Long-Term Outcome

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Outline

Long-Term Outcome 2:45-4:15
• ASD as one phase in a continually evolving, lifelong neurological syndrome
• Shift from DD to Mental Health paradigm
• Family function / dysfunction: The elephant in the room
• Proposed care model

Summary / Open Q&A; 4:15 - 5:00

Transition to Middle School

“Friendship is getting more complex and he is falling further behind his peers... We think he may be lonely.”

Parent of a 10 y.o. boy with ASD and normal IQ

Over time, the ice melts...

• Atypical behaviors improve over time

Transition to Middle School

Now that he’s 10, he’s less cute. It was cute when he was 5; not when he’s 10.
Our son turned 13 last year. We are noticing that...the world interacts very differently to an autistic child vs. an autistic man.

Sometimes he is so average. Sometimes he is so autistic.

Mother of a 16 y.o. boy with ASD and uneven cognitive development

"Losing the Diagnosis" does not equal "Cured"

Atypicality
- Social:
  - Theory of Mind
- Language:
  - Pragmatics
  - Proody
- Cognitive
  - Central Coherence
- Sensory/Motor:
  - Aversions / Attractions
  - Clumsiness

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

Anxiety
- Generalized Anx. D/O
- OCD
- Depression
- Bipolar D/O

AD Model Mental Health Model

Progression of Interventions

IQ

Vocational Support
Educational Support
Community Living Skills
Mental Health Services
Caregiver Support

DD Model Mental Health Model

Adult outcome

- "Losing the diagnosis" does not mean "cured"
- Persistence of
  - Cognitive patterns
  - Behavioral patterns
  - Emotional patterns
- Symptoms ⇒ Quirks ⇒ Traits
- Non-ASD neuropsychiatric disorders
Mental Health in ASD.....

the elephant in the room

ASD and Mental Illness: Reality

ASD

Mental
Illness

ASD and Mental Illness: The Myth

ASD

Mental
Illness

Piet Mondrian (1872-1944) – Line over Form

Claude Monet (1840-1926) – Water Lilies
Core Features
Social
Language
Repetitive Behavior
Sensory/Motor

Dysregulation of Arousal
Hypactivity = Agitation

Anxiety D/O

Unipolar Depression

OCD

Core Features
Social
Language
Repetitive Behavior
Sensory/Motor

Dysregulation of Arousal
Hypactivity = Agitation

Mood Disorders
(Bipolar D/O)
Core Features
Social
Language
Repetitive Behavior
Sensory/Motor

Adults with ASD – Online Survey

Adults with ASD – Online Survey

It’s a family affair...

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

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Neuropsychiatric Co-Morbidity

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

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http://www.iancommunity.org/cs/ian_research_reports
TS, Anxiety, Depression, Bipolar D/O, ASD, ADHD

Parents of Children with ASDs: Depression or Bipolar D/O

Parents & Siblings of Children with ASDs: Issues of Attention and Mood
(self-report survey)

Epidemiologic Evidence

- ADHD
- Anxiety
- ASD
- Bipolar D/O
- Schizophrenia
Comorbidity Clusters in Autism Spectrum Disorders: An Electronic Health Record Time-Series Analysis
Doshi-Velez et al, Pediatrics, Volume 133, Number 1, January 2014

• Electronic health record review
• 4,934 children (78% boys), at least 15 years old
• Empirically observed clusters:
  – 1: Seizures: N=120
  – 2: Multisystem (GI, ENT, other): N=197
  – 3: Psychiatric D/O: N=212
  – 4: No associated morbidity: N=4316

“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…”
• c/w Wing’s “Active but odd” ASD phenotype

Examining the comorbidity of bipolar disorder and autism spectrum disorders: a large controlled analysis of phenotypic and familial correlates in a referred population of youth with bipolar I disorder with and without autism spectrum disorders.

• Subjects & Methods:
  • Secondary analysis of data from a family study of youth with Bipolar I D/O (probands = 157, relatives = 487)
• Results
  • 30% (47/155) of Bipolar I probands met criteria for ASD
  • Onset of Bipolar I occurred earlier in the presence of ASD (4.7±2.9 y vs 6.3±3.7 y; p=.01)
Laboratory Evidence

- ADHD
- Anxiety
- ASD
- Bipolar D/O
- Schizophrenia

ASD & Schizophrenia: Epidemiology

- Prevalence
  - ASD ~ 1/100
  - SCZ ~ 1/100 (lifetime risk)
- Joint occurrence of ASD and SCZ
  - Predicted (if independent): 1/10,000
  - Observed (small samples, ascertainment bias):
    - Outcome studies, children w. ASD: How many develop SCZ?
      - Howlin 2004 (N=68; none developed SCZ; underpowered)
    - Childhood Onset Psychosis: 50% had prior PDD
      - Rapport et al 2009, Unenge & Helenb6ck 2012
    - Adults with ASD: 7-35% meet criteria for SCZ
      - Howlin 2000, Stahlberg 2004; Mouridsen 2008a, b
    - Adults with SCZ: Unknown how many meet criteria for ASD

Refs: King & Lord 2011; deLacy & King 2013

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

Cross-Disorder Group of the Psychiatric Genomics Consortium


Pleiotropy: One gene affects multiple phenotypic traits

Developmental brain dysfunction: revival and expansion of old concepts based on new genetic evidence

Morena De Luca et al., 2013

Network Topologies and Convergent Aetiologies Arising from Deletions and Duplications Observed in Individuals with Autism


The Real Elephant in the Room

Child w. ASD + Parent with 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.

Frequency in clinical cohorts* | Intellectual disability or developmental delay | Autism spectrum disorder | Schizophrenia | Epilepsy
--- | --- | --- | --- | ---
22q11.2 | 1 in 167 | ✓ | ✓ | ✓ | ✓
16p11.2 | 1 in 241 | ✓ | ✓ | ✓ | ✓
3q21.3 | 1 in 309 | ✓ | ✓ | ✓ | ✓
15q23-q43.3 | 1 in 358 | ✓ | ✓ | ✓ | ✓
7q11.2 | 1 in 415 | ✓ | ✓ | ✓ | ✓
5q11.2-q13 | 1 in 553 | ✓ | ✓ | ✓ | ✓
2p15.3-q11 | 1 in 709 | ✓ | ✓ | ✓ | ✓
16p11.31 | 1 in 788 | ✓ | ✓ | ✓ | ✓
17p12 | 1 in 985 | ✓ | ✓ | ✓ | ✓
1p11.2 | 1 in 985 | ✓ | ✓ | ✓ | ✓
9q34.1 | 1 in 1854 | ✓ | ✓ | ✓ | ✓
5a25 | 1 in 2707 | ✓ | ✓ | ✓ | ✓
3p20 | 1 in 2291 | ✓ | ✓ | ✓ | ✓

Table 1: Variable expressivity in selected microdeletion syndromes

Morena De Luca et al., 2013
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

Vignette #1

• “Obedience is very important to me.”
  – Father of 10 y.o. boy with ASD
  – Father has untreated anxiety d/o
  – Works in law enforcement
  – Keeps unsecured firearms in the home
  – Perceives his son with ASD as “a predator,” because “everything is all about him”

Individual Mental Health as a contributor to family mental health

• Parents of children with ASD:
  – High frequency of neuropsychiatric disorders (esp. anxiety, depression)
  – Decreased Theory of Mind skills
  – Limits adult’s ability to respond in a flexible manner to the extraordinary demands from child w. ASD

Anxiety, OCD, ASD

Danger Signs

• Inflexibility
  – Fixed roles
  – Fixed solutions

• Hypervigilance
  – Lack of trust in care providers

• Social Isolation
  – “Circle the wagons” mentality
  – “Nobody helps us!”

Vignette #2

• “Nobody helps us.”
  – Mother of 14 y.o. boy with ASD
  – Mother has untreated Anxiety D/O
  – Family has no social supports
  – Child is on homebound instruction
  – Spends hours / day watching violent video games
  – Threatens to “kill” the examiner during home visit
Does ASD predispose to violent crime?

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…

• ASD and MH are not mutually exclusive, separable entities
• Shifting responsibility onto “Mental Health Disorders”:
  1. Stigmatizes the MH population, and
  2. Ignores the MH needs of the ASD population

Emerging Perspectives on Adolescents and Young Adults With High-Functioning Autism Spectrum Disorders, Violence, and Criminal Law
Lerner, M et al; J. Am Acad of Psychiatry and the Law Online, 4/2012

• “Link between ASD and violent crime is inconclusive and is supported by only 11 of 147 studies on the subject

• A recent small-sample study indicated a reduced incidence of law breaking among individuals with high-functioning ASD, but…an increased history of violent behavior and criminal damage… In other words, while the overall rate of criminal behavior diminished, violent behavior and damage associated with this behavior increased…
Case Series of adult males referred for forensic evaluation

Charges:
- Arson (1)
- Sexual assault (4)
- Attempted murder (1)

Asperger’s syndrome in forensic settings
Murrie DC, Warren JI, and Kristiansson M
Int J Forensic Ment Health 1:59–70, 2002

Case History
AB: 31 y.o. male, arrested for arson
Referred for forensic psychiatric evaluation after 11 episodes
No prior criminal history or clinical diagnosis

His parents described a developmental history in which he was generally shy and quiet and considered “peculiar” by teachers. In school, he had some concentration difficulties due to being extremely careful about details. His parents described a series of special interests, to which AB devoted extensive research time....His parents also described a strict adherence to routines. For example, they described meals as “ceremonies” in which every part was to be performed in a certain order. When his parents tried to make changes in his routines, AB became very irritated....

Asperger’s syndrome in forensic settings
Murrie DC, Warren JI, and Kristiansson M
Int J Forensic Ment Health 1:59–70, 2002

According to his parents, about one year before the crimes AB became increasingly irritable and verbally aggressive. During this time, he tended to isolate himself more often, to purchase numerous pornographic magazines, and to ruminate about episodes during his childhood in which he believed schoolmates mistreated him.

During evaluation, AB described the year prior to his offense as a period in which he became increasingly preoccupied with those who had wronged him and increasingly convinced that he needed to avenge himself. He reportedly considered burglary for revenge, but later began to fantasize about firesetting. When AB saw an arson report on the news, he decided that firesetting was the best way to solve his problems.

AB was referred for forensic evaluation after he was charged with 11 cases of arson. For two months, he broke into summer homes in his neighborhood, dousing them with gasoline and setting them ablaze.

When apprehended by police, he immediately confessed to the crimes and explained that they were a means of revenge against schoolmates who had harassed him during his youth. Investigation revealed that there was actually no relationship between the summer homes and the schoolmates, but AB described small details of the houses that had reminded him of peers who had harassed him. He reported feeling satisfied and calm after the fires.

CD, a 27 year-old male, was referred for evaluation after a sexual offense involving a teenage male. At the time of the evaluation CD carried an Asperger’s diagnosis based on adult functioning and early history. In kindergarten, for example, he was described as “oblivious to everyone around him.” Mental health records from his adulthood also noted his marked social impairments and deficits in nonverbal communication. CD graduated high school with a mediocre academic record, and worked for several years as a fast-food worker with limited customer contact.

Although he was intensely preoccupied with having intercourse, his efforts to find partners tended to be rather passive and naive. CD summarized his courtship strategy as “hanging around” a woman “until sex happened.”
Unfortunately, his attempts at sexual contact—both those that resulted in intercourse and those that did not—tended to result in CD being used or exploited by others. For example, he repeatedly took women from his housing project shopping for lingerie, thinking that doing so could be a prelude to sexual contact, but the women would leave after he made the purchase...He also related stories of attempts to make sexual contact that resulted in women stealing possessions or money from him, and in one instance, beating him severely.

His first contact with the legal system and our subsequent evaluation occurred after CD had repeated sexual contact with a 15-year-old male over a period of several days. CD met the young man, who reportedly had no place to stay at the time, in their apartment complex laundromat and the two subsequently went to CD's home. Over the ensuing days, CD bought the young man a variety of presents, gave him money, and had an active sexual relationship with him.

The contact ended when CD was no longer willing to give the youth money. The youth left CD's home, taking his stereo. When CD went to the police station to report this theft, he was subsequently arrested for sexual assault against a minor.

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.
### Research Objectives:

- To compare childhood arrestees with matched comparison groups on levels of autistic symptoms
- To assess the predictive value of autistic symptoms for future delinquent behavior

- **Children's Social Behavior Questionnaire (CSBQ)**
- **Observed Antisocial Behavior Questionnaire**
- **Diagnostic Interview Schedule for Children (DISC)**

### Community Sample:

- 422 children detained or arrested for the first time <12
- Refusals 117

### Participants

- 24 m F/U
- N = 235
- Males: 87%
- Mean IQ: 88

### Controls:

- Normal children
- Children with ASD

### Results:

- Indicators of atypicality:
  - ASD > Arrestees > Normals, p < 0.01
- For Arrestees:
  - CBSQ score predicted future delinquent behavior (p < 0.001, even after adjusting for externalizing behavior)

### Conclusions:

- Childhood arrestees... have more autistic symptoms than children from the general population, and less than autistic individuals
- Among the arrestees, autistic symptoms were uniquely positively associated with future delinquent behavior
- Although mediated by co-occurring externalizing disorders, autistic symptoms predicted delinquent behavior over and above externalizing disorders

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<th>Community Sample: 422 children detained or arrested for the first time &lt;12</th>
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[LA Fitness Center Shooting In Pennsylvania Leaves 4 Dead](http://autismgadfly.blogspot.com/2009/08/will-neurodiversity-diagnose-george.html)

August 5, 2009

Will neurodiversity diagnose George Sodini with autism?

Last night...a man entered a gym in the vicinity of Pittsburgh Pennsylvania. He walked into a room where a "Latin impact" aerobics class was being held. He turned out the lights and drew a gun out of his gym bag. He started shooting, killing three women and then killing himself....
“..... Apparently, the man was frustrated by the fact that he was 48 years old and had not had a girlfriend for a long time. In fact he kept a detailed online diary describing his frustrations and his plan to go out and kill some women at some point; apparently revenge for being rejected so much. Looking at the diary we see his occupation was a software designer, a job that Simon Baron-Cohen, Temple Grandin and others have claimed requires autistic traits....”

Sodini had written: ‘The biggest problem of all is not having relationships or friends, but not being able to achieve and acquire what I desire in those or many other areas....Everything stays the same regardless of the effort I put in....”

Sound familiar? Well, this is someone with computer skills and social impairments who was frustrated by celibacy. Perhaps neurodiversity could diagnose him with autism as they have diagnosed Bill Gates....”

“....Of course, most persons who suffer from loneliness regardless of whether or not they are autistic will not go out on a shooting spree, but it is frustrating. This man was clearly deranged. He may or may not have had an autism spectrum disorder, but I feel in order to be fair neurodiversity should take the bad with the good. If they are going to preach about what a gift autism is and say that Bill Gates, Stephen Spielberg, Einstein, Jefferson, etc. prove that autism is such a gift because these individuals have or had it, why not say that Sodini may have been autistic also.”

**What you can do**

**NASP: School-based Mental Health Services**

- “Mental health is directly related to children’s learning and development. It encompasses or intersects with interpersonal relationships, social-emotional skills, behavior, learning, academic motivation, certain disabilities, mental illness (e.g., depression or bipolar disorder), crisis prevention and response, school safety and substance abuse. Each of these issues affects not only the success and well-being of the individual student but also the school climate and outcomes for all students.

- “School-Based Health Clinics” where students and their families can come to the school for all medical, social-emotional, and/or behavioral health services.

The Student is your charge, but often the unit of treatment is the family
• Assess mental health of all players
• Assess relationships between / among the players (“family systems approach”)
• The child’s parents & siblings will be involved with this child long after you have left the stage.

Summary
• ASD in a child is a red flag for developmental and/or mental health disorders in parents / siblings
• Optimal outcome for the child with a disability depends upon addressing the parents’ mental health issues, as well as the child’s developmental and mental health needs

Summary
• ASD has a natural history for improvement over time, insofar as visibly atypical features are concerned
• Cognitive & behavioral patterns persist
• Mental Illness is not “a separate problem.” Rather, impaired MH is another expression of shared neurobiology
• Over time, mental health issues present a progressively greater challenge, that may supersede the ASD

Summary
• To be successful, intervention needs to be multimodal and family-centered
  – Mental health intervention
    • Child: Self-awareness, self-esteem, self-regulation
    • Parents: Address their own MH issues
    • Family: Take a family-system approach
      – Flexibility / Resilience within the family structure
      – Siblings are at high risk for genetically based morbidity, and/or collateral damage bec/o family system dysfunction
  • Educational / Vocational services
  • Psychotropic Medication - often

Summary
• Need for Adult Services
  – Clinics for “Long-Term Survivors of Childhood ASD” patterned after Long-Term Survivors of Childhood Cancer
    • Mental Health
    • Job coaching
    • Social contact
    • Family / Caregiver support (parents, partners)
    • Developmental screening of offspring

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Summary

- Need for Better Research
  - Prevalence of ASD in adults?
  - Psychiatric Comorbidity
  - Obstacles
    - Privacy issues
      - “Informative censoring”
    - Cross-Disciplinary collaboration
      - Child / Adult
      - DD / Mental Health
    - Long-term funding

Resources

- Married with Special Needs Children; A couples’ guide to keeping connected. Marshak LE and Prezant, FP. Woodbine, 2007
- Voices from the spectrum. Parents, grandparents, siblings, people with autism, and professionals share their wisdom. Ariel, CN and Naseef, R (eds). Jessica Kingsley, 2006
- The American Association of Marriage and Family Therapy http://www.aamft.org/MIS15/AAMFT/
- The Bowen Center: http://www.thebowencenter.org/