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

Over time, the ice melts...

- Atypical behaviors improve over time

...But society is raising the bar.

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

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

Adult outcomes for children who “lose the diagnosis”
(Coplan, J. Making Sense of Autistic Spectrum Disorders, fig 5.8)

Adult outcome

• “Losing the diagnosis” does not mean “cured”
• Persistence of
  – Cognitive patterns
  – Behavioral patterns
  – Emotional patterns
• Symptoms ⇒ Quirks ⇒ Traits
• Non-ASD neuropsychiatric disorders

“Losing the Diagnosis” does not equal “Cured”
Mental Health in ASD.....

The elephant in the room

ASD and Mental Illness: The Myth

ASD

Mental Illness

ASD and Mental Illness: Reality

ASD

Mental Illness

Piet Mondrian (1872-1944) – Line over Form

Claude Monet (1841-1926) – Water Lilies
Core Features
- Social
- Language
- Repetitive Behavior
- Sensory/Motor

Cognitive Rigidity
- Insistence on sameness
- Perfectionism

Dysregulation of Arousal
- Hypoactivity → Agitation

Organization of Attention
- Sensory Processing

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

Adults with ASD – Online Survey

It’s a family affair…
**TS, Anxiety, Depression, Bipolar D/O, ASD, ADHD**

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

**Parents & Siblings of Children with ASDs:**

- Issues of Attention and Mood (self-report survey)

- ADD/ADHD
- Anxiety
- Depression
- Bipolar D/O

**Epidemiologic Evidence**

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

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

IAN Research Report #7 - October 2008: Parental Depression History
http://www.iancommunity.org/cs/ian_research_reports/ian_research_report_oct_2008

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http://www.iancommunity.org/cs/ian_research_reports/ian_research_report_oct_2008
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

Prevalence of associated diagnoses in subgroup 3, over the first 15 years of life.

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)

“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

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

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=40; none developed SCZ; underpowered)
      - Childhood Onset Psychosis: 50% had prior PDD
    - 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

Laboratory Evidence

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

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

**Cross-Disorder Group of the Psychiatric Genomics Consortium**


Figure 1: Evidence for genome-wide pleiotropy between psychiatric disorders.

Pleiotropy: One gene affects multiple phenotypic traits

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


PLOS Genetics, June 6 2013

http://www.plosgenetics.org/article/info%3Adoi%2F10.1371%2Fjournal.pgen.1003523

- 192 genes form an interconnected cluster
- Patients with copy number variations within this cluster possess on average, 3 CNVs
- Many of these genes are implicated in psychiatric disorders in humans (anxiety, e.g.), and/or behavioral abnormalities in animal models (abnormal nurturing behavior, e.g.)

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**

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

Danger Signs

- **Inflexibility**
  - Fixed roles
  - Fixed solutions
- **Hypervigilance**
  - Lack of trust in care providers
- **Social Isolation**
  - “Circle the wagons” mentality
  - “Nobody helps us!”

Vignette #1

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

Anxiety, OCD, ASD

- **OCD [Assault rifle]**
- **Anxiety**
- **ASD Anxiety**

Vignette #2

- **“Nobody helps us.”**
  - Mother of 14 y.o. boy with ASD
  - 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
  - Mother has untreated Anxiety D/O
Does ASD predispose to violent crime?

FOR EVERY COMPLEX PROBLEM THERE IS A SIMPLE SOLUTION... AND IT IS WRONG

H. L. Mencken

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...*

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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...*

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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

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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

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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

- 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 JL, and Kristiansson M
Int J Forensic Ment Health 1:59–70, 2002

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.

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Often, he left jobs after conflicts with supervisors or other staff. His boss described AB as so wedded to routines that he was unable to be flexible or cope with unanticipated changes.

Socially, he had some friendships, but these occurred one at a time. He was reportedly bullied, or at least showed an over-sensitivity to behaviors by peers. For example, years later, he reported being unable to forget incidents such as being shot at with a water gun.

AB lived with his parents and had no sexual or romantic relationships. But, he explained that if he could just afford a large apartment, he would immediately be married.

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

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.

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

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

Common Themes
- Interpersonal Naiveté: A naïve and often impoverished understanding of human relationships...not only leaves Asperger’s syndrome patients vulnerable to mistreatment by others, but also may lead them to seek interpersonal contact in misguided ways...CD maintained a sexual relationship with a teenage male and demonstrated his ignorance of the inappropriateness of this relationship by going to the police to complain that the youth took his stereo when the relationship ended.

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

Common Themes
- Immediate Confession: At least four of the six men were quick to confess to the police. This could reflect a variety of traits ranging from deficient shame, poor judgment, lack of experience, or an impaired appreciation of the social and legal consequences of a confession, to simple forthrightness, rule-abiding behavior or honesty. This warrants additional research, as it would be of considerable significance if such admissions were not fully competent or voluntary.

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

Common Themes
- Sexual Frustration: At least five of the six men had sexual problems, and four were quite harmful to others when acting upon their sexual drive, highlighting the quandary faced by men who are interpersonally less equipped to initiate or sustain the types of intimate relationships commonly associated with consensual sexual contact...Clinicians working with Asperger’s syndrome patients should recognize that social impairments combined with a desire for attachment or sexual experience could lead to illegal behavior...The use of pornography was one socially tolerated ways by which several of the men in our sample pursued an impersonal sexual outlet....
Autistic symptoms in childhood arrestees: longitudinal association with delinquent behavior

• 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
Participants N = 308 Males: 87%
Mean IQ: 88
Refusals 117
24 m F/U N = 235
Controls: Normal children Children with ASD

Autistic symptoms in childhood arrestees: longitudinal association with delinquent 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

Autistic symptoms in childhood arrestees: longitudinal association with delinquent behavior

• 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)

LA Fitness Center Shooting In Pennsylvania Leaves 4 Dead


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….Everthing 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

House Rule #1

• Get both parents to come in for the interview & informing session
  – Have a sofa if possible, and watch the body language
  – “What do you think about what your spouse just said?”
Probe Questions
(In ascending order of intimacy)

- Do you and your partner ever go out as a couple? When was the last time?
- Who else do you have as supports?
- What have you told your other children / parents?
- Tell me a little bit about yourself / how you were raised / your own mental health?

House Rule #2

- No medication unless parents agree to behavioral and MH evaluation for their child and/or themselves, if you deem it necessary

House Rule #3

- The family is a system ➔ The unit of treatment is the family
- Assess mental health of all players
- Assess relationships among the players
- Fostering the family’s ability to move forward is my #1 goal. The child’s parents & siblings will be involved with my patient long after I have left the stage.

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

http://www.nasponline.org/advocacy/overview_sbmh.pdf

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 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
- 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
- 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
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/\text{MIS15/AAMFT/}
- The Bowen Center: http://www.thebowencenter.org/

Thank you