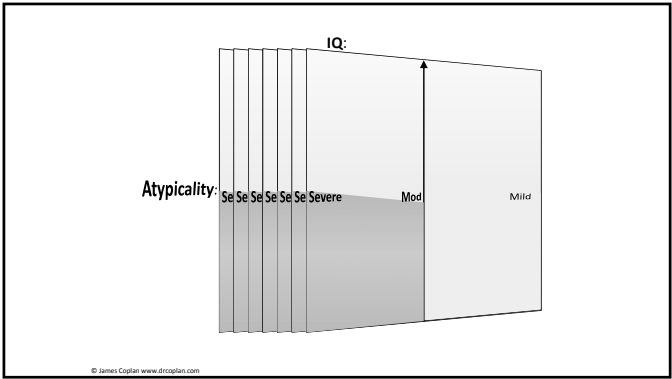
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Basic Principles

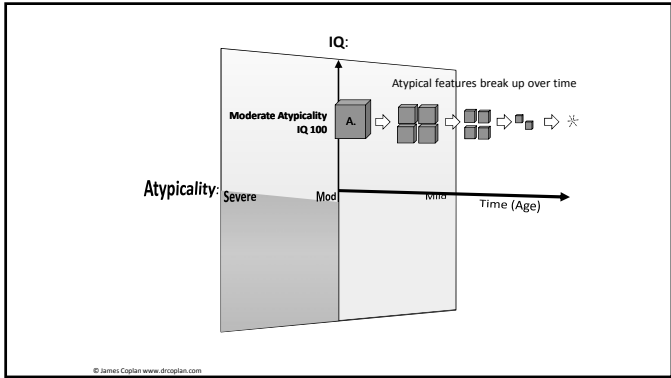
Now imagine a series of XY graphs, like a loaf of sliced bread, where each “slice” represents a successive moment in time....



Basic Principles

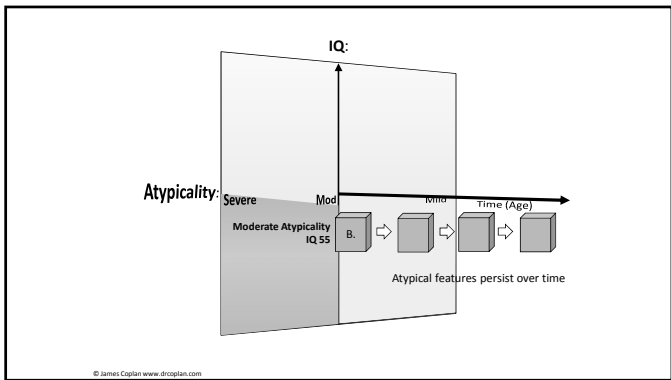
Different combinations of atypicality and IQ lead to different outcomes.

- ❖ In children with  $IQ \geq 70$ , atypicality fades dramatically over time.
  - About 15% of these “high functioning” children grow off the spectrum, although they may still manifest features of a “borderland diagnosis” as adults.



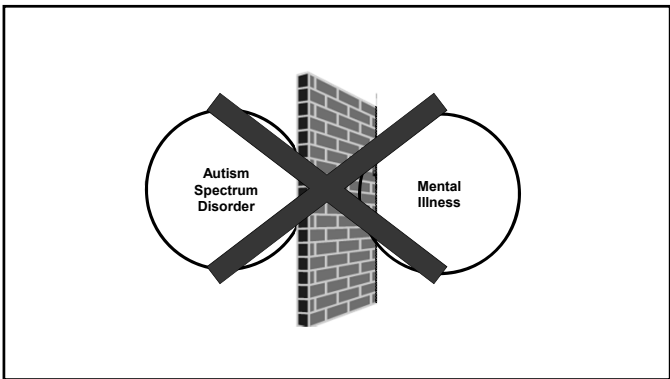
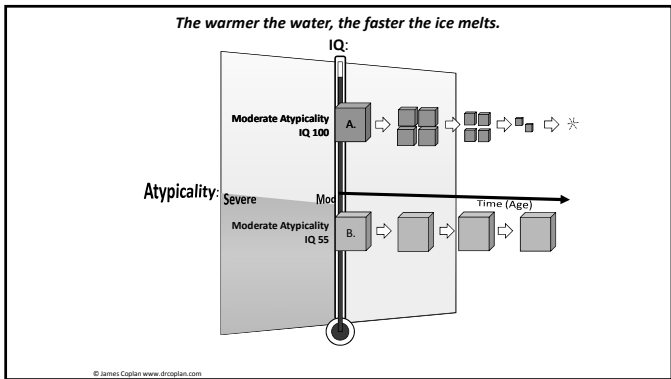
Basic Principles

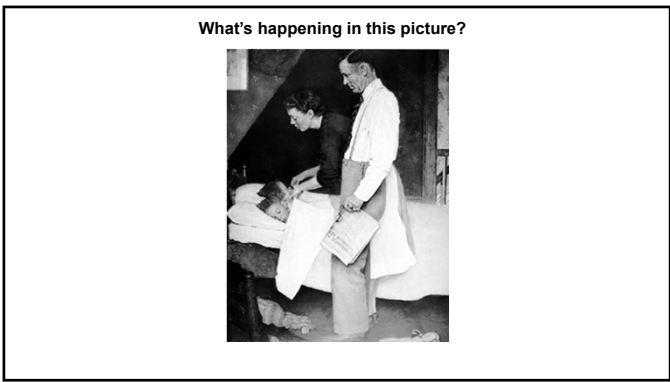
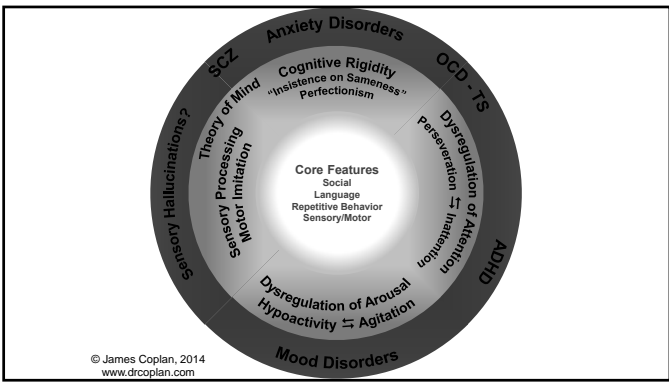
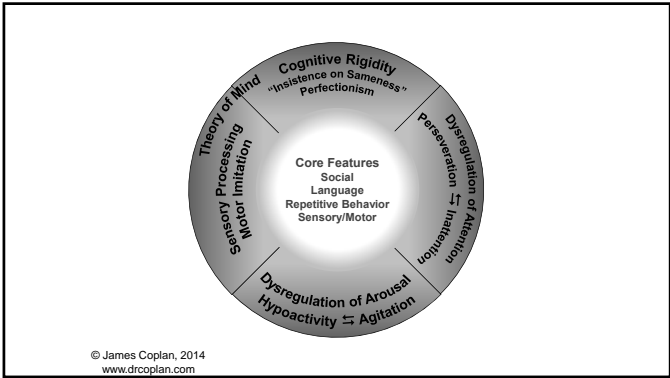
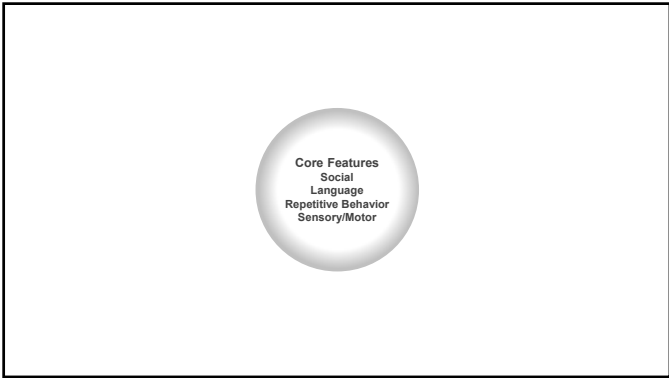
- ❖ In children with IQ < 70, atypicality fades slowly, and much less dramatically

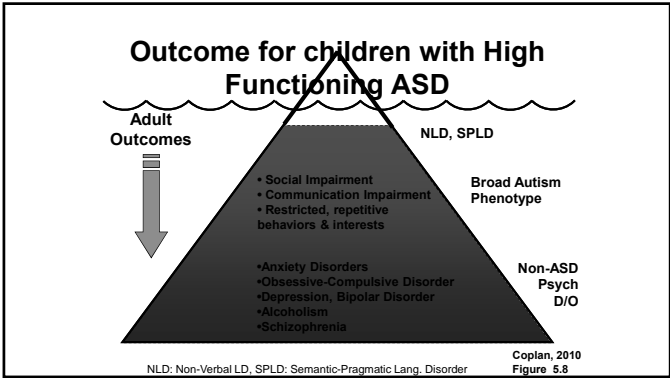
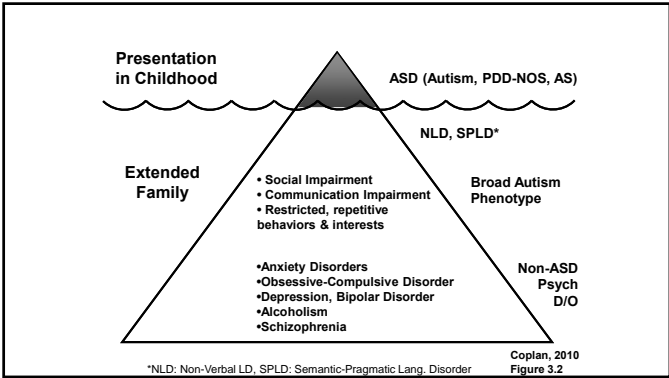


Basic Principles

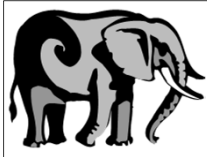
- ❖ Think of atypicality as a chunk of ice, floating in the water
- ❖ Think of IQ as the water temperature
- ❖ The warmer the water, the faster the ice melts








### The Elephant in the Room



Child w. ASD ( ± MH D/O) + Parent w. MH D/O = 

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### ASD Across the Lifespan - II

- Looking Forward
  - Outcome Studies: Back to the Future
- Next Steps
  - Knowledge is Power / Know what you don't know
  - Services and Service Models
  - Advocacy

### Transition to Adulthood

*Our son turned 13 last year. We are noticing that...the world interacts very differently to an autistic child vs. an autistic man.*

MRN 04-0011




### Autism Spectrum Disorders in adults living in households throughout England

Report from the Adult Psychiatric Morbidity Survey 2007

Survey Goal: To determine the prevalence of adults with ASD living in the community

<http://www.ic.nhs.uk/zubs/asdpsychiatricmorbidity07>

### NHS Survey 2007



- National sample of survey of adults living in the community
- Excludes persons in residential care, mental health facilities, prison
- Therefore, *under-counts* adults with severe disability

<http://www.ic.nhs.uk/pubs/asdpsychiatricmorbidity07>

### NHS Survey 2007

Phase 1  
•Autism Quotient (20-Item Screen)  
•N=2,854

Phase 2  
•ADOS (Autism Diagnostic Observation Schedule)  
•N=618

Prevalence of ASD: 1 %  
•Male: 1.8% (1 in 56)  
•Female: 0.2% (1 in 500)

<http://www.ic.nhs.uk/pubs/asdpsychiatricmorbidity07>

### NHS Survey 2007

#### Prevalence of ASD (ADOS 10+), by age

All adults	2007		
	Age group		
	16-44	45-74	75+
	%	%	%
ASD (ADOS score of 10+) <sup>a</sup>	1.1	0.9	0.8

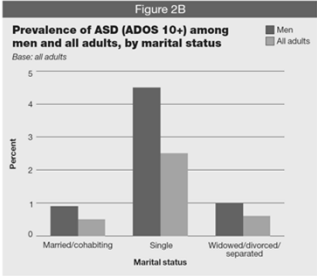
Prevalence x Age: Not statistically significant

<http://www.ic.nhs.uk/pubs/asdpsychiatricmorbidity07>

### NHS Survey 2007

#### Figure 2B

Prevalence of ASD (ADOS 10+) among men and all adults, by marital status



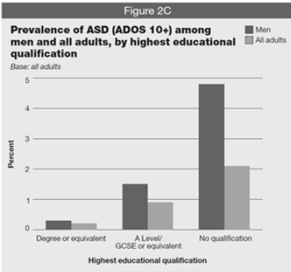
Base: all adults

<http://www.ic.nhs.uk/pubs/asdpsychiatricmorbidity07>

### NHS Survey 2007

#### Figure 2C

Prevalence of ASD (ADOS 10+) among men and all adults, by highest educational qualification



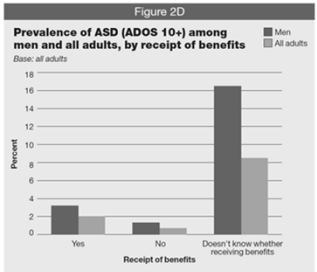
Base: all adults

<http://www.ic.nhs.uk/pubs/asdpsychiatricmorbidity07>

### NHS Survey 2007

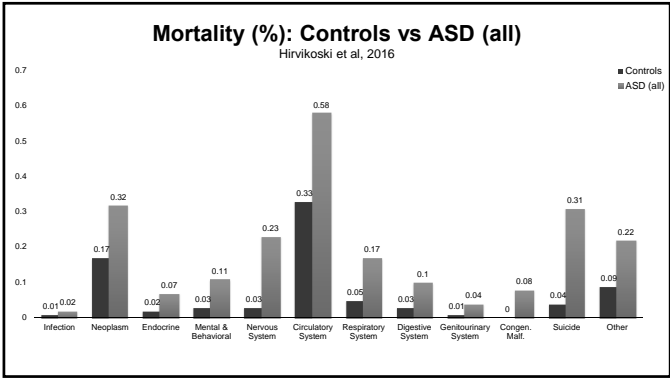
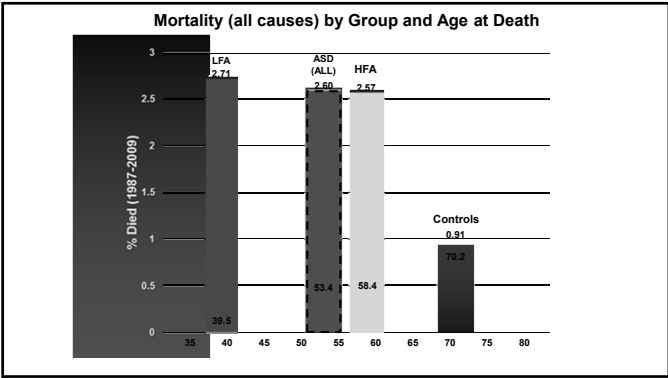
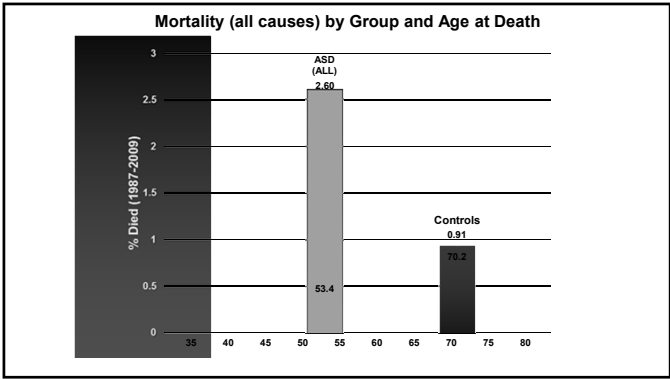
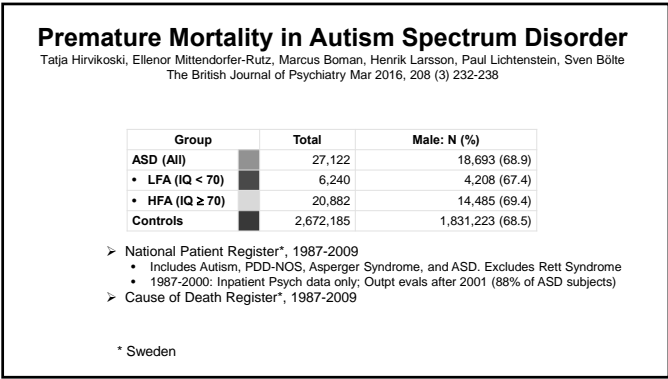
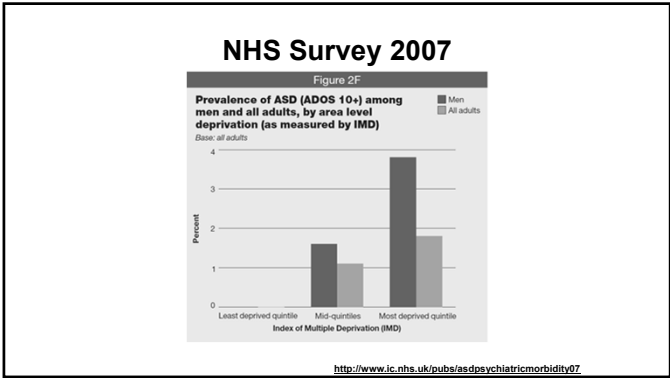
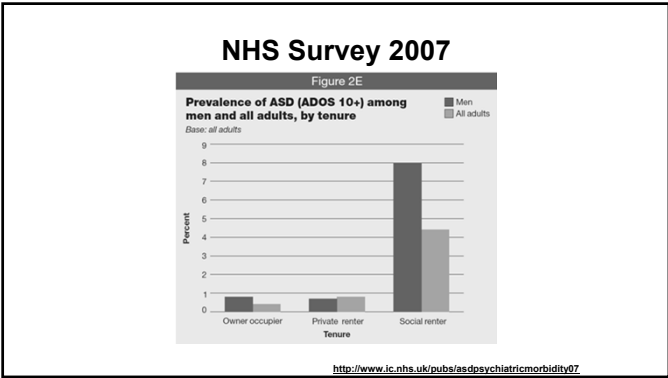
#### Figure 2D

Prevalence of ASD (ADOS 10+) among men and all adults, by receipt of benefits

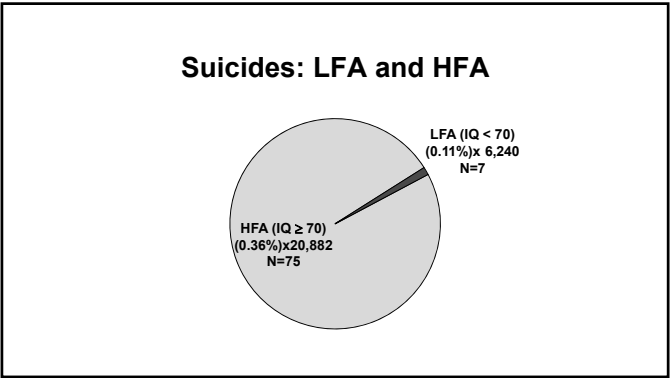
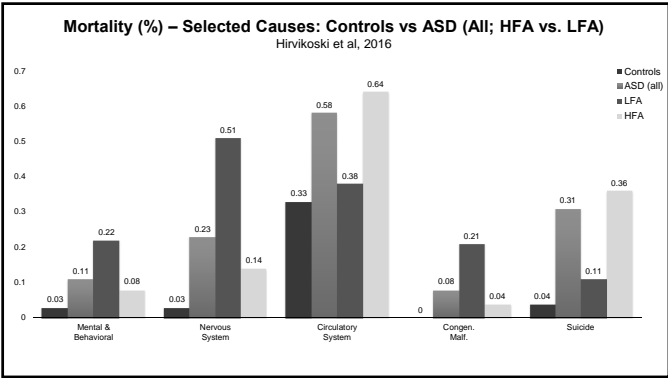


Base: all adults

<http://www.ic.nhs.uk/pubs/asdpsychiatricmorbidity07>







**Suicide by Group and Gender**

Table 5 Cause-specific mortality analysed separately for females and males\*

	Control females n of deaths (%)	ASD females OR (95% CI) n of deaths (%)	Control males n of deaths (%)	ASD males OR (95% CI) n of deaths (%)
Suicide	213 (0.03)	13.05** (8.73–19.53) 27 (0.32)	881 (0.05)	6.28 (4.79–8.23) 56 (0.33)

ASD, autism spectrum disorder; OR, odds ratio; CI, confidence interval.

- Premature Mortality in Autism Spectrum Disorder**  
Tatja Hirvikoski, Ellenor Mittendorfer-Rutz, Marcus Boman, Henrik Larsson, Paul Lichtenstein, Sven Bölte  
The British Journal of Psychiatry Mar 2016, 208 (3) 232-238
- Problems with these data
    - Age of subjects & controls not stated
      - Cannot contextualize mortality rates to age
    - Age at Dx of ASD is very high.
      - Late Dx, or late registration into system?
    - Male:Female mortality ratio among controls
    - Context for Suicide?

**Premature Mortality in Autism Spectrum Disorder**  
Tatja Hirvikoski, Ellenor Mittendorfer-Rutz, Marcus Boman, Henrik Larsson, Paul Lichtenstein, Sven Bölte  
The British Journal of Psychiatry Mar 2016, 208 (3) 232-238

Table 2 Characteristics of the study groups

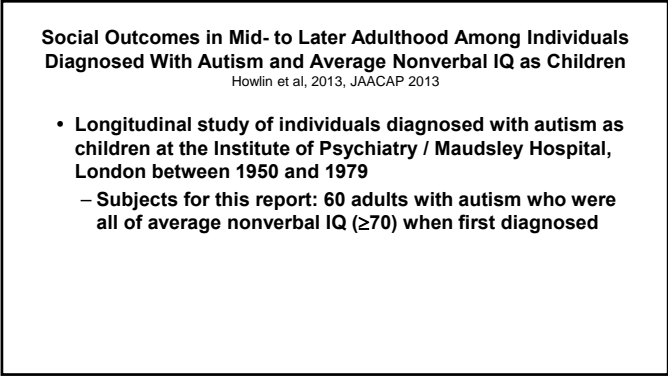
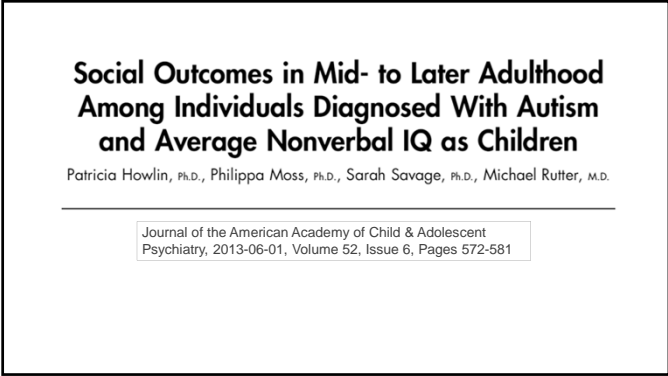
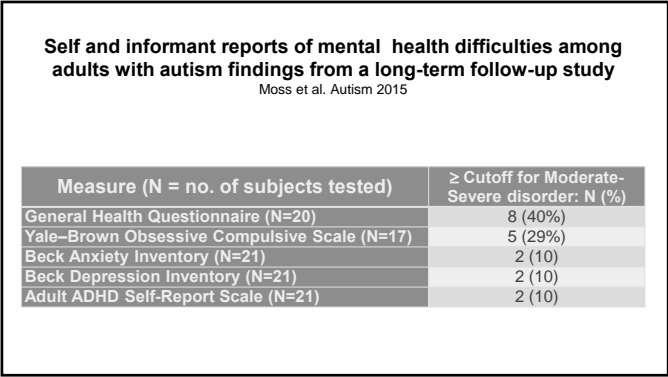
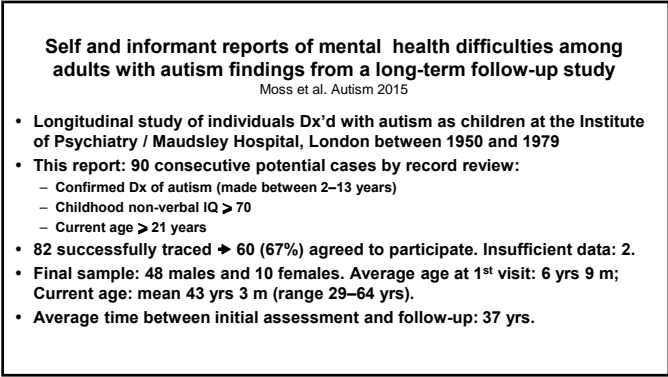
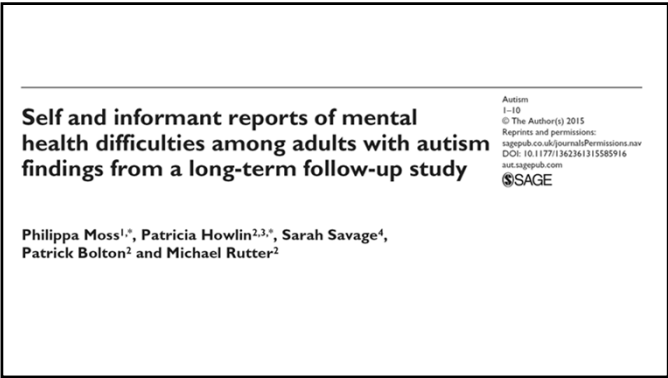
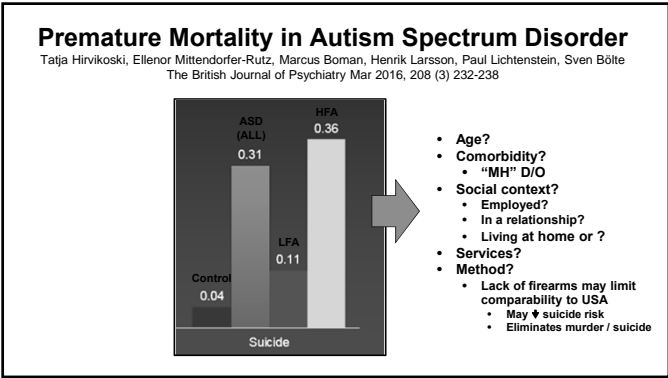
	Control	ASD in total	Low-functioning ASD	High-functioning ASD
n total (%)	2,672 185	27 122	6240 (23.01)	20,882 (76.99)
Females n (%)	840 962 (31.47)	8429 (31.08)	2032 (32.56)	6397 (30.63)
Males n (%)	1,831 223 (68.53)	18,693 (68.92)	4208 (67.44)	14,485 (69.37)
Age at first registered diagnosis, years: mean (s.d.) median	N/A	19.83 (14.54)	16.49 (13.83)	20.83 (14.59)

ASD, autism spectrum disorder.

**Premature Mortality in Autism Spectrum Disorder**  
Tatja Hirvikoski, Ellenor Mittendorfer-Rutz, Marcus Boman, Henrik Larsson, Paul Lichtenstein, Sven Bölte  
The British Journal of Psychiatry Mar 2016, 208 (3) 232-238

	Controls Number of deaths (%)	Raw Data
Total	24 358 (0.91)	24,358 / 2,672,185 = 0.0091 = 0.91%
Females	11 693 (1.39)	11,693 / 840,962 = 0.0139 = 1.39%
Males	12 665 (0.69)	12,665 / 1,831,223 = 0.0069 = 0.69%

Female : Male Mortality = 2 : 1



Social Outcomes in Mid- to Later Adulthood Among Individuals Diagnosed With Autism and Average Nonverbal IQ as Children  
Howlin et al, 2013, JAACAP 2013

• Subject characteristics:

– Mean age at Dx of ASD: 6.75 yr (range: 2-13)

– Present age: Mean 44.2 yr (range: 29-64)

– Mean childhood PIQ: 86.3

• Findings at Re-Evaluation:

– Mean current IQ: 88.2 (no change)

– Significant ↓ in atypical features (ADI) over time

Social Outcomes in Mid- to Later Adulthood Among Individuals Diagnosed With Autism and Average Nonverbal IQ as Children  
Howlin et al, 2013, JAACAP 2013

ADI/ADI-R Domains <sup>a</sup>	Diagnostic Confirmation n=60	Mid/Late Adulthood n=58 <sup>b</sup>	Significance
n (%) meeting cutoff in 3 core domains	53 (88)	26 (45)	Fisher p = .01
n (%) meeting cutoff in 2 domains	7 (12)	32 (55)	
RRBI			
Mean [sd]	7.4 [2.1]	3.6 [2.2]	4.3 .01
n (%) meeting cutoff	59 (98)	36 (62)	
ADI total			
Mean [SD]	39.5 [8.4]	27.0 [8.4]	2.3 .02

RRBI: Restricted and Repetitive Behaviors and Interests

Table 1. Changes in Autism Diagnostic Interview/Revised (ADI/R) Scores Over Time

Social Outcomes in Mid- to Later Adulthood Among Individuals Diagnosed With Autism and Average Nonverbal IQ as Children  
Howlin et al, 2013, JAACAP 2013

	N (%)
University (BA 2, PhD 3)	5 (8.5%)
HS diploma	5 (8.5%)
General Certificate of Education	7 (11.6%)
No formal educational qualifications	43 (72%)

Educational Attainment

Social Outcomes in Mid- to Later Adulthood Among Individuals Diagnosed With Autism and Average Nonverbal IQ as Children  
Howlin et al, 2013, JAACAP 2013

Rating	Where Living <sup>a</sup>	n (%)
0	Independently	8 (13)
1	Semi-sheltered accommodation (n = 5) or with parents but high degree of autonomy (n = 3)	8 (13)
2	At home, limited autonomy	10 (17)
	Residential home, limited autonomy	12 (20)
3	Specialist autistic placement or another placement with little/no autonomy	20 (33)
	Secure hospital care	2 (3)

Note: <sup>a</sup>All individuals in residential care had been there since early adulthood (age 18–21).

Table 2. Residential Status

Social Outcomes in Mid- to Later Adulthood Among Individuals Diagnosed With Autism and Average Nonverbal IQ as Children  
Howlin et al, 2013, JAACAP 2013

Highest Occupation	Job Type (N = 60)	n (%)
Professional or highly skilled	Computer programmer [construction design]; engineer (nuclear research)	2 (3)
Nonmanual skilled	Project manager × 2 (civil service; telecom); artist (self-employed); accounts clerk (× 2); town planner; civil servant	7 (12)
Manual skilled	Electronics work	1 (2)
Partly skilled	Postal workers (× 2)	2 (3)
Unskilled and untrained	Postal work (family firm); McDonald's; sales assistant; cleaning/sorting in theatrical costumiers; factory assembly/packing work	5 (8)
Ph.D. student/voluntary lobbying work		1 (2)
Sheltered/voluntary employment	Basic industrial work/cleaning × 2; care-home/charity shop × 4; railway guard; kitchen/ gardening work × 2	9 (15)
Never worked/long-term unemployed		33 (55)

Table 3. Employment Status

Social Outcomes in Mid- to Later Adulthood Among Individuals Diagnosed With Autism and Average Nonverbal IQ as Children  
Howlin et al, 2013, JAACAP 2013

Rating	Friends/Acquaintances <sup>a</sup> (n = 59 <sup>b</sup> )	n (%)
0	One or more friend of approximately same age	5 (9)
1	One or more friend but restricted range of interests	9 (15)
2	No specific friendships but seeks contact with others in group situations	8 (14)
3	Never any peer relationships involving selectivity/sharing	37 (63)
	Close relationships <sup>a</sup> (n = 60)	
0	Close reciprocal relationship[s] (e.g., sexual relationship/marriage) past or present	4 (7)
1	Some reciprocal relationships but short duration and/or reduced sharing of activities	6 (10)
2	Only ever very brief relationships, involving minimal sharing of activities	4 (7)
3	No reciprocal relationships lasting >1 month or never had relationship	46 (77)

Note: <sup>a</sup>Friends are characterized as individuals seen for outings, visits outside the home but not necessarily involving emotional intimacy/sharing of feelings. Close relationships are characterized as involving close personal contacts (including sexual); sharing of feelings and activities.  
<sup>b</sup>One informant could not report on this area.

Table 4. Social relationships

Social Outcomes in Mid- to Later Adulthood Among Individuals Diagnosed With Autism and Average Nonverbal IQ as Children  
Howlin et al, 2013, JAACAP 2013

Adult Outcome Rating*	%
Good / Very Good	18%
Fair	23%
Poor / Very Poor	59%

Global rating of outcome based on education, employment, social, and residential levels (N=44).

\* Higher Reciprocal Social Interaction score on ADI was associated with better outcome



Post-High School Service Use Among Young Adults With an Autism Spectrum Disorder

Paul T. Shattuck, PhD; Mary Wagner, PhD; Sarah Narendorf, MSW; Paul Sterzing, MSSW; Melissa Hensley, MSW

Arch Pediatr Adolesc Med. 2011;165(2):141-146. doi:10.1001/archpediatrics.2010.279

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Arch Pediatr Adolesc Med. 2011;165(2):141-146

- National Longitudinal Transition Study-2
  - 11,000 students age 13-16, receiving or received special ed services
  - Periodic re-evaluation, 2001-2009
- Use of the following services by young adults with ASD, in the prior 2 years or since leaving high school:
  - mental health services, medical evaluation and assessment, speech therapy, and case management

Post-High School Service Use Among Young Adults with an Autism Spectrum Disorder

Paul T. Shattuck, PhD; Mary Wagner, PhD; Sarah Narendorf, MSW; Paul Sterzing, MSSW; Melissa Hensley, MSW  
Arch Pediatr Adolesc Med. 2011;165(2):141-146

Service	Utilization (%)
No Services*	39.1
Mental Health	35.0
Medical	23.5
Speech	9.1
Case Management	41.9

\* Likelihood of receiving no services:

- 3x higher for non-whites compared to whites
- 6 x higher for families with <\$25K annual income compared to >\$75 k annual income

J Autism Dev Disord (2013) 43:2710–2719  
DOI 10.1007/s10803-013-1833-8

ORIGINAL PAPER

Social Participation Among Young Adults with an Autism Spectrum Disorder

Gael I. Orsmond · Paul T. Shattuck · Benjamin P. Cooper · Paul R. Sterzing · Kristy A. Anderson

Social Participation Among Young Adults with an Autism Spectrum Disorder

- Orsmond, Shattuck, Cooper et al, 2013
- National Longitudinal Transition Study-2
    - 11,000 students age 13-16, receiving or received special ed services
    - Periodic re-evaluation, 2001-2009
  - Subjects for this study:
    - N= 620 who had graduated from HS (Current age: 21-25)
    - Educational classification
      - ASD
      - ID
      - ED
      - LD

Social Participation Among Young Adults with an Autism Spectrum Disorder

Orsmond, Shattuck, Cooper et al, 2013

	ASD	ID	ED	LD
Sex				
Male	85.0	54.7	72.3	64.5
Race				
White	70.0	57.2	60.1	66.8
Overall health				
Excellent	27.9	20.9	23.9	25.4
Very good	37.3	29.6	25.0	30.8
Good	26.5	31.0	24.9	30.8
Fair/poor	8.3	18.6	26.2	13.0

Social Participation Among Young Adults with an Autism Spectrum Disorder

Orsmond, Shattuck, Cooper et al, 2013

	ASD	ID	ED	LD
How well youth converses				
No trouble	12.0	45.3	67.2	70.4
Little trouble	41.3	32.7	24.6	21.9
Lot of trouble	29.9	14.7	4.9	4.8
Not at all	16.9	7.3	a	2.9
Functional skills scale				
4 ("Highest")	19.8	24.0	44.8	52.3
3	33.8	45.9	42.6	32.3
2	29.5	21.3	12.6 <sup>b</sup>	15.4 <sup>b</sup>
1 ("Lowest")	17.0	8.7		

Social Participation Among Young Adults with an Autism Spectrum Disorder

Orsmond, Shattuck, Cooper et al, 2013

	ASD	ID	ED	LD
Currently attending postsecondary school				
No	87.6	97.6	87.2	82.7
Currently has a paid job				
No	66.5	61.7	52.2	33.0
Current residence				
With a parent/guardian	82.0	70.3	46.6	48.4
Alone/with a roommate	7.8	25.6	46.9	50.6
Under supervision	10.2	4.1	6.4	1.1
Currently attending adult day program				
No	87.5	94.3	99.5	100

Social Participation Among Young Adults with an Autism Spectrum Disorder

Orsmond, Shattuck, Cooper et al, 2013

	ASD	ID	ED	LD
How often sees friends				
Never	38.6	19.5***	15.9***	7.1***
< Weekly	16.5	20.0	8.6*	10.7
About once / week	16.0	12.6	13.7	14.4
>Once per week	28.8	47.9**	61.8***	67.8***
How often friends call				
Never	47.2	16.5***	7.2***	4.4***
< Monthly	19.5	17.1	12.0	5.5***
1-3 / Month	15.3	25.0*	23.6	26.3*
>Once weekly	18.0	41.4***	57.2***	63.8***
Never invited to activities	48.1	37.0*	22.9***	10.4***
Socially isolated ["Never" to all]	28.1	8.9***	2.7***	2.0***

\* p < .05, \*\* p < .01, \*\*\* p < .001

Social Participation Among Young Adults with an Autism Spectrum Disorder

Orsmond, Shattuck, Cooper et al, 2013

	ID	ED	LD
Never sees friends	0.4**	0.5	0.2***
Friends never call	0.3**	0.2**	0.2***
Never invited to activities	0.8	0.6	0.3**
"Socially isolated"	0.3*	0.2*	0.2**

Odds ratios of social isolation among young adults with ID, ED, or LD, compared to young adults with autism, controlling for covariates.

- Covariates: Gender, age, race, ethnicity, parent household income, years since leaving high school, overall health, how well youth converses, functional skills, currently attending postsecondary school, currently has a paid job, current residence, currently attending adult daycare

Special Issue Article



Autism  
1-9  
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DOI: 10.1177/1362281315585643  
aut.sagepub.com  
SAGE

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

Julie Lounds Taylor<sup>1,2,3</sup>, Natalie A Henninger<sup>1</sup> and Marsha R Mailick<sup>4</sup>

Longitudinal patterns of employment and postsecondary education for adults with autism and average-range IQ  
Taylor et al 2015

- Longitudinal study (1998-2012) of families of adolescents and adults with ASD (N=406)
  - This study: N = 73 (Male: 79.5%)
  - ≥3 time points of post-HS vocational / educational data
    - Mean duration of F/U not stated
  - Verbal
  - IQ ≥ 70 (range: 70-142; 40% had IQ ≥ 100)
  - Autism: 94.6%, PDD-NOS or Asperger Syndrome: 5.4%

Longitudinal patterns of employment and postsecondary education for adults with autism and average-range IQ  
Taylor et al 2015

Table 1. Types of competitive employment positions held by adults with ASD in this sample.


Type of position	N
Retail	9
Office and administrative support	7
Production/factory work	6
Cleaning/maintenance	5
Food preparation/serving	4
Personal care and service	3
Education/training/library	2
Art/entertainment/sports	2
Computer/mathematical	1
Community/social services	1
Healthcare support	1
Installation/maintenance/repair	1
Other	1

Longitudinal patterns of employment and postsecondary education for adults with autism and average-range IQ  
Taylor et al 2015

Employment and PSE* Status	N / %	Comment
3. <i>Consistently engaged</i> in competitive employment and/or a degree-seeking PSE program	18 (24.7%)	<ul style="list-style-type: none"><li>• 0/15 of the female subjects in this group</li><li>• 18/18 males had fathers with some college program</li></ul>
2. <i>Sometimes engaged</i> in competitive employment or PSE, but at other time points in the study participated in less independent vocational activities (e.g. supported employment, sheltered workshop) or were unemployed	31 (42.5%)	
1. <i>Never engaged</i> in competitive employment or a degree-seeking PSE program at any point in the study	24 (32.9%)	<ul style="list-style-type: none"><li>• Maladaptive &amp; atypical behaviors, but not IQ, differ from Groups 3 and 2</li><li>• Fathers: Significantly lower educational attainment than fathers in Groups 3 and 2</li><li>• Mothers <i>less</i> depressed than Grps 3 and 2</li></ul>

\*PSE = Post Secondary Education

Unlawful Behaviors in Adolescents and Adults with Autism Spectrum Disorders  
Woodbury-Smith, Marc  
2014, Adolescents and Adults with Autism Spectrum Disorders, 269-281



Woodbury-Smith 2014

“A small yet significant number of primarily higher functioning people with ASD will engage in unlawful behavior. The etiology of their behavior may be understood as arising from a combination of *generic forensic risk factors* along with *factors more specific to the autism phenotype*. To most appropriately inform rehabilitation,\* a comprehensive assessment will consider all of these factors.”

• \* and primary prevention! jc

Generic Childhood Risk Factors for Adult Criminality

Reavis 2013

- Parental substance abuse
- Parental Mental Illness
- Parental criminal behavior
- Loss of parent (foster care; parental death or divorce)
- Witness domestic violence
- Childhood abuse (physical, sexual, psychological)

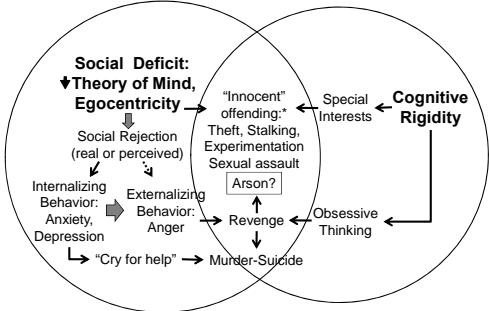
Factors specific to autism phenotype....

Wing 1997

(Wing, L. Asperger's syndrome: Management requires diagnosis. Journal of Forensic Psychiatry, 8(2), 253-257)

- Assumption that own needs supersede all other considerations
- Lack of awareness of wrongdoing
- Intellectual interest (Asperger: "Autistic acts of malice")
- Pursuit of "special" interests (objects, people)
- Hostility towards family
- Hyperarousal
- Vulnerability
- Cry for help
- Revenge

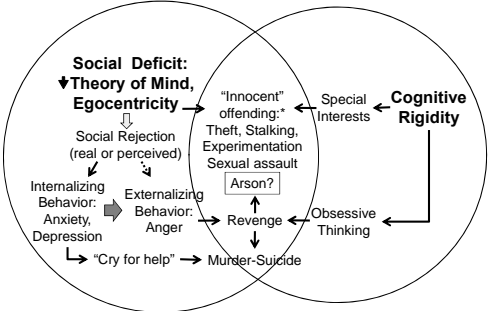
Proposed Pathways from Core Features of ASD to Offending



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\*No awareness of, or intent to do harm

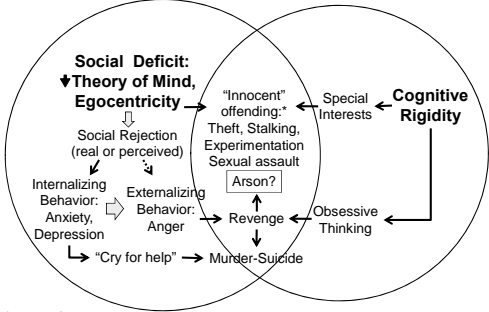
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Proposed Pathways from Core Features of ASD to Offending



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ASD Across the Lifespan - II

- Looking Forward
  - Outcome Studies: Back to the Future
- Next Steps
  - Knowledge is Power / Know what you don't know
  - Services and Service Models
  - Advocacy

The Art of War  
Sun Tsu



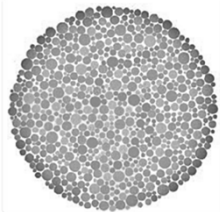
Know your enemy and know yourself, and in 100 battles you will never be defeated

Know what you don't know



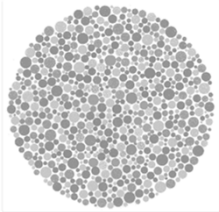
Know what you don't know

Ishihara Color Blindness Test Plate 4



Know what you don't know

Ishihara Color Blindness Test Plate 4



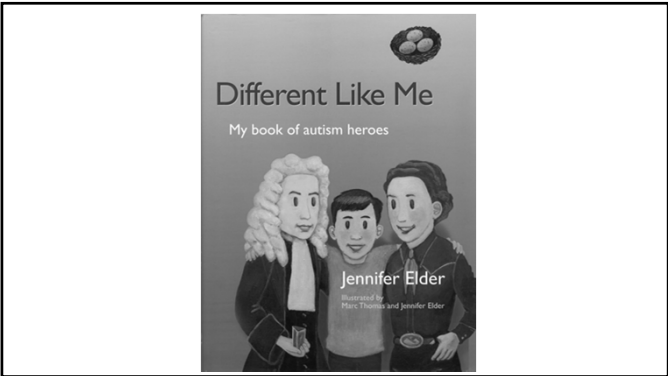
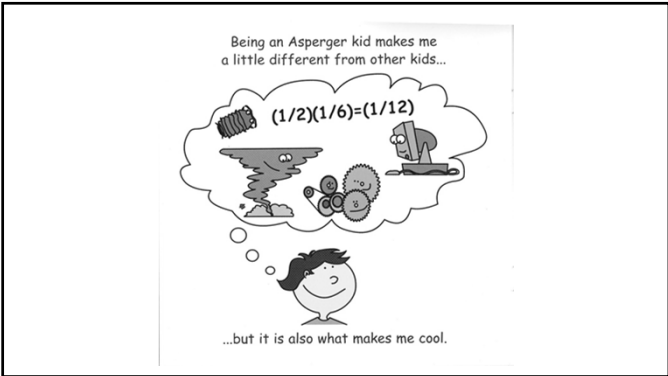
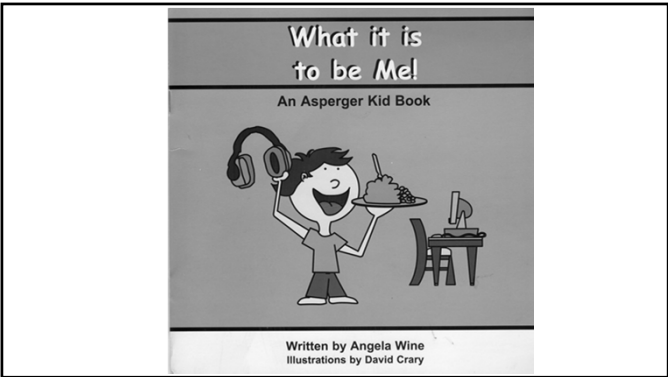
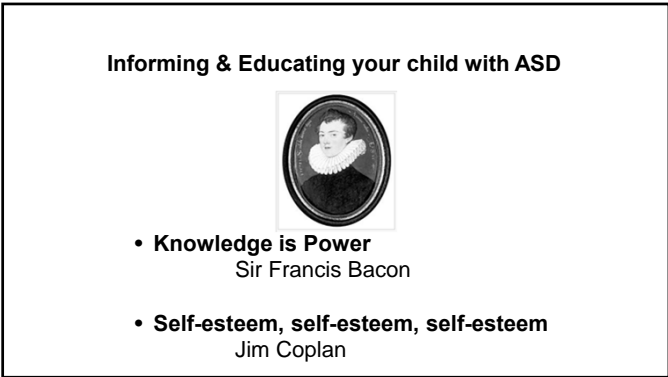
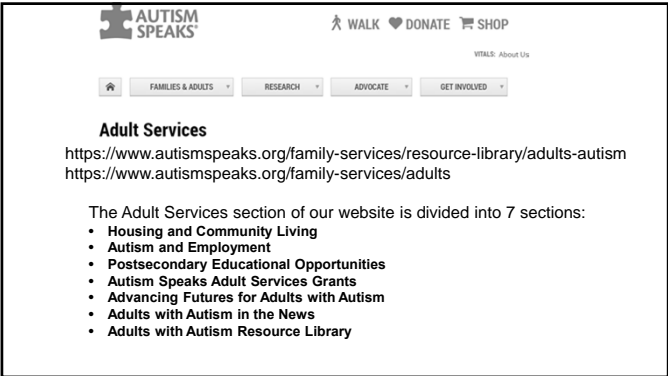
Know what you don't know

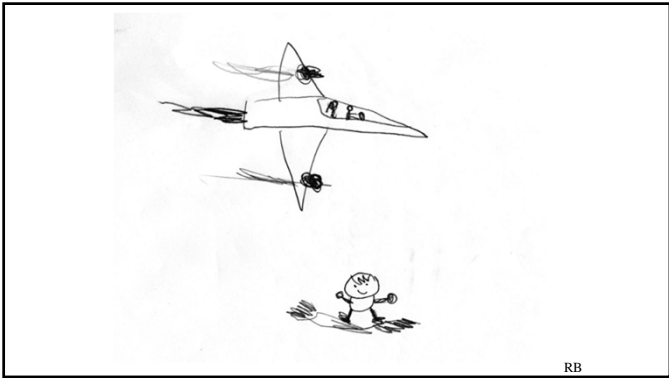
- “I was in High School before I realized that my classmates couldn't do computer assisted design in their head the way I can. But I was also in High School before I realized that they were capable of passing invisible messages back and forth that I can't see.” (Paraphrase of Temple Grandin; *Thinking In Pictures*)



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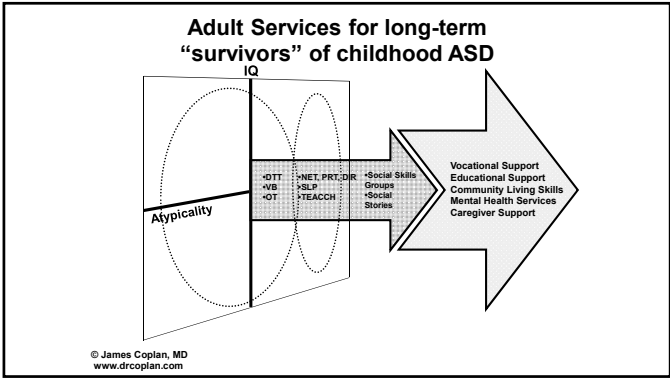
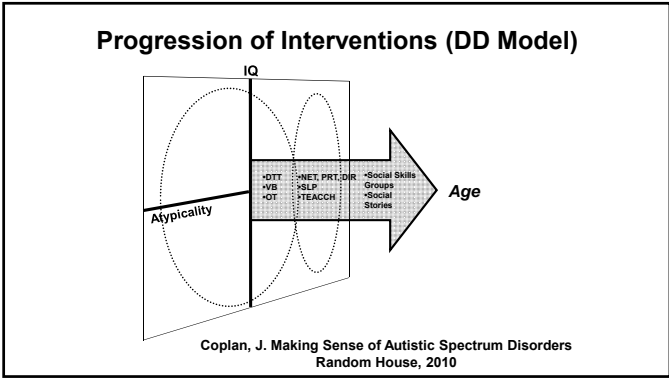
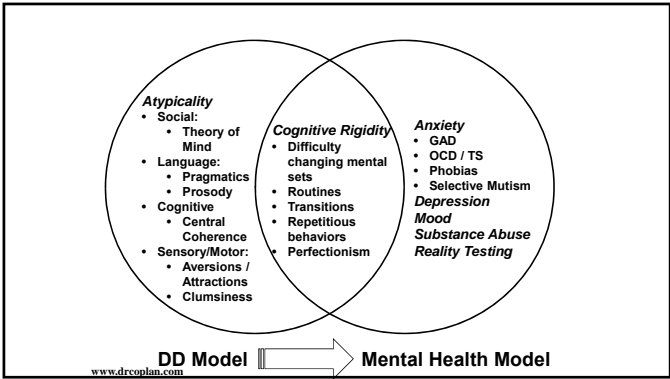
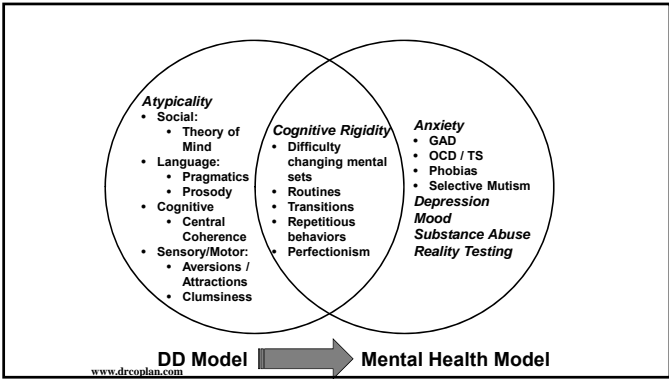




**Parents' Mental Health as a contributor to family health**

- **Parents of children with ASD**
  - Frequency of neuropsychiatric d/o (esp. anxiety)
  - “Subclinical” issues with Theory of Mind
    - May interfere with parents' ability to achieve full differentiation
    - May interfere with parents' ability to respond in a flexible manner to the extraordinary demands of child w. ASD
- **Getting help for yourself is the best way to help your child with ASD**

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**Well-behaved people seldom make history**

- 1954: Brown vs. Board of Education
- 1964: Civil Rights Act
- 1964, 1972: EEOC (Equal Employment Opportunity Commission)
- 1975: PL 94-142 (Education for All Handicapped Act)
- 1990: Americans with Disabilities Act

What now?

*Ignore your rights.... And they'll go away.*



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