Mental Health and Autism Spectrum Disorder: The Elephant in the Room

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Disclosures

- Dr. Coplan is author of Making Sense of Autistic Spectrum Disorders: Create the brightest future for your child with the best treatment options (Bantam-Dell, 2010), and receives royalties on its sale
- This presentation will include a discussion of off-label drug treatments

Outline

1) Statement of the Problem
   1) Compartmentalized Thinking
   2) “Us vs. Them”: What I learned from Newtown – part 1
2) Show me the data
   1) Intra-individual
   2) Intra-familial (with a glance at Family Mental Health)
   3) Basic Science
3) ASD, Mental Illness, and Violence
   1) What do the data show?
   2) Newtown Part 2
4) Where do we go from here?
   1) Individual & Family care
   2) System change

ASD and Mental Illness: The Myth

The History of Science in 1 Slide

Description & Classification*
(Group items into categories, based on externally visible characteristics)

Analysis
(Explain & predict, based on an understanding of why and how things happen)

* Plato (428-328 BCE): “Carve Nature at its joints.” We can't explain why or how things happen, but if we observe carefully and group similar items into categories, eventually the big picture will emerge.
Problems with classification schemes based on appearance

- Different underlying mechanisms can produce similar-appearing results
- Similar underlying mechanism can produce different-appearing results

Which 2 go together?

Psychiatry: Where we are today

**Description & Classification**
(based on externally visible characteristics)

**Analysis**
(based on an understanding of fundamental mechanisms)

**DSM5:**
Categories based on symptoms → quest for symptom homogeneity within categories

**DSM 6**
(classification based on causation and brain systems)

Keep sub-dividing until clinical uniformity within categories has been achieved.

Make Diagnoses
Mental Health in ASD: The elephant in the room

Comorbidity:

“A, B, C, etc. are completely different entities, that sometimes happen to co-exist.”

Comorbidity:

“As DSM would have it.....

Continuum:

“ASD and Mental Illness are different entities that sometimes co-exist”

Continuum:

“ASD shades into Mental Illness, with no ‘bright line’ of separation.”

Not Piet Mondrian, but Claude Monet...

Metamorphosis:

Over time, symptoms of ASD evolve into symptoms of Mental Illness.
In the world of Metamorphosis...
“Losing the diagnosis” does not mean “cured”

- Persistence of
  - Cognitive patterns
  - Behavioral patterns
  - Emotional patterns
- Emergence of Non-ASD psychiatric disorders
  - Anxiety
  - Depression
  - Mood Disorders
  - Schizophrenia

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Presentation in Childhood
ASD (Autism, PDD-NOS, AS)
- Social Impairment
- Communication Impairment
- Restricted, repetitive behaviors & interests

Extended Family
Broad Autism Phenotype
- Anxiety Disorders
- Obsessive-Compulsive Disorder
- Depression, Bipolar Disorder
- Alcoholism
- Schizophrenia

Non-ASD Psych D/O

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

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Outcome for children with High Functioning ASD

Adult Outcomes

- Social Impairment
- Communication Impairment
- Restricted, repetitive behaviors & interests

NLD, SPLD
Broad Autism Phenotype

- Anxiety Disorders
- Obsessive-Compulsive Disorder
- Depression, Bipolar Disorder
- Alcoholism
- Schizophrenia
Non-ASD Psych D/O

Psychiatry: Coming soon...

Description & Classification
(based on externally visible characteristics)

Analysis
(based on an understanding of fundamental mechanisms)

DSM5:
Categories based on symptoms → quest for symptom homogeneity within categories

DSM6
Classification based underlying biology; “Mapping ASD from the inside out”
(King & Lord 2011)

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Mental Health in ASD:
The elephant in the room

Core Features
Social
Language
Repetitive Behavior
Sensory/Motor

Outline
1) Statement of the Problem
2) Compartmentalized Thinking
4) ASD, Mental Illness, and Violence - Newton 2
5) Where do we go from here?

Autism Canada’s Statement On The Sandy Hook Elementary School Tragedy 12/17/2012

- It has been reported that the shooter at Sandy Hook Elementary School had autism. In the weeks and months to come there will be much more information about his condition, but today it has never been more important to understand that autism / Asperger's is not a mental health condition. Autism is a neurological condition, ...
ARI Statement on the Newtown, CT Tragedy

The staff at the Autism Research Institute is deeply saddened by yesterday’s tragic events at Sandy Hook Elementary School in Newtown, Connecticut...

Some public comments have drawn potentially inaccurate and stigmatizing conclusions about a link between the diagnosis [of autism] and a propensity for violence and lack of empathy...

**Autism is not a mental health disorder - it is a neurodevelopmental disorder...**

Autism Society of America Statement
12/17/2012

- No evidence exists to link autism and premeditated violence...
- Individuals with autism who act aggressively typically do so because they are reacting to a situation...
- Many of the individuals with Asperger’s syndrome who have committed crimes had co-existing psychiatric disorders...

We have a problem here... 
(3 problems, actually)

1. There is no bright line between Autism Spectrum D/O and “Psychiatric” disorders
2. Shifting responsibility onto persons with “mental illness”:
   - Stigmatizes the mentally ill, and
   - Ignores the mental health needs of persons with ASD

Outline

1) Statement of the Problem
2) Show me the data
   a) Intra-individual
   b) Intra-familial (with a glance at Family Mental Health)
   c) Basic Science
3) ASD, Mental Illness, and Violence
4) Where do we go from here?

(a) Intra-Individual

- When co-morbidity approaches 100%, is it still “co”- morbidity?
  - Or is it an integral part of the disorder itself?
Mental Health in ASD:
The elephant in the room

CEC-DADD
January 22-23, 2015

Children with ASDs, age 10+:
Neuropsychiatric co-morbidity

IAN Research Report #1 - May 2007
http://www.iancommunity.org/ca/ian_research_reports

Psychiatric Symptom Impairment in
Children with Autism Spectrum Disorders

- 115 pts w. ASD at University Hosp. Child Devel. Clinic
  - Age 6-12 yr; Male: 86 %; White: 91 %
  - MeanIQ: 85
    - >70: 91 (77 %)
    - <=70: 24 (23 %)
  - Spectrum Dx:
    - Autistic Disorder: 31 %
    - Asperger’s Disorder: 19 %
    - PDD-NOS: 50 %

- Child and Adolescent Symptom Inventory-4R
  - Parent & teacher ratings

Disorder Prevalence (%)* Impairment**
ADHD (any type) 83% 82%
Oppositional defiant disorder 53% 34%
Conduct disorder 23% 9%
Anxiety disorders 70% 47%
Generalized anxiety disorder 48% 32%
Social phobia 51% 23%
Major Depressive D/O, Dysthymia 45% 19%
Manic episode 53% 18%
Schizophrenia 48% 10%
Any disorder 84% 84%

* Combined Parent & Teacher ratings
** “Impairment” = Symptoms “Often or Very Often”

Psychiatric Symptom Impairment in
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Any disorder 84% 84%

Mood D/O in ASD:
Comorbidity or Continuum?

157 youth >15 y.o.
with BPD-I

ADOS
BPD-I only 110 (70%)
BPD + ASD 47 (30%)*

*Onset of BPD-I was significantly earlier in children with ASD


ASD, Psychosis, and Schizophrenia (SCZ)

Not “Red & Yellow,”
but “Orange.”
**Psychosis**

- Psychosis: A symptom of mental illness characterized by radical changes in personality, impaired functioning, and impaired reality testing (hallucinations / delusions).
- Psychosis may appear as a symptom of:
  - Mood d/o
  - Personality d/o
  - Schizophrenia
  - Schizophreniform d/o, Schizoaffective d/o, etc.
- Psychotic disorders (Brief psychotic d/o, psychotic d/o due to a general medical condition, substance-induced psychotic d/o, etc.)

**Schizophrenia**

- A chronic psychotic disorder (or a group of disorders) marked by severely impaired thinking, emotions, and behaviors.
- Symptoms:
  - (+): Hallucinations, delusions, disorganized speech (loose associations); inappropriate, odd, or catatonic behavior
  - (-): Apathy / avolition; anhedonia, poor social function, speech
  - Cognitive: Impairment of attention, memory, planning (executive function), insight

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**The association between early autistic traits and psychotic experiences in adolescence**


- Avon Longitudinal Study of Parents and Children (ALSPAC) birth cohort


Questions at age 7:
- Speech development
- How they got on with others (social interaction problems)
- Odd rituals or unusual habits that were hard to interrupt

Questions at age 12: Any of the following in past 6 mo?
- Hallucinations (visual, auditory)
- Delusions (being spied on, persecution, thoughts being read, reference, control, grandiose ability, other)
- Thought interference (thought broadcasting, insertion and withdrawal)
“Is Schizophrenia on the Autism Spectrum?”
King & Lord, 2011

- “Schizotypal Personality” is distinguished by “unusual preoccupations, unusual perceptual experiences, odd thinking and speech (e.g., overelaborate, or stereotyped), inappropriate or constricted affect, behavior or appearance that is odd, eccentric, or peculiar; lack of close friends or confidants other than first-degree relatives, and social anxiety…”

“Is Schizophrenia on the Autism Spectrum?”
King & Lord, 2011

- “What arguably distinguishes schizophrenia spectrum from autism spectrum in two individuals who otherwise share all of these symptoms is the presence of paranoid ideation…"

“Is Schizophrenia on the Autism Spectrum?”
King & Lord, 2011

- “Given the degree of overlap, one might reasonably ask if paranoid thinking could be a logical downstream consequence of a common underlying difficulty in the perception of social communication”

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

Central Coherence

- The ability to see the big picture
Joseph Jastrow, 1899

Q: What’s happening in this picture?

Virtual Borders

Gaetano Kanizsa, 1976

Q: What’s happening in this picture?


Q: What’s happening in this picture?

A: The boy is hoarding animals.


Q: What’s happening in this picture?

A: The kitten is on the boy’s back and is about to eat him.


Tom & Central Coherence

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?
Tom & Central Coherence

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: Clean!
A: I don’t know. We haven’t got to that part of the story yet.

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.”

Q: How does the boy feel?
Q: How does the boy feel?
A: “I don’t know, because I can’t see his mouth.”
Possible Relationship Between ASD and SCZ

How would your behavior change, if you suddenly lost Theory of Mind and Central Coherence?

Primary failure to develop ToM & CC
Loss of previously acquired ToM & CC

Autism Spectrum Disorder
Schizophrenia Spectrum Disorder

Birth
Adolescence

Possible Relationship Between ASD and SCZ

How would your behavior change, if you suddenly lost Theory of Mind and Central Coherence?

Primary failure to develop ToM & CC
Loss of previously acquired ToM & CC

Autism Spectrum Disorder
Schizophrenia Spectrum Disorder

Birth
Adolescence

Kanner, 1943

[T]here is a great deal of obsessiveness in the family background. The very detailed diaries and reports and the frequent remembrances, after several years, that the children had learned to recite twenty-five questions and answers of the Presbyterian Catechism, to sing thirty-seven nursery songs, or to discriminate between eighteen symphonies, furnish a telling illustration of parental obsessiveness.
Parents & Siblings of Children with ASDs: Issues of Attention and Mood (parent report survey)

IAN Research Report #1 - May 2007
http://www.iancommunity.org/cs/ian_research_reports

Anxiety, ASD

Generalized Anxiety D/O

ASD Anxiety D/O

R.D. MRN 07-0427

Anxiety

RD. 7 y.o. F, nl IQ, PDD-NOS & Anxiety. Father: GAD

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Anxiety

RD. 7 y.o. F, nl IQ, PDD-NOS & Anxiety. Father: GAD

www.drcoplan.com
Mental Health in ASD: The elephant in the room

**TS, Anxiety, ASD**

- Generalized Anxiety D/O
- Poor Eye Contact (not ASD)
- ASD with normal NV IQ
- Tourette Syndrome
- Anxiety

S.W.; MRN 08-0485

**Anxiety, Depression, ASD, Agitation**

- Anxiety / Agoraphobia
- Depression
- Suicidal Mentation
- ASD Anxiety Agitated behavior
- 27 mos
- 38 mos

MRN 12-0815
MRN 13-0876

**TS, Anxiety, Depression, Bipolar D/O, ASD, ADHD**

- Depression
- Bipolar D/O
- Generalized Anxiety D/O w. Panic Attacks
- ASD
- TS
- ADHD

AH, MRN 13-0887

**BPD, OCD, Anxiety, AS**

- Bipolar Disorder
- OCD
- Anxiety
- Asperger Syndrome
- Anxiety
- Speech Delay
- “Processing Disorder”

C.A.; MRN 12-0811

Severe mood problems in adolescents with autism spectrum disorder


- 91 adolescents w. ASD (M: 83)
- Methods:
  - IQ, Adaptive function, neuropsych measures
  - “Severe Mood Problems (SMP) Scale”
    - Explosive rage
    - Low mood
    - Depressive thoughts
    - Labile mood
  - Maternal self-report (GHQ)
    - maternal mood, anxiety and somatic difficulties

Results

- High SMP: 24 (26%)
  - Predictors of High SMP:
    - Emotional & behavioral problems at age 12
    - Autism severity (by parent report)
    - Maternal GHQ: “The current analyses suggest a specific relationship between maternal affective symptoms and SMP in offspring”
  - Not predictors:
    - Full Scale IQ
    - Adaptive function
Bullying Experiences Among Children and Youth with Autism Spectrum Disorders.
Cappadocia, M.C., J.A. Weiss, and D. Pepler, JADD, 2011

Subjects
- 192 children / young adults w. ASD age 5–21
  - HFA (14%)
  - AS (54%)
  - PDD-NOS (13%)
  - Autism (19%)

Results
- Bullied (physical, verbal, social, cyber) within the past month: 77%
  - 1 time: 11%; 2-3 times: 23%; ≥ 4 times: 43%

Risk factors for being bullied \( \rho^* \)

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>( \rho^* )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child - Gender</td>
<td>NS</td>
</tr>
<tr>
<td>Child - Age (being younger)</td>
<td>&lt; .05</td>
</tr>
<tr>
<td>Child - Social skills deficit</td>
<td>NS</td>
</tr>
<tr>
<td>Child - Communication difficulties</td>
<td>&lt; .05</td>
</tr>
<tr>
<td>Child - Internalizing mental health problems</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>Child - Externalizing mental health problems</td>
<td>NS</td>
</tr>
<tr>
<td>Parent - Mental health problems</td>
<td>&lt; .01</td>
</tr>
<tr>
<td>Child - Fewer friends at school</td>
<td>&lt; .05</td>
</tr>
</tbody>
</table>

*NS = Not statistically significant. Smaller \( \rho \) = less likely to occur by chance.

The Real Elephant in the Room

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

Family Mental Health
(“We give our children roots and wings” — Hodding Carter)

Family Mental Health is a key ingredient in outcome for all children, but especially for the child with developmental disability, who is less able to work around obstacles arising from family dysfunction than a child with normal development.

Signs of Family Mental Health
- Cognitive, Emotional, and Tactical Flexibility
  - Shifting alliances (adults vs. kids, “boys vs. girls,” etc.)
  - Shifting roles (role of “hero” or “in the doghouse”)
  - Shifting solutions (one size does not fit all; “equitable” vs. “equal”)
  - Shifting combinations for activities. All legitimate combinations should come up once in a while.
- Sense of humor / playfulness / resilience

Danger Signs
- Inflexibility
  - Fixed roles
  - Fixed solutions
- Hypervigilance
  - Lack of trust in care providers
- Social Isolation
  - “Circle the wagons”
  - “Nobody helps us!”
Vignette #1

• “Obedience is very important to me.”
  – Father of 10 y.o. boy with ASD
  • Fa: Untreated anxiety d/o
  • Keeps unsecured firearms in the home
  • Describes son with ASD as “a predator,” because “everything is all about him”

Vignette #2

• “Nobody helps us.”
  – Mother of 14 y.o. boy with ASD
  • Mo.: Untreated Anxiety D/O
  • Family has no social supports
  • Child is on homebound instruction
  • Spends hrs/day playing violent video games
  • Threatens to “kill” the examiner during evaluation when E. interrupts game play

Family Function: Resources

• The American Association of Marriage and Family Therapy
  – http://www.aamft.org/iMIS15/AAMFT/
• The Bowen Center
  – http://www.thebowencenter.org/

(c) - Basic Science

• ADHD
• ASD
• Bipolar D/O (BPD)
• Generalized Anxiety Disorder (GAD)
• Major Depressive D/O (MDD)
• Schizophrenia (SCZ)

Genetic relationship between five psychiatric disorders estimated from genome-wide SNPs

Cross Disorder Group of the Psychiatric Genomics Consortium

Genetic relationship between five psychiatric disorders estimated from genome-wide SNPs

Fig. 1. Evidence for genome-wide pleiotropy between psychiatric d/o.

Two more terms

• Pleiotropy: Similar genetic mechanisms ➤ Different-appearing outcomes
• Phenocopy: Different genetic mechanisms ➤ Similar-appearing outcomes
Revisiting the Relationship Between Autism and Schizophrenia: Toward an Integrated Neurobiology
deLacy N. & King, B

“There appears to be no question that a phenotypic continuum links the schizophrenia and autism spectra; moreover, it incorporates neuropsychiatric deficits associated with all of the classic neurodevelopmental disorders [ID...DD... ASD...ADHD, and SCZ]. Affected persons display some subset of symptoms from this neurodevelopmental superset, in individually varying phenotypes likely molded by pleiotropy, different types of genetic defects, and epigenetic mechanisms.... [I]n “idiopathic” ASD and SCZ, an underlying genomic continuum has also been uncovered.”
Outline

1) Statement of the Problem
2) Show me the data
3) ASD, Mental Illness, and Violence
   1) What do the data show?
   2) Newtown – Part 2
   4) Where do we go from here?

Woodbury-Smith 2014

- “There are...no epidemiological community studies of unlawful behavior in ASD
- Small sample size and bias in ascertainment...limit the extent to which [the available] data can be... extrapolated to the wider ... ASD population
- Nonetheless, these data do suggest that small numbers of adults with ASD may be predisposed to violent unlawful behavior.”

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

Everyone is at some risk for committing crime

<table>
<thead>
<tr>
<th>RISK OF OFFENDING</th>
<th>No. of Individuals</th>
</tr>
</thead>
<tbody>
<tr>
<td>LOW</td>
<td></td>
</tr>
<tr>
<td>HIGH</td>
<td></td>
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</tbody>
</table>

Relative Risk

<table>
<thead>
<tr>
<th>VIOLENT CRIME?</th>
<th>ASD?</th>
<th>YES</th>
<th>NO</th>
<th>Risk of violence</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td></td>
<td>A</td>
<td>B</td>
<td>A / (A + B)</td>
</tr>
<tr>
<td>NO</td>
<td>C</td>
<td>D</td>
<td></td>
<td>C / (C + D)</td>
</tr>
</tbody>
</table>

“ASD-Yes” needs to be big enough to capture some children who commit crime. For example: If crime rate = 1%, we need at least 100 children with ASD to be reasonably sure of capturing at least one who commits crime (ignoring sampling error): A=1, B=99. If we assume a prevalence of ASD of 1 in 48, then (C+D) = 4,700 (Total sample size: 4,800)
**Case Control Studies**

Start with individuals who have already committed crime.

<table>
<thead>
<tr>
<th>VIOLENT CRIME?</th>
<th>ASD?</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>YES</td>
<td>A</td>
<td>B</td>
</tr>
<tr>
<td>NO</td>
<td>C</td>
<td>D</td>
</tr>
</tbody>
</table>

**ODDS of having ASD**

- (A/C): Odds that offender has ASD
- (b/d): Odds that non-offender has ASD
- Odds Ratio: (A/C) / (b/d) = ODDS RATIO

-Odds Ratio: “Convenience Samples”
- Clinical
- Criminal Justice

“Controls”: Drawn from non-criminal population (but not all of B and D)

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**Asperger’s syndrome in forensic settings**

Murrie DC, Warren JI, and Kristiansson M

Int J Forensic Ment Health 1:59–70, 2002

**Common Themes**

- **Deficient Empathy:** Each of the four men charged with a sex offense, as well as the man who attempted murder, seemed genuinely unaware of the harm they caused their victims. Likewise, the arsonist appeared untroubled that he destroyed property belonging to strangers, rather than to those against whom he sought revenge.

- **Interpersonal Naïveté:** A naïve and often impoverished understanding of human relationships... leaves AS patients vulnerable to mistreatment by others (and) may lead them to seek interpersonal contact in misguided ways.

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**Identifying Individuals with Autism in a State Facility for Adolescents Adjudicated as Sexual Offenders: A Pilot Study**

Sutton et. Al. Focus on Autism and Other Developmental Disabilities v 28 (3) 9/2013

State facility for adjudicated youth sex offender program

N = 46

Refusals

N = 3

Released prior to completion of study

N = 6

Participants

N = 37

Mean age 17 yr (range 14-20)

22/37 (59%): (+) on ASDS and DSM-IV-TR for Autism or AS

**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….

Lorna Wing
7 October 1928 – 6 June 2014

“Asperger Syndrome” - 1981

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

Social Deficit:
- Theory of Mind,
- Egocentricity

Cognitive Rigidity

Social Deficit:
- *No awareness of, or intent to do harm

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Social Skills Deficit + Cognitive Rigidity

“With his teachers, L. is defiant, argumentative and refuses to complete tasks. He manipulates all situations and has much difficulty with the teacher/pupil hierarchy. He is very comfortable telling adults what to do and why... He has great difficulty seeing the consequences of his actions and views punishment or consequences as personal attacks....”

9 y.o. boy with superior IQ & AS
MRN 10-0660

Gary McKinnon is a Scottish systems administrator and hacker who was accused in 2002 of perpetrating the “biggest military computer hack of all time,” although McKinnon himself – who has a diagnosis of Asperger’s Syndrome – states that he was merely looking for evidence of free energy suppression and a cover-up of UFO activity and other technologies potentially useful to the public.

On 16 October 2012, after a series of legal proceedings in Britain, Home Secretary Theresa May withdrew her extradition order to the United States.

http://en.wikipedia.org/wiki/Gary_McKinnon

Proposed Pathways from Core Features of ASD to Offending

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http://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(14)70248-2/fulltext
25 June 2014

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

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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/PIIS2215-0366614/00248-2/fulltext
Results (98% response rate):
- Suicidal ideation: 66%
- Plans or attempts at suicide: 35%
- Depression: 31%
- Adults with AS were ~10x more likely to report lifetime experience of suicidal ideation than individuals from the general UK population (OR 9.6, p<0.0001), people with 1, 2, or more medical illnesses (p<0.0001), or people with psychotic illness (p=0.019)

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

Proposed Pathways from Core Features of ASD to Offending

Social Deficit: Theory of Mind, Egocentricity
- Social Rejection (real or perceived)
  - Internalizing Behavior: Anxiety, Depression
  - "Cry for help:", Suicidal ideation

Special Interests ← Cognitive Rigidity
- "Innocent" offending:
  - Theft, Stalking, Experimentation
  - Sexual assault, Arson?

"Cry for help": Suicidal ideation

*No awareness of, or intent to do harm

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Statutory Obligations and Authority of the Child Fatality Review Panel and the CT Office of the Child Advocate

CFRP "shall review the circumstance of the death of a child placed in out-of-home care or whose death was due to unexpected or unexplained causes to facilitate development of prevention strategies to address identified trends and patterns of risk and to improve coordination of services for children and families in the state."

Records Reviewed

- AL:
  - Medical Records
  - Educational record
  - Emails, On-line materials (AL)
  - Police Interviews & evidence
- Mrs. L:
  - Medical records (partial)
  - Emails (partial)
- Invited interviews
  - Mr. L
  - Former classmates, School personnel, Healthcare providers

Mental Health in ASD:
The elephant in the room

Statutory Obligations and Authority of the Child Fatality Review Panel and the CT Office of the Child Advocate

Some information contained in this report may typically be considered confidential. OCA has deep respect for the laws and practice of confidentiality, but pursuant to Connecticut General Statute Sec. 46a-13k et seq., OCA has the authority to disclose confidential information where the interest of a child or the public is affected.

Adam Lanza

- 0-3: Extremely active, poor sleeper, avoided touch, delayed speech; invented own language
- EI Eval (~32 mo): “Fell well below expectations in social-personal development”
- Neurodevelopmental Eval (age 5)
  - Rituals; odd repetitive behavior
  - Sensory aversions (touch, texture)
  - SIB, Tantrums
- Danbury Hosp. (age 13); Yale Child Study Ctr (age 14): PDD-NOS, OCD, Anorexia
- Progressive social isolation

Mrs. Lanza

- “Frequently preoccupied with what she felt were her potentially serious and possibly terminal health issues” (Immune d/o; MS; normal exam & autopsy)
  - Refused psychiatric treatment for herself
- Authors cannot conclude what may have been at the root of Mrs. Lanza’s real or imagined health conditions…..A review of Mrs. Lanza’s correspondence however…paints a picture of a woman who seemed preoccupied with anxieties, either about AL or herself. This is a dynamic that continues to be seen as AL moves through adolescence

Mrs. Lanza

- “A pattern of attempts to bend or manage the environment for AL”
  - “I would like his emphasis to be on learning rather than coping”
- Rejects medical advice for medication and appropriate psychotherapy and academic placement for AL
- “A dynamic of mutual dependency” between Mrs. L and AL, accompanied by progressive isolation of AL from outside contact (school, Mr. L)

Care that did not follow best practices

- Primary Care
  - No f/u of weight loss
  - No f/u of OCD
- Psychiatric Care
  - Community psychiatrist: facilitated mother’s agenda rather than treating AL
- Educational services
  - Did not evaluate in timely or complete manner
  - Did not address Mental Health / Social issues
**Mental Health in ASD:**

The elephant in the room

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**Outline**

1) Statement of the Problem
2) Show me the data
3) ASD, Mental Illness, and Violence
4) Where do we go from here?
   1) Individual & family care
   2) Systems Change

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**Individual Care**

- Not “Co-Morbidity,” but Continuum and Metamorphosis
- “Losing the diagnosis” does not = “cure”
- Shift from Developmental Disability model to Mental Health model
- Need for adult services

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**Progression of Interventions (DD Model)**

Coplan, J. Making Sense of Autistic Spectrum Disorders
Random House, 2010

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**Adult Services for long-term “survivors” of childhood ASD**

© James Coplan, MD
www.drcoplan.com

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“Siloed Service Systems”

- Primary Care Pediatrician
- Yale Child Study Center
- Public Schools
Mental Health in ASD: The elephant in the room

Cognitive Rigidity
- Difficulty changing mental sets
- Routines
- Transitions
- Repetitious behaviors
- Perfectionism

Anxiety
- GAD
- OCD/TS
- Phobias
- Selective Mutism
- Depression
- Mood
- Substance Abuse
- Reality Testing

Family Care
• Recognize that ascertaining a child with ASD means strong possibility that one or both parents have Mental Health issues and/or family dysfunction that need to be addressed
  – This may be the single biggest element of the problem available for intervention
  – Addressing this issue will take a lot of people out of their comfort zone

School-Based MH Services
• Proactively monitor student mental health
  – Don’t wait for academic failure or disruptive behavior
  – Positive Behavior Support for Internalizing Behavior
  – Embed MH services within schools?

Systems Change
• ASD community needs to make common cause with MH community in advocating for child and adult MH services
  – Distinction between ASD and “psychiatric disorder” not scientifically tenable
  – Not financially viable
  – Not in the best interests of persons with ASD
• Barriers
  – Hard to shift mental sets
  – Fear, Stigma
  – Institutional inertia / turf

Comprehensive Care

The Child
- Physical health
- Mental Health
- Neurodev. Dx

The Family
- Physical & Mental health
- Family Health

The System
- Education
- Medical
- Mental health
- Legal

Thank you