ASD Through the Lifespan
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Neurodevelopmental Pediatrics of the Main Line, PC
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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

The Royal Earlswood Asylum for Idiots (est. 1854)

ON SOME OF THE
MENTAL AFFECTIONS
OF
CHILDHOOD AND YOUTH
MINING
THE LETTSOMIAN LECTURES
DELIVERED BEFORE THE MEDICAL SOCIETY OF LONDON
IN 1827
TOGETHER WITH OTHER PAPERS
BY
J. LANGDON DOWN, M.D.

www.drcoplan.com
“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....

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.

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....

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.

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

1938

Aktion T4

This poster, from around 1938, reads: “60,000 Reichmarks 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.”

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

Impaired Socialization

• “Aloof”
• “Withdrawn”
• Limited eye contact
• Indifferent to others
Idiosyncratic Language

- Echolalia
- Delayed Echolalia
- Pronoun Reversal
- Odd inflection

Repetitious Behaviors

- Rigid Routines
- Stereotypies
- Lining up / spinning objects

Unusual sensory responses

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

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

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
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

“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, 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, 1938 → 1943

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

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]
Kanner’s contributions

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

“I made water”
MRN 13-0829

The World Turns Upside Down
AUTISTIC DISTURBANCES OF AFFECTIVE CONTACT
By Leo Kanner
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—nay, 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

Frankl’s unpublished manuscript:

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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- DSM and False Dichotomies
  - “Normal” vs. “Abnormal”
  - ASD vs. “Mental Illness”

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

ASD has a Natural History

Quantifying severity of ASD, and changes over time

“Natural History” of ASD

1 - Social Interaction

“Our child is among us, but not with us.”

Parent of a 4 year old with ASD

### Clinical Domain

**Decreasing Atypicality / Increasing Age**

**Severe / Youngest**
- No eye contact
- No physical affection
- Cannot be engaged in imitative tasks

**Moderate / Older**
- Decreased eye contact, gives affection "on his own terms"
- May invade personal space of others (not true affection)
- Engageable in imitative tasks, although with difficulty

**Mild / Older**
- Good eye contact
- Shows interest in others, often does not know how to join in
- Easily engaged in imitative activities
- Rigid; has difficulty if perceives that rules have been broken
- Difficulty with "Theory of Mind" tasks

---

### 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

---

### 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?
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.*

*6 ½ y.o. boy with superior IQ
EC; MRN 01-0918

Introspection
Awareness of one’s own thoughts & feelings

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

Results:
• Suicidal ideation: 66%
• Plans or attempts at suicide: 35%
• Depression: 31%
   Delayed Dx: Lack of treatment 
   Poor outcome?
   Introspection?

2 - Language

“My child talks, but he doesn’t communicate.”

Mother of a 3 year old with autism

Quantifying severity of ASD - 2

<table>
<thead>
<tr>
<th>Clinical Domain</th>
<th>Severe / Youngest</th>
<th>Moderate / Older</th>
<th>Mild / Older</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Language</td>
<td>- Pragmatics</td>
<td>- Proseody</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decreasing Atypicality / Increasing Age -a</td>
<td></td>
<td></td>
<td></td>
</tr>
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</table>
Quantifying severity of ASD - 2

<table>
<thead>
<tr>
<th>Clinical Domain</th>
<th>Decreasing Atypicality / Increasing Age</th>
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<tbody>
<tr>
<td></td>
<td>Severe / Youngest</td>
</tr>
<tr>
<td>2. Language</td>
<td></td>
</tr>
<tr>
<td>Pragmatics</td>
<td></td>
</tr>
<tr>
<td>Prosody</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Disproportionate voice; may &quot;act deaf&quot;</td>
</tr>
<tr>
<td></td>
<td>May use gestures as a means of compensating for absence of spoken language</td>
</tr>
<tr>
<td></td>
<td>May use &quot;hand-over-hand&quot; to guide caregiver to desired objects</td>
</tr>
</tbody>
</table>

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.”

3 - Repetitious Behavior

“My child has over-attention deficit disorder.”

Father of a 10 year old with autism and perseverative behavior

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

www.drcoplan.com
### Clinical Domain

#### Decreasing Atypicality / Increasing Age ➔

<table>
<thead>
<tr>
<th>Clinical Domain</th>
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</thead>
<tbody>
<tr>
<td>3. Repetitious Behaviors</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Extreme distress if routines are changed in any way</td>
<td>Some, but with diminishing effect as adolescent</td>
<td>May demonstrate conscious awareness of repetitive behaviors; may re-emerge if changes in routine</td>
<td></td>
</tr>
<tr>
<td>- Fascination with odd objects (tags, wheels, fans, etc.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Motoric</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Frequent, intense stereotypical movements (flapping, spinning, toe-walking)</td>
<td>Motor stereotypes occasional, may re-emerge when excited</td>
<td>Motor stereotypes rare or absent</td>
<td>Motor stereotypes rare or absent</td>
</tr>
</tbody>
</table>


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### 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)

---

### What’s happening in this picture?

*The man is drowning.*
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:

Now group by color, then by size:

Cognitive Rigidity
(Difficulty shifting mental sets)

Group first by size, then by color:

Now group first by color, then by size:

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)

Perseveration
Obsessive Interests & Perseveration

“We went to Washington and stayed at a hotel.”

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

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.”

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

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, ml IQ, PDD-NOS & Anxiety. Father: GAD
MRN: 07-0427

Anxiety

RD. 7 y.o. F, ml IQ, PDD-NOS & Anxiety. Father: GAD
MRN: 07-0427

Compulsions

15 y.o. boy Asperger Syndrome

Depression

KO; 10 yr old female, PDD-NOS, normal IQ

4 - Sensory & Motor Processing

Abnormal responses to sensory stimuli

Quantifying severity of ASD - 4

<table>
<thead>
<tr>
<th>Clinical Domain</th>
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</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Severe / Youngest</td>
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</tr>
<tr>
<td></td>
<td>Mild / Older</td>
</tr>
</tbody>
</table>

4. Sensorimotor:  
- Intense aversion or attraction to specific classes of stimuli  
- Clumsiness

- Auditory: Hyperacusis, covers ears, seeks deaf 
- Visual: Self-stimulation (lights/patterns), looks at objects from odd angles, does face reading, deep pressure; aware to light touch 
- Olfactory: Sniffing
- Extreme food selectivity 
- Pain threshold 
- Fears: Heightened / blunted

Same, but diminishing intensity 
Same, but diminishing intensity

Quantifying severity of ASD - 4


Mirror Neurons: The Missing Link?

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


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    - 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”

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
Basic Principles

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

Different combinations of atypicality and IQ lead to different outcomes.

- In children with IQ ≥ 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 warmer the water, the faster the ice melts.
Core Features
Social
Language
Repetitive Behavior
Sensory/Motor

What's happening in this picture?

“Two strangers got into the house and are handing out newspapers.”

What's happening in this picture?

“They are stealing the children.”
ASD (Autism, PDD-NOS, AS)

Broad Autism Phenotype
- Social Impairment
- Communication Impairment
- Restricted, repetitive behaviors & interests
- Anxiety Disorders
- Obsessive-Compulsive Disorder
- Depression, Bipolar Disorder
- Alcoholism
- Schizophrenia

Non-ASD Psych D/O

NLD, SPLD*

* NLD: Non-Verbal LD, SPLD: Semantic-Pragmatic Lang. Disorder

Outline for children with High Functioning ASD

Adult Outcomes
- Social impairment
- Communication Impairment
- Restricted, repetitive behaviors & interests
- Anxiety Disorders
- Obsessive-Compulsive Disorder
- Depression, Bipolar Disorder
- Alcoholism
- Schizophrenia

Non-ASD Psych D/O

NLD, SPLD

Extended Family

Coplan, 2010

Figure 3.2

Presentation in Childhood

ASD (Autism, PDD-NOS, AS)

NLD, SPLD*

Non-ASD Psych D/O

Coplan, 2010

Figure 3.2

NLD: Non-Verbal LD, SPLD: Semantic-Pragmatic Lang. Disorder

The Elephant in the Room

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

© James Coplan, 2010

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

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

Prevalence of ASD (ADOS 10+), by age

<table>
<thead>
<tr>
<th>Age group</th>
<th>2007</th>
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</thead>
<tbody>
<tr>
<td>16-44</td>
<td>%</td>
</tr>
<tr>
<td>45-74</td>
<td>%</td>
</tr>
<tr>
<td>75+</td>
<td>%</td>
</tr>
</tbody>
</table>

ASD (ADOS score of 10+) 1.1 0.9 0.8

Prevalence x Age: Not statistically significant

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
Premature Mortality in Autism Spectrum Disorder

Tatja Hirvikoski, Ellenor Möttönen-Riipi, Marcus Boman, Henrik Larsson, Paul Lichtenstein, Sven Bölte
The British Journal of Psychiatry Mar 2016, 208 (3) 232-238

<table>
<thead>
<tr>
<th>Group</th>
<th>Total</th>
<th>Male: N (%)</th>
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<tbody>
<tr>
<td>ASD (All)</td>
<td>27,122</td>
<td>18,693 (68.9)</td>
</tr>
<tr>
<td>• LFA (IQ &lt; 70)</td>
<td>6,240</td>
<td>4,208 (67.4)</td>
</tr>
<tr>
<td>• HFA (IQ ≥ 70)</td>
<td>20,882</td>
<td>14,485 (69.4)</td>
</tr>
<tr>
<td>Controls</td>
<td>2,672,185</td>
<td>1,831,223 (68.5)</td>
</tr>
</tbody>
</table>

- National Patient Register*, 1987-2009
  - Includes Autism, PDD-NOS, Asperger Syndrome, and ASD. Excludes Rett Syndrome
- 1987-2000: Inpatient Psych data only; Outpt evals after 2001 (88% of ASD subjects)
- Cause of Death Register*, 1987-2009

* Sweden

Mortality (all causes) by Group and Age at Death

Hirvikoski et al., 2016
Mortality (%) – Selected Causes: Controls vs ASD (All; HFA vs. LFA)
Hirvikoski et al, 2016

<table>
<thead>
<tr>
<th>Cause</th>
<th>Controls ASD in Total</th>
<th>LFA in Total</th>
<th>HFA in Total</th>
<th>Raw Data</th>
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<tr>
<td>Suicide</td>
<td>2.01</td>
<td>0.03</td>
<td>0.03</td>
<td>0.0091</td>
</tr>
<tr>
<td>Mental &amp; Behavioral Disorders</td>
<td>0.29</td>
<td>0.04</td>
<td>0.04</td>
<td>0.0139</td>
</tr>
<tr>
<td>Suicide</td>
<td>0.54</td>
<td>0.06</td>
<td>0.06</td>
<td>0.0069</td>
</tr>
<tr>
<td>Nervous System</td>
<td>0.32</td>
<td>0.04</td>
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<td>0.01</td>
<td>0.01</td>
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</tr>
<tr>
<td>Other</td>
<td>0.12</td>
<td>0.01</td>
<td>0.01</td>
<td>0.0069</td>
</tr>
<tr>
<td>Total</td>
<td>6.00</td>
<td>0.25</td>
<td>0.25</td>
<td>0.0822</td>
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Table 2: Characteristics of the study groups

<table>
<thead>
<tr>
<th>ASD in Total</th>
<th>Low-functioning ASD</th>
<th>High-functioning ASD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>18,630 (39.5)</td>
<td>2,672 (57.1)</td>
</tr>
<tr>
<td>Females</td>
<td>15,728 (34.5)</td>
<td>2,000 (45.5)</td>
</tr>
</tbody>
</table>

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

Tuja Hirvikoski, Eleanor Tillander-Olszewska, Marcus Bonnes, Henrik Larsson, Paul Lichtenstein, Sven Bölte

The British Journal of Psychiatry Mar 2016, 208 (3) 232-238

Self and informant reports of mental health difficulties among adults with autism findings from a long-term follow-up study

Philippa Moss¹, Patricia Howlin¹,², Sarah Savage⁴, Patrick Bolton¹ and Michael Rutter¹

Self and informant reports of mental health difficulties among adults with autism findings from a long-term follow-up study

Moss et al. Autism 2015

Measure (N = no. of subjects tested) ≥ Cutoff for Moderate-Severe disorder: N (%)

General Health Questionnaire (N=20) 8 (40%)
Yale-Brown Obsessive Compulsive Scale (N=17) 5 (29%)
Beck Anxiety Inventory (N=21) 2 (10)
Beck Depression Inventory (N=21) 2 (10)
Adult ADHD Self-Report Scale (N=21) 2 (10)

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

Howlin et al. 2013, JAACAP 2013

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

Howlin et al. 2013, JAACAP 2013

 longitudial study of individuals diagnosed with autism as children at the Institute of Psychiatry / Maudsley Hospital, London between 1950 and 1979

– Subjects for this report: 60 adults with autism who were all of average nonverbal IQ (≥70) when first diagnosed

Longitudinal study of individuals Dx’d with autism as children at the Institute of Psychiatry / Maudsley Hospital, London between 1950 and 1979

– This report: 90 consecutive potential cases by record review:
  – Confirmed Dx of autism (made between 2–13 years)
  – Childhood non-verbal IQ ≥ 70
  – Current age ≥ 21 years

– 82 successfully traced → 60 (67%) agreed to participate. Insufficient data: 2.
– Final sample: 48 males and 10 females. Average age at 1st visit: 6 yrs 9 m;
  Current age: mean 43 yrs 3 m (range 29–64 yrs).
– Average time between initial assessment and follow-up: 37 yrs.


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

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 increase in atypical features (ADI) over time

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

<table>
<thead>
<tr>
<th>Age (yr)</th>
<th>N (%)</th>
<th>Mean ADI-R Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.75</td>
<td>5</td>
<td>72</td>
</tr>
<tr>
<td>44.2</td>
<td>4</td>
<td>88</td>
</tr>
</tbody>
</table>

Table 2. Educational Attainment

<table>
<thead>
<tr>
<th>Education Level</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>University (BA)</td>
<td>5 (8.5%)</td>
</tr>
<tr>
<td>HS diploma</td>
<td>5 (8.5%)</td>
</tr>
<tr>
<td>General Certificate of Education</td>
<td>7 (11.6%)</td>
</tr>
<tr>
<td>No formal educational qualifications</td>
<td>43 (72%)</td>
</tr>
</tbody>
</table>

Table 3. Residential Status

<table>
<thead>
<tr>
<th>Residential Status</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>University (BA)</td>
<td>5 (8.5%)</td>
</tr>
<tr>
<td>HS diploma</td>
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<td>7 (11.6%)</td>
</tr>
<tr>
<td>No formal educational qualifications</td>
<td>43 (72%)</td>
</tr>
</tbody>
</table>

Table 4. Employment Status

<table>
<thead>
<tr>
<th>Highest Occupation</th>
<th>Job Type (N = 50)</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional or highly skilled</td>
<td>Computer programmer (construction design); engineer (nuclear research)</td>
<td>2 (9)</td>
</tr>
<tr>
<td>Nonmanual skilled</td>
<td>Project manager; 2nd lead service; telecare; artist (self-employed)</td>
<td>7 (14)</td>
</tr>
<tr>
<td>Manual skilled</td>
<td>Executive work</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Part-time</td>
<td>Retail workers</td>
<td>2 (4)</td>
</tr>
<tr>
<td>Unskilled and untrained</td>
<td>Retail work (family firm); McDonald's; sales assistant; cleaning/caring in residential/custodial; factory assembly/packing</td>
<td>3 (6)</td>
</tr>
<tr>
<td>Ph.D. student/voluntary lobbying work</td>
<td>Basic industrial worker/degree &lt; 2; car/home/chauffeur shop &lt; 4</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Skilled/servant employment</td>
<td>Railway guard; kitchen/ gardening work</td>
<td>9 (18)</td>
</tr>
<tr>
<td>Never worked/long-term unemployed</td>
<td>33 (66)</td>
<td></td>
</tr>
</tbody>
</table>

Table 4. Social relationships

<table>
<thead>
<tr>
<th>Social relationship</th>
<th>Rating</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Close reciprocal relationships (e.g., sexual relationship/marriage)</td>
<td>4 (7)</td>
<td></td>
</tr>
<tr>
<td>Some reciprocal relationships but short duration and/or reduced sharing of activities</td>
<td>6 (10)</td>
<td></td>
</tr>
<tr>
<td>Only one very brief relationships, involving minimal sharing of activities</td>
<td>4 (7)</td>
<td></td>
</tr>
<tr>
<td>No reciprocal relationships lasting &gt;1 month or never had relationship</td>
<td>46 (77)</td>
<td></td>
</tr>
</tbody>
</table>
Social Outcomes in Mid- to Later Adulthood Among Individuals Diagnosed With Autism and Average Nonverbal IQ as Children

Howlin et al. 2013, JAACAP 2013

<table>
<thead>
<tr>
<th>Adult Outcome Rating*</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good / Very Good</td>
<td>18</td>
</tr>
<tr>
<td>Fair</td>
<td>23</td>
</tr>
<tr>
<td>Poor / Very Poor</td>
<td>59</td>
</tr>
</tbody>
</table>

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


Service Utilization (%)

<table>
<thead>
<tr>
<th>Service</th>
<th>Utilization (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Services*</td>
<td>39.1</td>
</tr>
<tr>
<td>Mental Health</td>
<td>35.0</td>
</tr>
<tr>
<td>Medical</td>
<td>23.5</td>
</tr>
<tr>
<td>Speech</td>
<td>9.1</td>
</tr>
<tr>
<td>Case Management</td>
<td>41.9</td>
</tr>
</tbody>
</table>

* 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

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

- 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

Social Participation Among Young Adults with an Autism Spectrum Disorder

Gaul I, Ormond · Paul T. Shattuck · Benjamin P. Cooper · Paul R. Sterling · Kristy A. Anderson

DOl 10.1007/s10803-015-2575-8

ORIGINAL PAPER
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

<table>
<thead>
<tr>
<th></th>
<th>ASD</th>
<th>ID</th>
<th>ED</th>
<th>LD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>54.7</td>
<td>72.3</td>
<td>64.5</td>
<td>66.8</td>
</tr>
<tr>
<td>Female</td>
<td>65.0</td>
<td>47.7</td>
<td>67.7</td>
<td>66.7</td>
</tr>
<tr>
<td>White</td>
<td>70.0</td>
<td>57.2</td>
<td>60.1</td>
<td>68.8</td>
</tr>
<tr>
<td>Non-white</td>
<td>29.0</td>
<td>42.8</td>
<td>39.9</td>
<td>31.2</td>
</tr>
<tr>
<td>Overall health</td>
<td>Excellent</td>
<td>27.9</td>
<td>20.9</td>
<td>23.9</td>
</tr>
<tr>
<td></td>
<td>Very good</td>
<td>37.3</td>
<td>29.6</td>
<td>25.0</td>
</tr>
<tr>
<td></td>
<td>Good</td>
<td>26.5</td>
<td>31.0</td>
<td>24.9</td>
</tr>
<tr>
<td></td>
<td>Fair/poor</td>
<td>8.3</td>
<td>18.6</td>
<td>26.2</td>
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<td>18.6</td>
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<th>LD</th>
</tr>
</thead>
</table>
| 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   | *     | 2.9   |

<table>
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<th>LD</th>
</tr>
</thead>
</table>
| Emotional skills scale
  - 4 (highest) | 19.8  | 24.0  | 44.8  | 52.3  |
  - 3      | 33.8  | 45.9  | 42.6  | 53.2  |
  - 2      | 29.5  | 21.3  | 12.0  | 15.4  |
  - 1 (Lowest) | 17.6  | 8.7   |      |      |

<table>
<thead>
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<th>LD</th>
</tr>
</thead>
</table>
| 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 | 82.9  | 79.3  | 46.6  | 48.4  |
  - Alone/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   |

<table>
<thead>
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<th>ASD</th>
<th>ID</th>
<th>ED</th>
<th>LD</th>
</tr>
</thead>
</table>
| How often sees friends
  - Never | 38.6  | 15.5** | 15.9*** | 7.5*** | 7.5*** |
  - < Weekly | 16.5  | 20.0  | 8.6*  | 10.7  | 10.7  |
  - About once / week | 16.9  | 12.6  | 13.7  | 14.4  | 14.4  |
  - Once per week | 28.8  | 47.9** | 61.6** | 67.8** | 67.8** |
| How often sees friends
  - Never | 47.2  | 16.5*** | 7.9*** | 4.4**  | 4.4**  |
  - < Monthly | 19.5  | 17.1  | 12.0  | 5.5**  | 5.5**  |
  - 1-3 / Month | 15.3  | 25.0** | 23.4  | 26.2** | 26.2** |
  - Once weekly | 18.0  | 41.4** | 57.2** | 63.8** | 63.8** |
| How often friends call
  - Never | 48.1  | 37.0** | 22.9*** | 10.5*** | 10.5*** |
| Socially isolated
  - *Never* to all | 28.1  | 8.9*** | 2.7*** | 2.0*** | 2.0*** |

---

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 day care.

---

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

### Employment and PSE* Status

<table>
<thead>
<tr>
<th>Status</th>
<th>N</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Never engaged in competitive employment or a degree-seeking PSE program at any point in the study</td>
<td>24 (32.9%)</td>
<td>Maladaptive &amp; atypical behaviors, but not IQ; differ from Groups 3 and 2; fathers: significantly lower educational attainment than fathers in Groups 3 and 2; mothers less depressed than Grps 3 and 2</td>
</tr>
<tr>
<td>2. Sometimes engaged 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</td>
<td>31 (42.5%)</td>
<td></td>
</tr>
<tr>
<td>3. Consistently engaged in competitive employment and/or a degree-seeking PSE program</td>
<td>18 (24.7%)</td>
<td>0/15 of the female subjects in this group; 18/18 males had fathers with some college</td>
</tr>
</tbody>
</table>

*PSE = Post Secondary Education

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

- 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

- 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

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 Tzu

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

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)

www.grasp.org
The Adult Services section of our website is divided into 7 sections:

- Housing and Community Living
- Autism and Employment
- Postsecondary Educational Opportunities
- Autism Speaks Adult Services Grants
- Advancing Futures for Adults with Autism
- Adults with Autism in the News
- Adults with Autism Resource Library

Informing & Educating your child with ASD

- Knowledge is Power
  Sir Francis Bacon

- Self-esteem, self-esteem, self-esteem
  Jim Coplan

Being an Asperger kid makes me a little different from other kids...

\[\frac{1}{2}\times\frac{1}{6}=\frac{1}{12}\]

...but it is also what makes me cool.

What it is to be Me
An Asperger Kid Book

Written by Angela Wine
Illustrations by David Cirpy

Different Like Me
My book of autism heroes

Jennifer Elder
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

- Getting help for yourself is the best way to help your child with ASD

DD Model Mental Health Model

Progression of Interventions (DD Model)

Adult Services for long-term “survivors” of childhood ASD
Well-behaved people seldom make history

- 1954: Brown vs. Board of Education
- 1964: Civil Rights Act
- 1975: PL 94-142 (Education for All Handicapped Act)
- 1990: Americans with Disabilities Act

What now?

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