

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 offlabel drug treatments



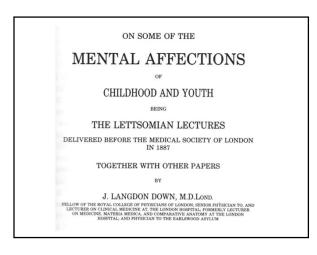
Outline

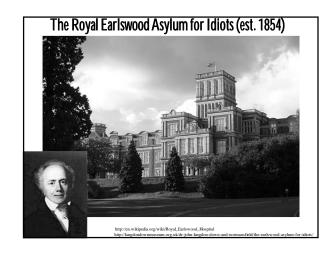
Part 1: Medical Co-Morbidities in ASD

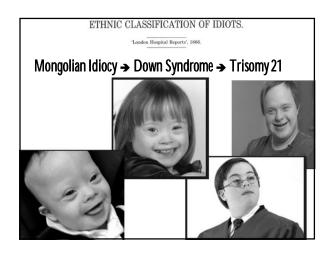
- · A brief history of ASD
- Co-Morbidities
 - Intellectual Disability
 - Dysregulation of Attention
 - Tics and Tourette Syndrome
 - Seizure Disorders
 - Genetic syndromes

Part 2: Mental Illness - The Elephant in the Room

A brief history of ASD Langdon Down Hans Asperger Leo Kanner







Langdon Down, 1887

I have alluded already to a group which I have ventured to describe as "accidental".... They are children who are born, or ready to be born, with all the potentiality of intelligence, but whose brain becomes damaged.... In these cases there is no outward sign of mental vacuity... no hereditary taint to mar the beauty of his visage...

14-16

Langdon Down, 1887

They are bright in their expression, often active in their movements, agile to a degree, mobile in their temperament, fearless as to danger, persevering in mischief, petulant to have their own way. Their language is one of gesture only; living in a world of their own they are regardless of the ordinary circumstances around them, and yield only to the counterfascination with music...

14-16

Langdon Down, 1887

These are the cases in which mothers entertain the strongest hope... I cannot enforce too strongly grave caution in the prognosis which should be given in such cases...

I know nothing more painful than the long motherly expectancy of speech; how, month after month, the hopes are kept at high tension, waiting for the prattle which never comes. How the self-contained and self-absorbed little one cares not to be entertained other than in his own dreamland, and by automatic movements of his fingers or rhythmical movements of his body....

15-16

Langdon Down, 1887

Even when 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.

72

Langdon Down, 1887

... [T]hey live entirely in a world of their own; they do not listen with a childlike curiosity to the conversation which is going on in their presence.... They hear what is said, but they do not attend, nor can their attention be arrested, except by diverting them into new channels by a more attractive trail. They usually have great intensity of purpose, and succeed in having their own way, the mothers giving up the contest for the sake of peace...

Automatic movements are also very common... these may include rhythmical movements of the fingers before the eyes

Pp 70-71

Langdon Down, 1887

This is a convenient place to treat of an interesting class of cases for which the term "idiots savants' has been given... This name has been applied to children who, while feeble-minded, exhibit special faculties which are capable of being cultivated to a very great extend. One youth who was under my care who could build exquisite model ships from drawings, and carve with a great deal of skill, who yet could not understand a sentence... Another ... who can draw in crayons with marvelous skill and feeling, in whom nevertheless there was a comparative blank in all higher faculties of mind.

58-59

Langdon Down, 1887

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

58-60

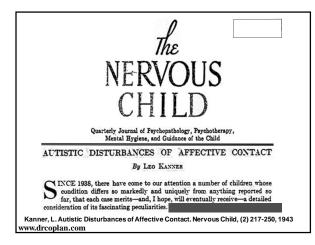
Langdon Down, 1887

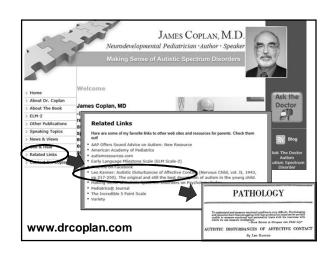
Often the memory takes the form of remembering dates and past events... One boy never fails to be able to tell the name and address of every confectioner's shop he has visited in London – and they have been numerous – and can as readily tell the date of every visit.

58-60

Why do we remember Kanner, but not Langdon Down?

- Association with Eugenics?
 - "Mongolism" / Social Darwinism
- WWI Social disruption / loss of continuity
- Ahead of his time?





Kanner, 1943

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

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

Impaired Socialization

- "Aloof"
- "Withdrawn"
- Limited eye contact
- Indifferent to others

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Idiosyncratic Language

- Echolalia
- Delayed Echolalia
- Pronoun Reversal
- Odd inflection

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Repetitious Behaviors

- Rigid Routines
- Stereotypies
- Lining up / spinning objects

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Unusual sensory responses

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

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Kanner, 1938 → 1943

- · Gradual improvement in early childhood
 - Social skills
 - Language
 - Cognitive flexibility
 - Sensory Aversions

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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 www.drcoplan.com

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...

www.drcoplan.com

Kanner, 1938 → 1943

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

* "Central coherence"

vanuer I. Autistic Disturbances of Affective Contact. Nervous Child, (2) 217-250, 1943

ww.drcoplan.com

Kanner, 1938 → 1943

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

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Kanner, 1938 → 1943

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

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Kanner, 1938 → 1943

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

Leo Kanner, 1943

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

Kanner, 1943

It is not easy to evaluate the fact that all of our patients have come of highly intelligent parents.

This much is certain, that there 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.

Kanner, 1943

One other fact stands out prominently. In the whole group, there are very few really warmhearted fathers and mothers. 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. Even some of the happiest marriages are rather cold and formal affairs. Three of the marriages were dismal failures.

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 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, 1971

•Deceased: 1

•Lost to follow-up: 2 •Institutionalized: 5 •Living on work farm: 1

•Living at home: 2
•BA degree / bank teller

•Sheltered workshop / machine operator

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Kanner's contributions

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

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Quantifying severity of ASD, and changes over time

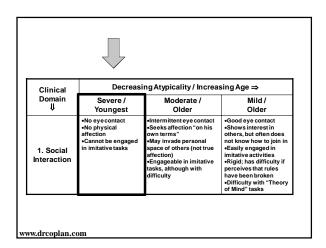
Clinical Domain
Social
Language
Repetitious Behavior
Sensory

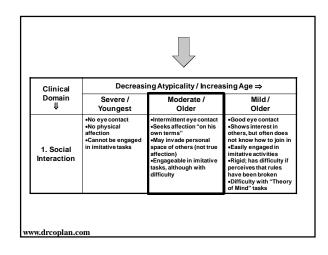
Decreasing Atypicality
Increasing Age

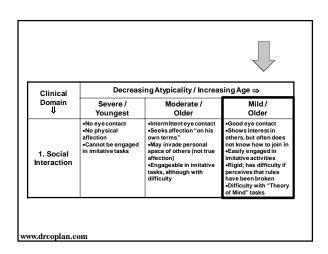
Mild /
Youngest
Older

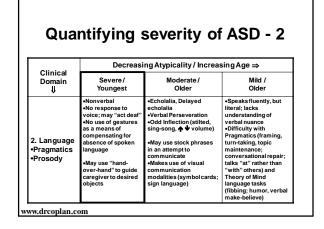
Older

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	Decreasing Atypicality / Increasing Age ⇒			
Clinical Domain ↓	Severe/ Youngest	Moderate / Older	Mild / Older	
2. Language •Pragmatics •Prosody	Nonverbal No response to voice; may "act deaf" No use of gestures as a means of compensating for absence of spoken language May use "hand- over-hand" to guide caregiver to desired objects		-Speaks fluently, but literal; lacks understanding of verbal nuance -Difficulty with Pragmatics (framing, turn-taking, topic maintenance; conversational repair; talks "at" rather than "with" others) and Theory of Mind language tasks (fibbing; humor, verbal make-believs	

Clinical	Decreasi	ng Atypicality / Increas	sing Age ⇒
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Quantifying severity of ASD - 3

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

Quantifying severity of ASD - 3

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

Quantifying severity of ASD - 3

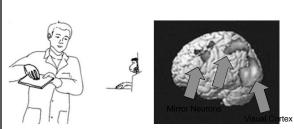
Clinical	Decreasing Atypicality / Increasing Age ⇒					
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Quantifying severity of ASD - 4

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

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Mirror Neurons: The Missing Link?



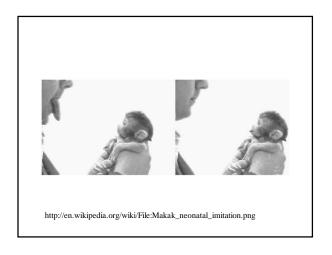
"The observation of actions done by another individual activates, besides visual areas, also areas that have motor properties."

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



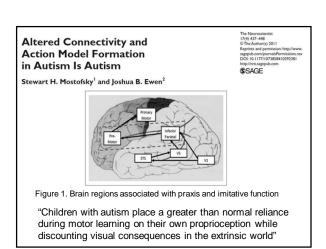
Figure 2.5. Stimulus faces of Andrew Meltzoff and a young mimic

 $\label{eq:Meltzoff} Meltzoff, Andrew N. \ and \ Moore, M. \ K. \ Imitation \ of facial \ and \ manual \ gestures$ by human neonates. Science 198:75-78, 1977







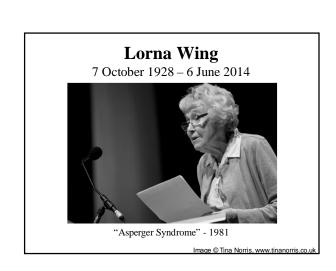


Archiv für Psychiatrie und Nervenkrankheiten 3. Juni 1944, Volume 117, Issue 1, pp 76-136

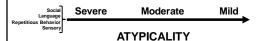
Die "Autistischen Psychopathen" im Kindesalter

Doz. Dr. Hans Asperger

"Relentlessly hyperverbal 'little professors"



"The Spectrum": ASD in One Dimension



Atypical features can range from severe to mild Atypical features diminish over time

Coplan J Atypicality, intelligence and age: a conceptual model of autistic spectrum disorder. Dev Med Child Neurol 2003

Intellectual Disability

Measuring intelligence in ASD

- How to operationalize the measurement of intelligence in ASD?
 - Omit ASD-specific areas of dysfunction or inflator scores:
 - Language
 - Social judgment
 - Savant skills
 - What's left?
 - Non-verbal Problem-Solving
 - · Adaptive skills (somewhat)
 - Play skills (somewhat)

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Non-verbal Problem-Solving

- Object permanence
- Tools (Spoon, Crayon)
- Cause & Effect
- Rule-based behavior

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Adaptive Skills

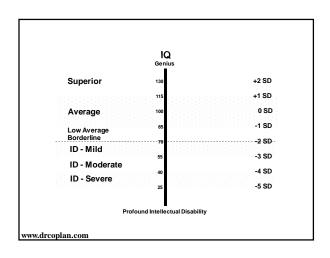
- Self-feeding
 - Finger-feeding
 - Cup
 - Spoon (tool use)
- Self-dressing
 - Unbuttoning, buttoning
 - · Zippers, Snaps
 - Tie shoes
- Toilet-training

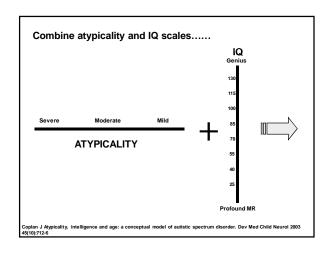
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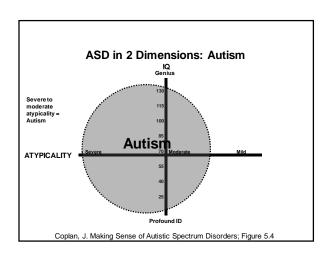
Play

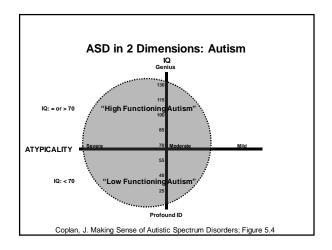
- Midline hand play (3 mo)
- Banging & Mouthing (7 9 mo)
- Casting (12 mo)
- Tools (crayon) ~ 14 mo
- Cause & Effect (14 to 16 mo & up)
- Imitative Play (24 mo)
- Imaginative Play (36 mo)
- Rule-based Play (48 mo)

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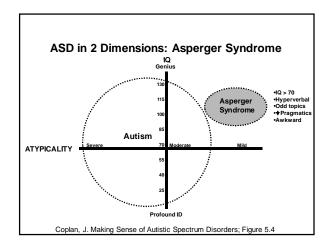




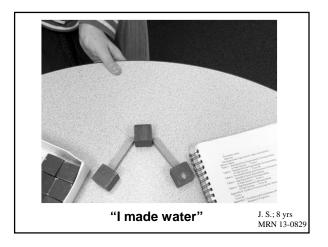


Yes, Virginia, there is a Santa Clause

• Or, in this case, Asperger Syndrome



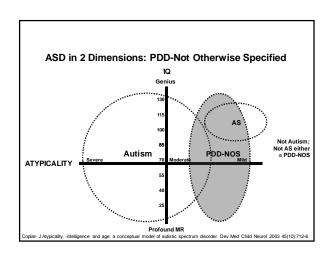




Asperger's Disorder will be Back[1]

Journal of autism and developmental disorders [0162-3257] Tsai, Luke: 2013 vol:43 iss:12 pg:2914 -2942 Luke Y. Tsai¹

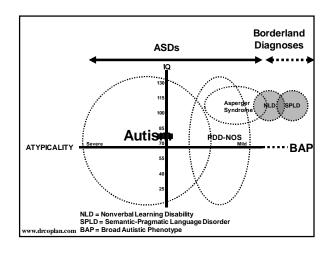
128 publications were identified through an extensive search of major electronic databases and journals. Based on more than 90 clinical variables, 94 publications concluded that there were statistically significant or near significant differences between Asperger's Disorder (AspD) and Autistic Disorder / HFA groups; 4 publications found both similarities and differences between the two groups; 30 publications concluded with no differences between the two groups. DSM-5 will eliminate Asperger's Disorder. However, it is plausible to predict that the field of ASD would run full circle during the next decade or two and that AspD will be back in the next edition of DSM.

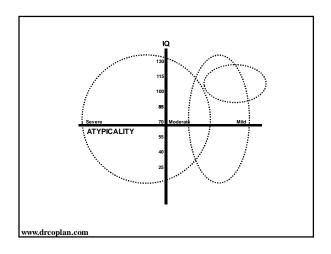


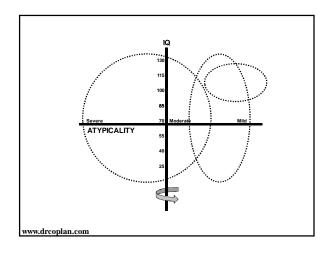
At the "Borderland" of ASD

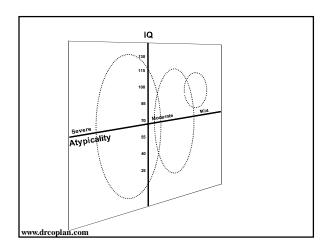
- Nonverbal Learning Disability (NLD)
 - ♣ Language pragmatics
 - Social skills
 - Disregard for personal space
 - **♣** Coordination / Sensory processing
 - Verbal IQ > Performance IQ
- Semantic-Pragmatic Language Disorder (SPLD)
 - ♣ Language pragmatics only
- (Broad Autistic Phenotype: Traits, not disorder)

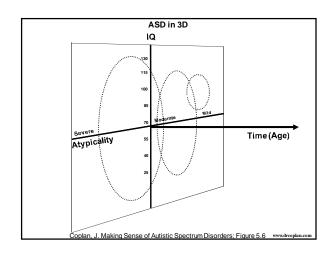
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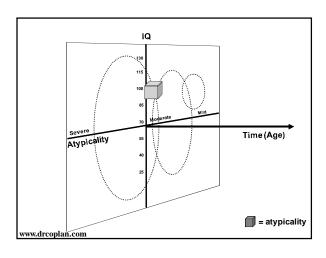


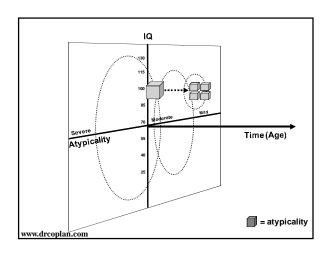


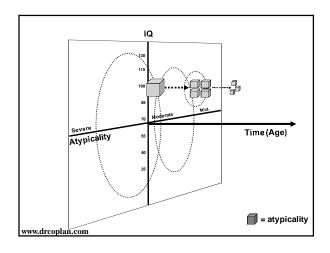


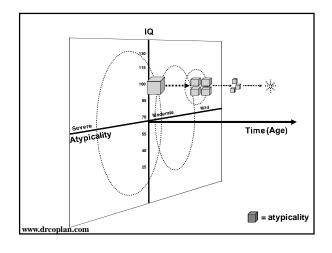


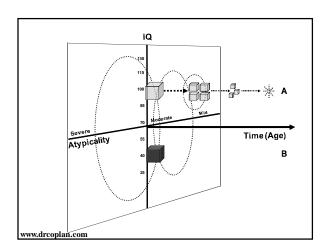


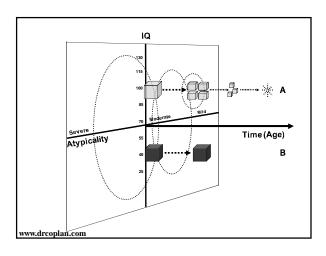


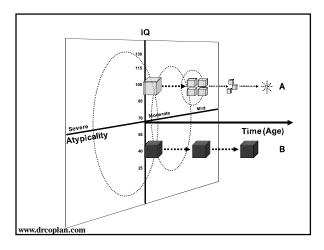


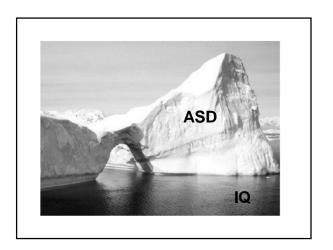


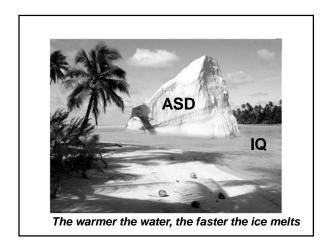


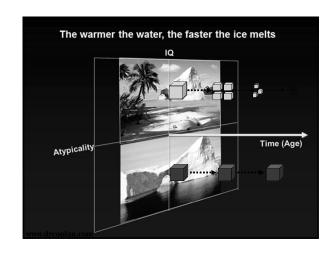


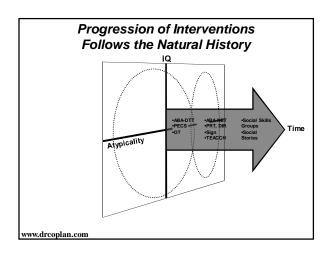


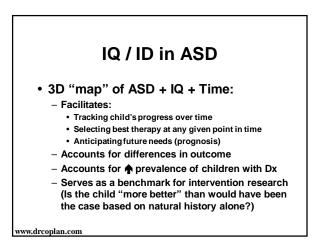




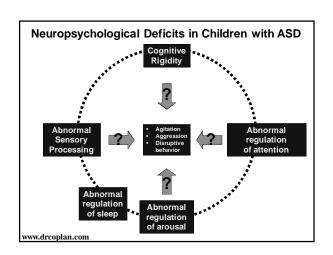


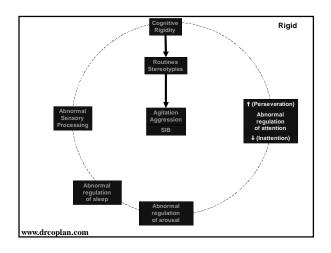


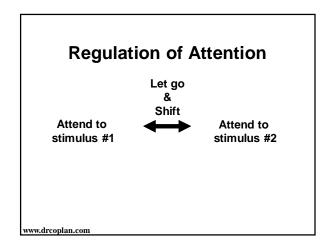


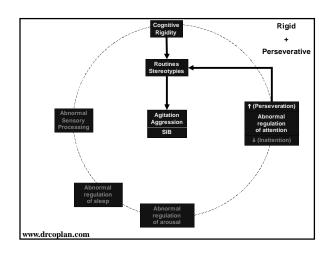


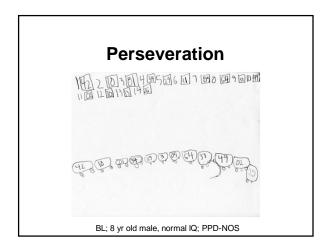
Dysregulation of Attention

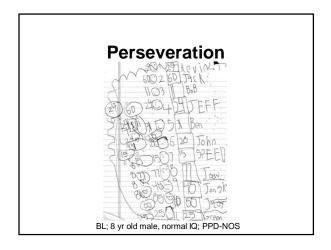


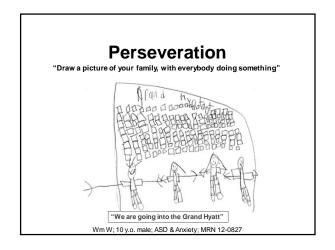


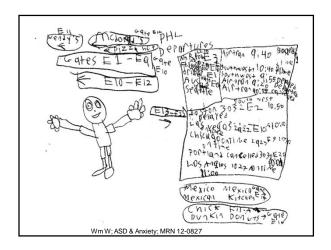


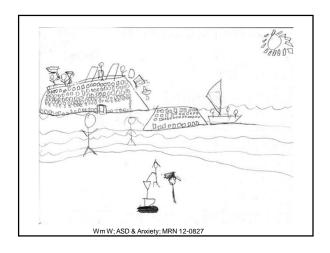


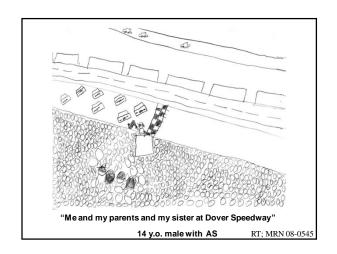


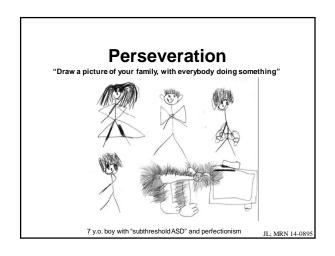


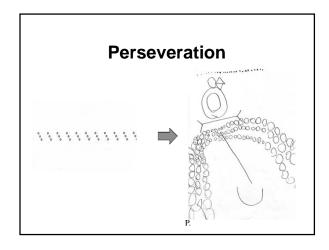


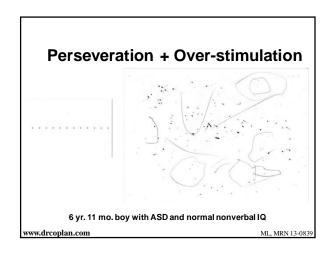








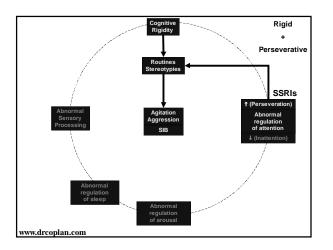




Abnormal Regulation of Attention (Perseveration)

- Interventions
 - Verbal preparation for transitions
 - Visual Schedules
 - SSRIs (OCD: Proven; ASD: likely)

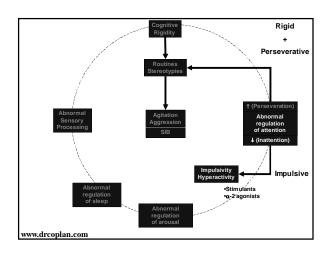
www.drcoplan.com



Abnormal Regulation of Attention - 2

- Inattention
 - Inability to focus
 - Impulsive
 - Distractible

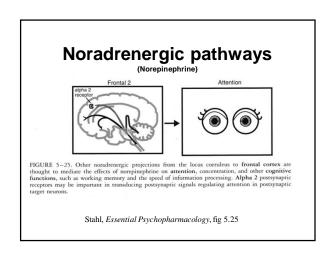
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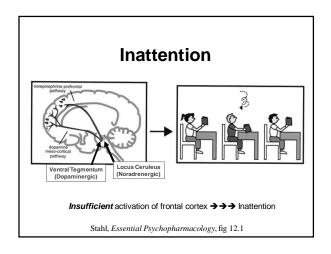


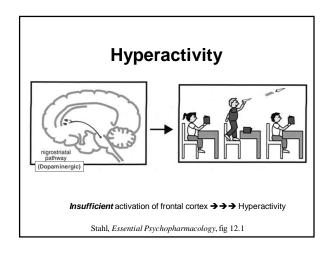
Inattention

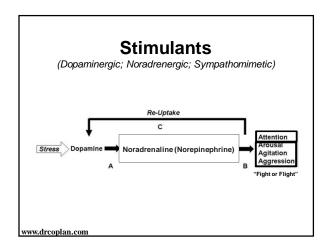
- Interventions
 - Limited stimuli
 - Short work periods
 - Medication
 - Stimulants (may ↑ anxiety / rigidity / agitation)
 - alpha-2 agonists

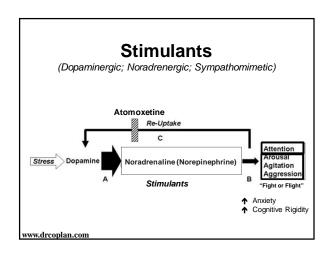
www.drcoplan.com

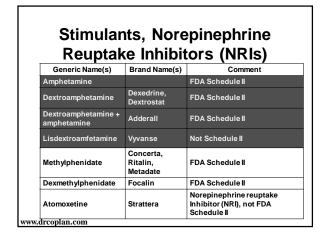


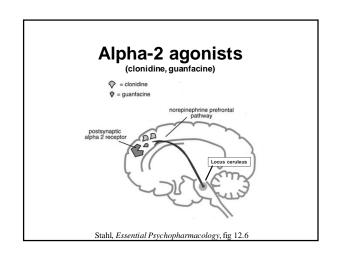












Alpha-2 Agonists

Generic Name	Brand Name(s)	Comment	
Clonidine	Catapres	More sedating than guanfacine	
Guanfacine	Tenex, Intuniv		

Frontal cortex / Locus Ceruleus: post-synaptic alpha-2 receptors
 Sympathetic outflow (autonomic nervous system): Pre-synaptic autoreceptors → ◆BP

www.drcoplan.com

Alpha-2 Agonists

Benefits

- ♠ Attention Span
- No exacerbation of anxiety / rigidity

Side Effects

- · Sleepiness: Common
- Emotional Lability (crying) - occasional
- Hypotension (low BP) rare

Bonus: Drug Class of first choice in the Rx of Tics

Tics / Tourette Syndrome

Gilles de la Tourette



1884: Maladie des tics

TS – Operational Definition

http://en.wikipedia.org/wiki/Tourette_syndrome http://www.tsa-usa.org/index.html

- Multiple physical (motor) tics and at least one vocal (phonic) tic, with a duration of at least 12 months
- Tics characteristically wax and wane, can be suppressed temporarily, and are preceded by a premonitory urge

TS – Operational Definition

http://en.wikipedia.org/wiki/Tourette_syndrome http://www.tsa-usa.org/index.html

- TS is one end of a spectrum of tic disorders, which includes provisional, transient and persistent (chronic) tics.
- Prevalence of TS:
- Estimated at 0.1 to 3% (differences attributed to study methodology and diagnostic criteria)
- Higher in samples with DD or MH d/o

TS, ADD, and ASD

Subjects: School-age children in the general population and children attending a county-wide tic disorder clinic

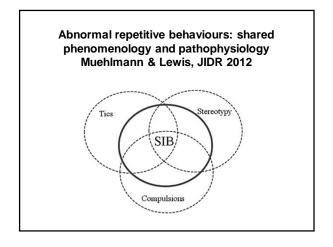
Prevalence of TS: 0.15% to 1.1%

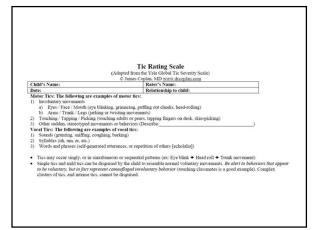
Boys:Girls ~ 4:1 to 6:1

Attention deficits and empathy/autism spectrum problems (including Asperger's disorder) were very common, each type of comorbidity affecting approximately two thirds of individuals with TS

Overall behavior problem scores were high, and affected children exhibited a marked degree of functional impairment.

Tourette's Disorder: Epidemiology and Comorbidity in Primary School Children; Kadesjo & Gillberg. Journal of the American Academy of Child & Adolescent Psychiatry. 39(5):548-555, May 2000

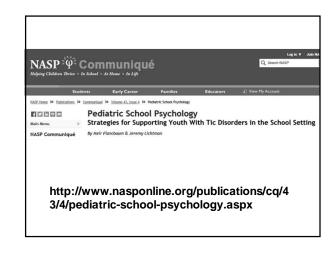




Severity >	0	1	2	3	4	5
Number of different motor or vocal tic patterns	None	1 motor or vocal tic Describe:	2-5 motor or vocal tics Describe:	>5 motor or vocal tics Describe:	As least one pattern of multiple simultaneous or sequential ties:	2 or more patterns of multiple simultaneous or sequential tics:
Frequency of tics	None	Rarely	Occasionally	Frequently	Almost always	Always
Intensity	None	Minimal (Not externally visible)	Mild (Visible, but not more forceful than typical voluntary actions)	Moderate (More forceful than typical voluntary actions, but not outside the range of normal.)	Marked (More forceful than typical voluntary actions; has an "exaggerated" character)	Severe (Extremely forceful and exaggerated. Rish of injury because of their forceful expression.)
Complexity	None If present, tics are "simple" - sudden, brief, and purposeless in character.	Borderline Some tics are not clearly "simple" in character, but may be readily camouflaged.	Mild Some tics are "complex" (purposeful in appearance), may mimic automatic behaviors, such as grooming, syllables, or brief meaningful unerances ("uh huh," "h"). May be readily camouffunged.	Moderate (More purposeful and sustained in appearance. Difficult to camouflage but may be rationalized or "explained" as normal behavior (picking, tapping, saying "you bet," brief echolalia).	Marked Difficult to camouflage; not be easily rationalized as normal behavior or speech (intense bodily movements, gestures, sustained echolalia)	Severe Extremely unusua mappropriate, bizarre or obscen
Interference	None	Minimal (Tics do not interrupt flow of behavior and speech)	Mild (Tics occasionally interrupt flow of behavior and speech)	Moderate (Tics frequently interrupt flow of behavior and speech, but do not disrupt intended action or communication)	Marked (Tics frequently interrupt flow of behavior and speech, and occasionally disrupt intended action or communication)	Severe Tics frequently disrupt intended action or communication

Your Role

- Recognition
 - Typical delay between onset & Dx: 5 yr
- Disentangle from comorbidities
 - ADD, ASD, "DBD," other
- Education
 - Parents, child, staff, classmates
- Collaboration
 - MD (meds), Psych: CBT

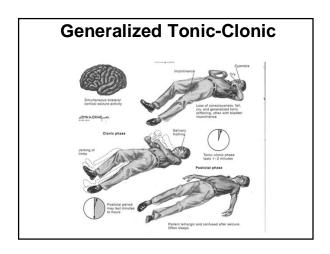


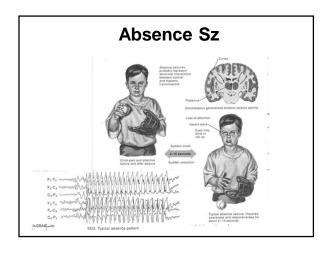
Interp://www.nasponline.org/resources/principals/tourettesprimer.pdf Student Services Tourette's Syndrome: A Primer for School Leaders The symptoms of Tourette's syndrome affect students academically as well as socially. By Steven R. Shaw, Amelia H. Woo, and Shana Valo

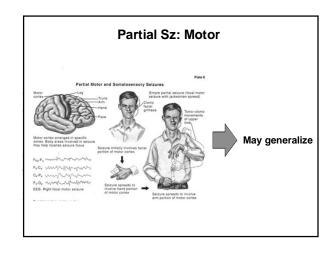
Seizure Disorders

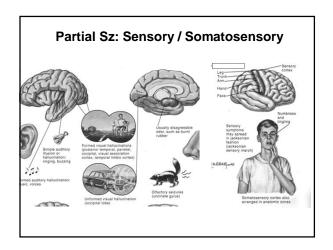
Definitions

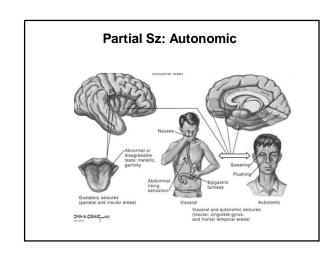
- Seizure: Sudden change in level of consciousness and or motor & sensory phenomena, due to electrical discharge in brain
- Epilepsy: Recurrent unprovoked seizures

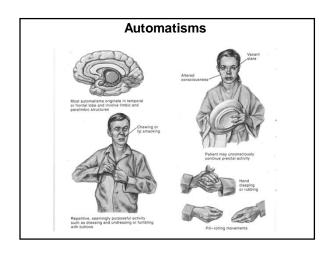


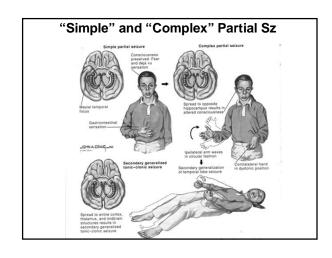


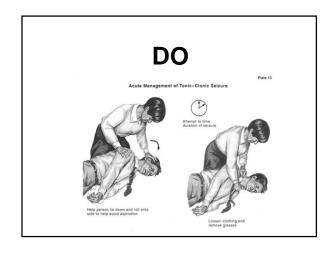


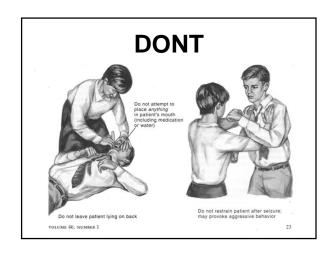




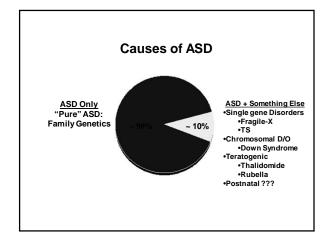








Genetic Syndromes



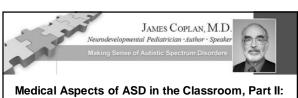
Genetic Syndromes that can cause ASD

- Fragile-X
- Trisomy 21
- Tuberous Sclerosis
- 22q (Velocardiofacial syndrome)
- Rett Syndrome (girls)
- Congenital Rubella
- And many others.....

Reading List

The educator's guide to medical issues in the classroom. Kline, FM, Silver LB, and Russel, SC. Brookes, 2001

The educator's guide to mental health issues in the classroom. Kline, FM & Sliver, LB. Brookes, 2004



Medical Aspects of ASD in the Classroom, Part II Mental Health - The Elephant in the Room

James Coplan, MD
Neurodevelopmental Pediatrics of the Main Line, PC
COPLAN@DRCOPLAN.COM
www.drcoplan.com



February 17-20, 2015

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 offlabel drug treatments



Outline

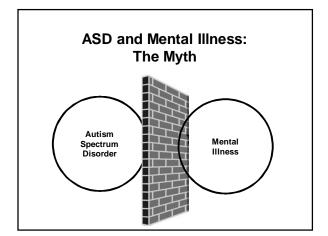
- 1) Statement of the Problem
 - 1) Compartmentalized Thinking
 - 2) "Us vs. Them": What I learned from Newtown part 1
- 2) Show me the data
 - 1) Intra-individual
 - 2) Intra-familial (with a glance at Family Mental Health)
 - 3) Basic Science
- 3) ASD, Mental Illness, and Violence
 - 1) What do the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

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
- 3) ASD, Mental Illness, and Violence
- 4) Where do we go from here?





The History of Science in 1 Slide

Description & Classification*

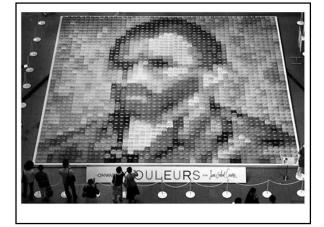
(Group items into categories, based on externally visible characteristics)



Analysis

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

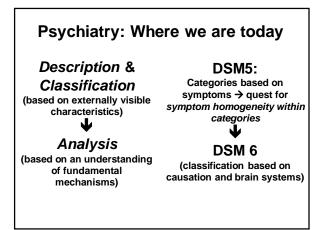
* Plato (428-328 BCE): "Carve Nature at its joints." We can't explain why or how things happen, but if we observe carefully, and group similar items into categories, eventually the big picture will emerge.

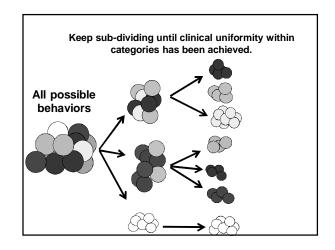


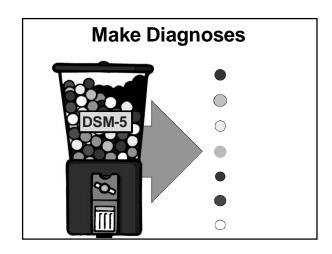
Problems with classification schemes based on appearance

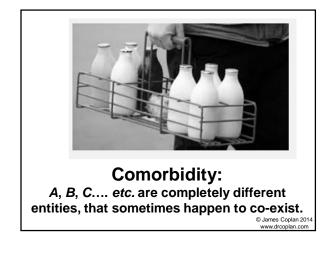
- Different underlying mechanisms can produce similar-appearing results
- Similar underlying mechanism can produce different-appearing results

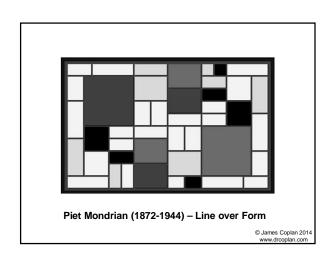


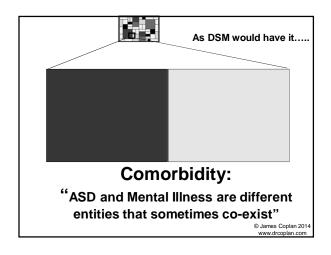


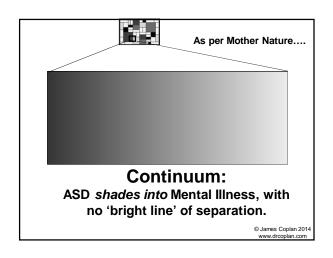


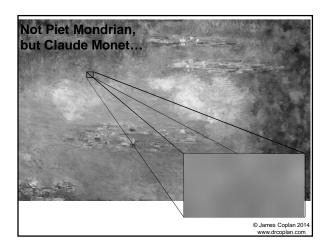


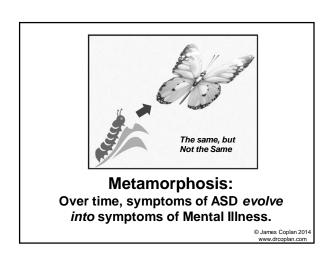


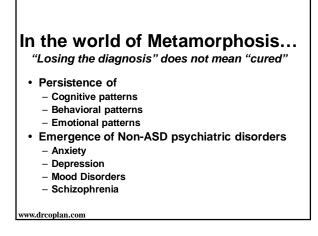


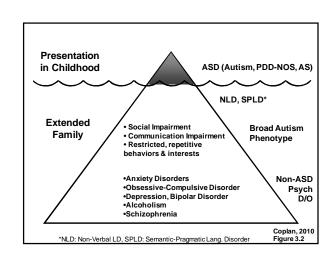


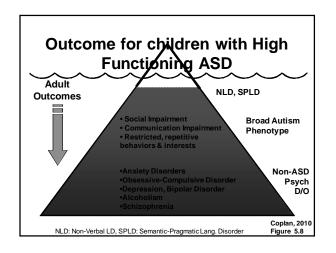




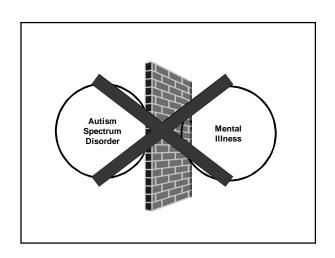


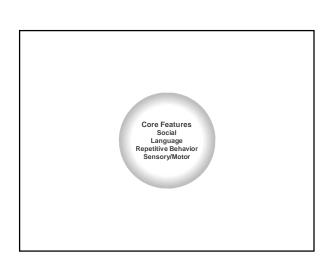


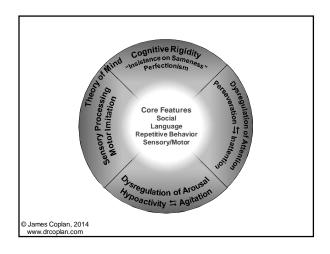


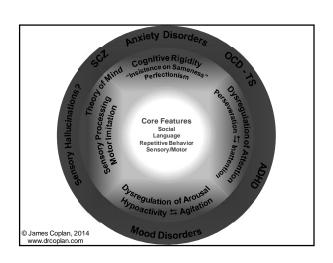


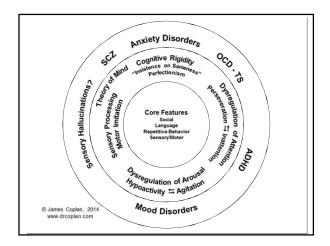












Outline

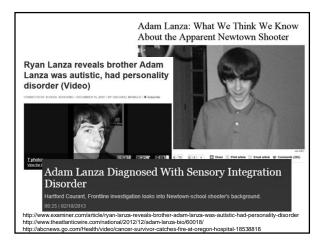
1)Statement of the Problem

1)Compartmentalized Thinking

2)"Us" vs. "Them" - What I learned from Newtown-Part 1

- 2) Show me the data
- 3) ASD, Mental Illness, and Violence-Newton 2
- 4) 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...

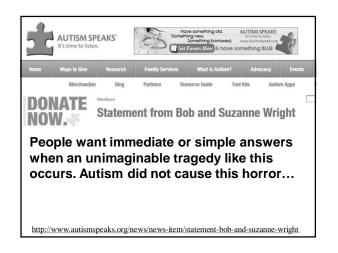
Some public comments have drawn potentially inaccurate and stigmatizing conclusions about a link between the diagnosis [of autism] and a propensity for violence and lack of empathy...

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)

- 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

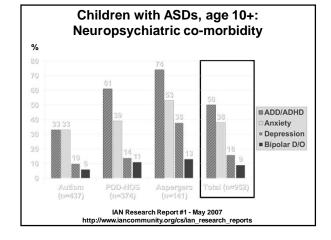
2)Show me the data

- a) Intra-individual
- b) Intra-familial (with a glance at Family Mental Health)
- c) Basic Science
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- 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?



Psychiatric Symptom Impairment in Children with Autism Spectrum Disorders

Kaat, A.J., et al. Journal of Abnormal Child Psychology, 2013

- 115 pts w. ASD at University Hosp. Child Devel. Clinic
 - Age 6-12 yr; Male: 86 %; White: 91 %
 - Mean IQ : 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

Psychiatric Symptom Impairment in **Children with Autism Spectrum Disorders**

Kaat, A.J., et al. Journal of Abnormal Child Psychology, 2013

Disorder	Prevalence (%)*			
Disorder	Impairment**	DSM-IV criteria		
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	94%	84%		

- * Combined Parent & Teacher ratings ** "Impairment" = Symptoms "Often or Very Often"

Mood D/O in ASD: **Comorbidity or Continuum? BPD-I only** 110 (70%) 157 youth >15 y.o. with BPD-I BPD + ASD 47 (30%) *Onset of BPD-I was significantly earlier in children with ASD 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. <u>J Clin Psychiatry.</u> 2013 Jun;74(6):578-86. Joshi G, Biederman J, Petty C, et al

ASD, Psychosis, and Schizophrenia (SCZ)

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

The association between early autistic traits and psychotic experiences in adolescence

Jones, R.B., et al., Schizophr Res, 2012. 136(1-3): p. 164-189

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

Birth cohort: N = 14,541(1991-1992)



12 yr old eval:

The association between early autistic traits and psychotic experiences in adolescence

Jones, R.B., et al., Schizophr Res, 2012. 136(1-3): p. 164-189

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)

The association between early autistic traits and psychotic experiences in adolescence Jones, R.B., et al., Schizophr Res, 2012. 136(1-3): p. 164-189

- "Childhood autistic traits, particularly speech problems and odd rituals or unusual habits, are associated with psychotic experiences in adolescence.
- This may be a result of a shared aetiology or because autistic traits may also be an early precursor of psychotic experience"

"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



www.drcoplan.com

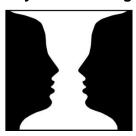
Theory of Mind

- 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

www.drcoplan.com

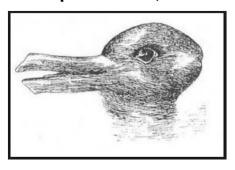
Central Coherence

• The ability to see the big picture



www.drcoplan.com

Joseph Jastrow, 1899



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!

Tom & Central Coherence

Muff

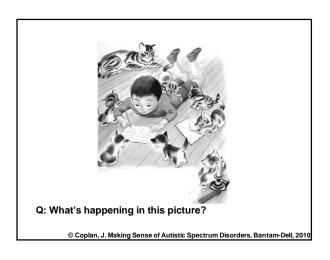
Muff is a little yellow kitten.

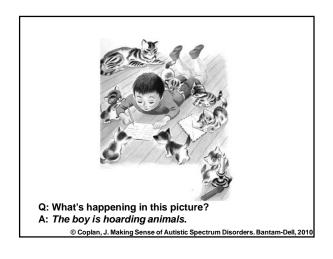
She drinks milk.

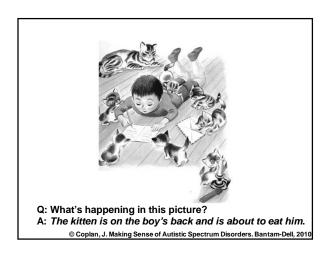
She sleeps on a chair.

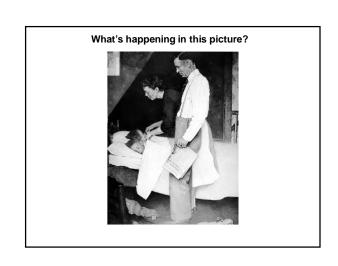
She does not like to get wet.

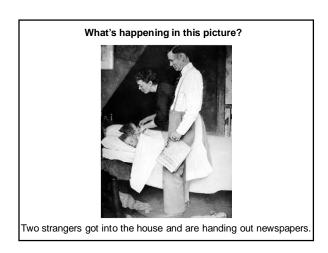
Q: How would Muff feel, if you gave her a bath? A: I don't know. We haven't got to that part of the story yet.



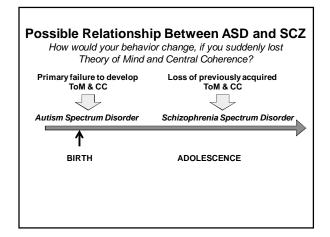




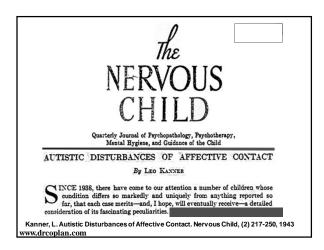


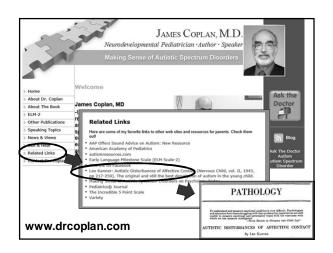












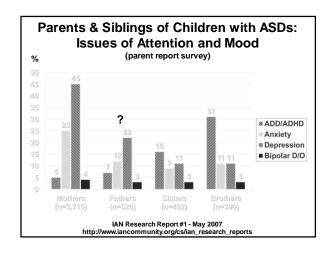
Kanner, 1943

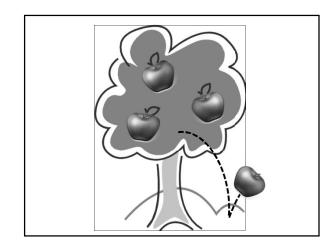
[T]here is a great deal of obsessiveness in the family background. The very detailed diaries and reports and the frequent remembrances, after several years, that the children had learned to recite twenty-five questions and answers of the Presbyterian Catechism, to sing thirty-seven nursery songs, or to discriminate between eighteen symphonies, furnish a telling illustration of parental obsessiveness.

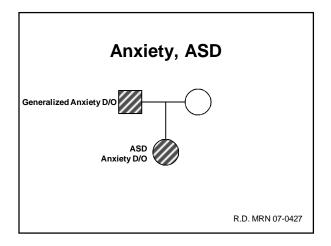
Kanner, 1943

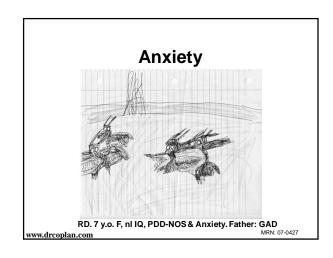
The child's aloneness from the beginning of life makes it difficult to attribute the whole picture exclusively to the type of early parental relations with our patient. We must, then, assume that these children have come into the world with innate inability to form the usual, biologically provided affective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

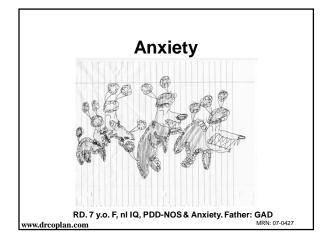
If this assumption is correct, a further study of our children may help to furnish concrete criteria regarding the still diffuse notions about constitutional components of emotional reactivity. For here we seem to have pure-culture examples of inborn autistic disturbances of affective contact. (italics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

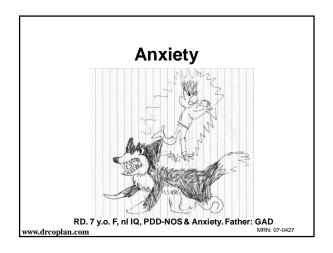


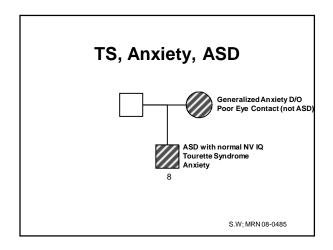


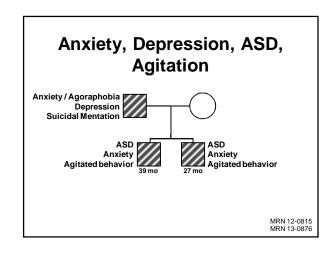


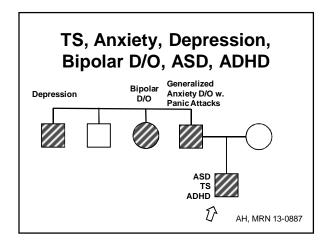


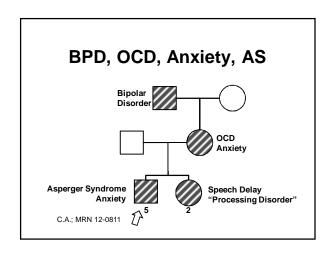












Severe mood problems in adolescents with autism spectrum disorder

Simonoff, E., et al., Journal of Child Psychology and Psychiatry, 2012. 53(11): p. 1157-116

- 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

Severe mood problems in adolescents with autism spectrum disorder

Simonoff, E., et al., Journal of Child Psychology and Psychiatry, 2012. 53(11): p. 1157-116

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%)

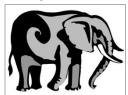
- · Bullied (physical, verbal, social, cyber) within the past month: 77%
 - 1 time: 11%; 2-3 times: 23%; ≥ 4 times: 43%

Cappadocia, M.C., J.A. Weiss, and D. Pepler, **Bullying Experiences Among Children and Youth** with Autism Spectrum Disorders. JADD, 2011

Risk factors for being bullied	p*
Child - Gender	NS
Child - Age (being younger)	< .05
Child - Social skills deficit	NS
Child - Communication difficulties	< .05
Child - Internalizing mental health problems	< .001
Child - Externalizing mental health problems	NS
Parent - Mental health problems	< .01
Child - Fewer friends at school	< .05

*NS = Not statistically significant. Smaller p = less likely to occur by chance.

The Real Elephant in the Room



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



Nature - Nurture

Nurture: Family Systems Theory

Nature: Genetics

Family Systems Theory

Murray Bowen, 1913-1990

• "A theory of human behavior that views the family as an emotional unit and uses systems thinking to describe the complex interactions in the unit"

http://www.thebowencenter.org/pages/theory.html

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

© James Coplan, 201

ww.drconlan.c

Danger Signs

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

Family Systems Theory

- "Emotional interdependence presumably evolved to promote the cohesiveness and cooperation families require to protect, shelter, and feed their members"
- People have a "thinking brain," language, a complex psychology and culture, but... the emotional system affects most human activity and is the principal driving force in the development of clinical problems."

http://www.thebowencenter.org/pages/theory.html

www.drcoplan.com

Family Systems Theory

- > Differentiation of Self
- > Triangles
- > Nuclear Family Emotional System
- Family Projection Process
- · Multigenerational Transmission Process
- Emotional Cutoff
- Sibling Position
- Societal Emotional Process

http://www.thebowencenter.org/pages/theory.html

www.drcoplan.com

Poorly Differentiated Poorly Differentiated

Differentiation of Self

 "A person with a well-differentiated 'self' recognizes his realistic dependence on others, but he can stay calm and clear headed enough in the face of conflict, criticism, and rejection to distinguish thinking rooted in a careful assessment of the facts from thinking clouded by emotionality."

http://www.thebowencenter.org/pages/theory.html

www.drcoplan.com

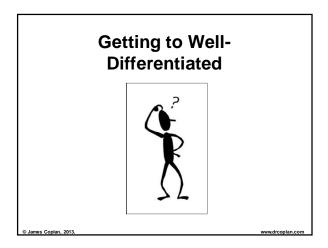
Differentiation of Self

- "People with a poorly differentiated 'self' depend so heavily on the acceptance and approval of others that either they quickly adjust what they think, say, and do to please others, or they dogmatically proclaim what others should be like and pressure them to conform."
- In both cases, the underlying objective is conflict avoidance (jc)

http://www.thebowencenter.org/pages/theory.html

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.drcoplan.com



Sense of Self

- Identity
 - Adolescence
 - Who am I and where do I fit into the world?
- Self-confidence: Childhood
 - The sum total of all of one's successes +
 - Successful recovery from life's bumps
- > True
 - Infancy: I cry, and my mother meets my needs

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Still Face Experiment (Tronick et al. 1978) All the state of the stat

Sense of Self

≻Identity

- Adolescence
 - Who am I and where do I fit into the world?

> Self-confidence: Childhood

- The sum total of all of one's successes +
- Successful recovery from life's bumps
- Trust
 - Infancy: I cry, and my mother meets my needs

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Family Systems Theory

- ➤ Differentiation of Self
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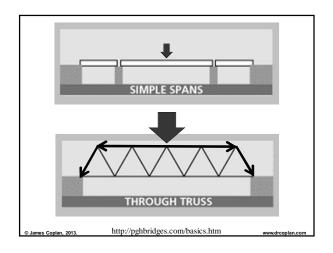
http://www.th.ch.cu.co.contor.org/pog.co/th.com

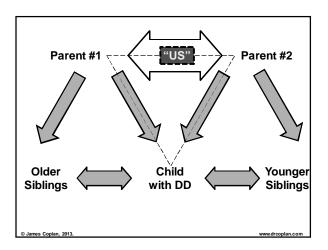
http://www.thebowencenter.org/pages/theory.html

Triangles

- · A triangle is a three-person relationship system
- · A triangle is the smallest stable relationship system
- Paradoxically, triangles can contain much more tension than a dyad [2-person system]... because the tension can shift around three relationships
- · Triangles are building blocks of larger emotional systems

http://www.thebowencenter.org/pages/theory.html



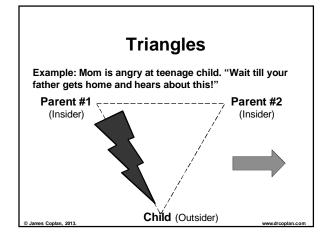


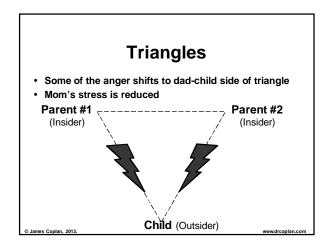
Triangles

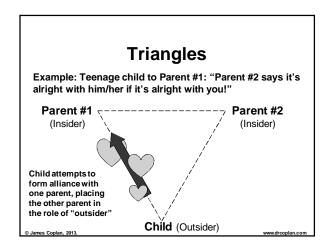
- The essential nature of triangles endows them with strength, because it permits avoidance of one-on-one confrontation
- but at the same time, creates a situation with two "insiders" and an "odd man out," who is trying to become an insider

http://www.thebowencenter.org/pages/theory.html

www.drcoplan.com







Family Systems Theory

- > Differentiation of Self
- > Triangles
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- Family Projection Process
- **Multigenerational Transmission Process**
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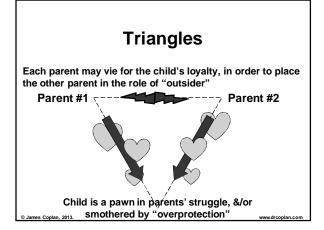
http://www.thebowencenter.org/pages/theory.html

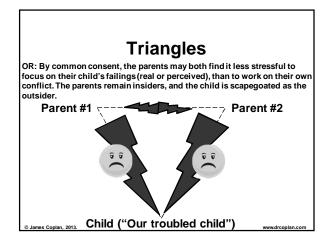
Nuclear Family Emotional Systems

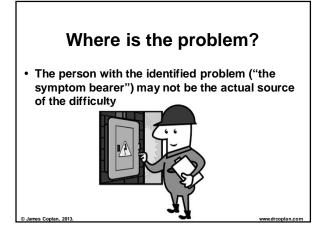
- · "The basic relationship patterns result in family tensions coming to rest in certain parts of the family. The more anxiety one person or one relationship absorbs, the less other people must absorb. This means that some family members maintain their functioning at the expense of others."
- Triangles can lead to dysfunctional but stable interrelationships that work to the detriment of one or more family members

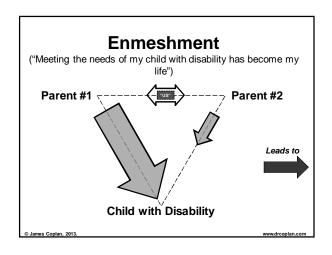
http://www.thebowencenter.org/pages/theory.html

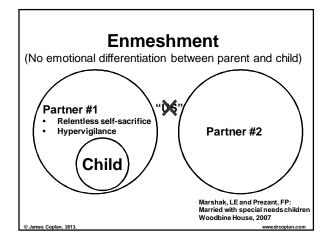
Triangles Example: Primary conflict is between parents Parent #1 Parent #2 Child

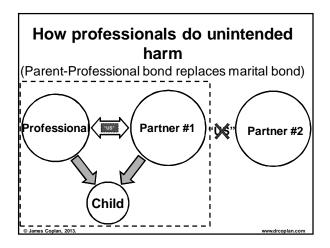












"House Rules"

- Whenever possible, make sure that both parents are present.
- Exceptions:
 - One parent is:
 - In prison
 - Deceased
 - In the armed forces stationed overseas

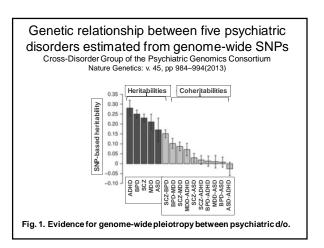
D James Coplan, 2013. www.drcoplan.com

Family Function: Resources

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

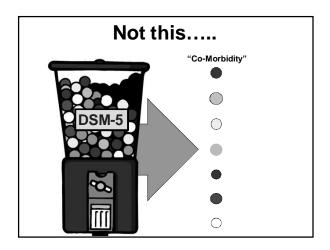
Nature (Genetics)

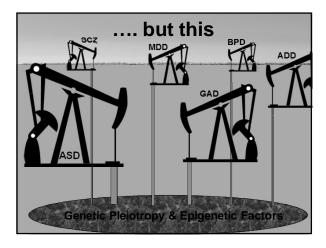
- ADHD
- ASD
- Bipolar D/O (BPD)
- Generalized Anxiety Disorder (GAD)
- Major Depressive D/O (MDD)
- Schizophrenia (SCZ)



Revisiting the Relationship Between Autism and Schizophrenia: Toward an Integrated Neurobiology deLacy N. & King, B Ann Rev Clin Psychol Vol. 9: 555-587 March 2013

"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."





Nature plus Nurture: The double whammy

- · Child with ASD may receive a genetic "load" for mental health d/o, AND
- have a parent with dysfunctional behavior because the parent has a mental health d/o

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?



Unlawful Behaviors in Adolescents and Adults with Autism Spectrum Disorders

Woodbury-Smith, Marc

2014, Adolescents and Adults with Autism Spectrum Disorders, 269-281



Woodbury-Smith 2014

- "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."

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

Case Series of adult males referred for forensic evaluation

Charges:

- Arson: 1 (serial fire-setting x 11 episodes)
- 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

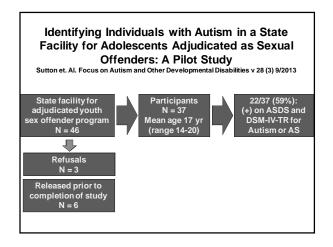
Common Themes

- 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 Naiveté: 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

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: 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.
- Sexual Frustration: 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....



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)

60:00

Factors specific to autism phenotype....

Lorna Wing

7 October 1928 – 6 June 2014



"Asperger Syndrome" - 1981

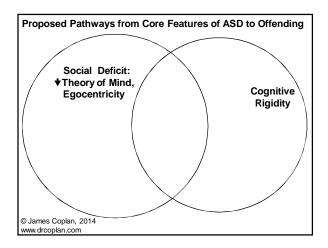
Image © Tina Norris, www.tinanorris.co.uk

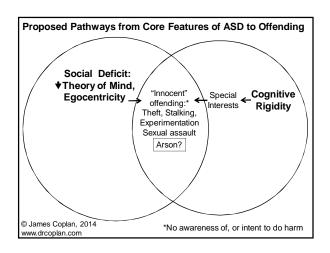
Factors specific to autism phenotype....

Wing 1997

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

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





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

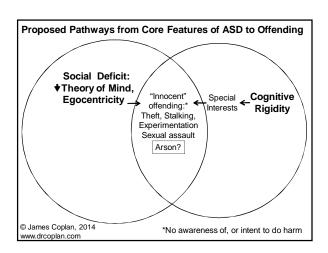
Education and Training in Autism and Developmental Disabilities, 2014, 49(1), 102–110

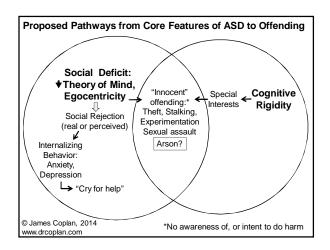
© Division on Autism and Developmental Disabilities Post, M, Storey K, Haymes, L, et al

Stalking Behaviors by Individuals with Autism Spectrum Disorders in Employment Settings: Understanding Stalking Behavior and Developing Appropriate Supports

Characteristics of stalkers

- Unaware that the victim is not interested in them.
- 2. Have an obsessive personality.
- 3. Have above average intelligence.
- Don't have meaningful relationships outside of the one they are trying to establish.
- Don't have discomfort or anxiety about their stalking behavior.
- Not aware that their behaviors are hurting others.
- 7. May become violent. (Snow, 1998).



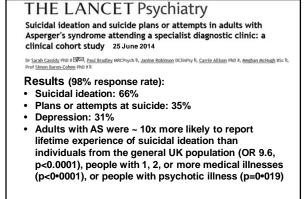


THE LANCET Psychiatry Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study 25 June 2014 or Sarah Casaldy PhO 8 18500, paul Bradley MRCPsych B, Janine Robinson OctioPsy B, Carrie Allison PhO B, Menhan McHugh BSC B, Prod Simon Baron-Cohor PhO B B Subjects 374 adults newly diagnosed with Asperger Syndrome Men: 256 Women: 118 Mean age at Dx: 31.5 yr (range 17-67 yr) 87 (23%) in full-time education at the time of study

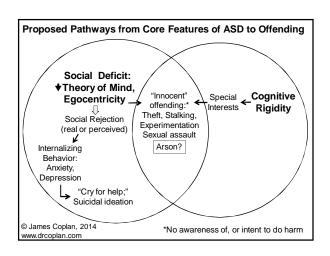
- Self-Report Questionnaire, lifetime experience of:
- Suicidal thoughts
- · Suicidal plans or attempts
- · Depression

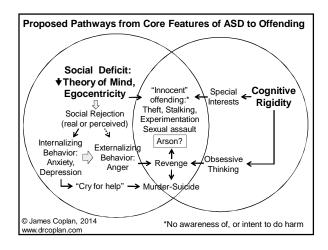
Methods:

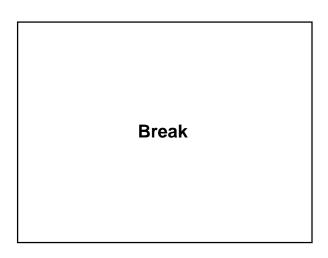
http://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(14)70248-2/fulltext



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









SHOOTING AT SANDY HOOK ELEMENTARY SCHOOL REPORT OF THE OFFICE OF THE CHILD ADVOCATE

http://www.ct.gov/oca/lib/oca/sandyhook11212014.pdf

Newtown ES / Sandy Hook CT

- 12/14/2012: Adam Lanza kills his mother, 20 elementary school children, six educational personnel, and himself
- 1/30/13: State Child Fatality Review Panel directs the state Office of the Child Advocate to investigate the circumstances leading to the death of the children at Sandy Hook, with a focus on any public health recommendations that may emanate from a review of the shooter's personal history

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

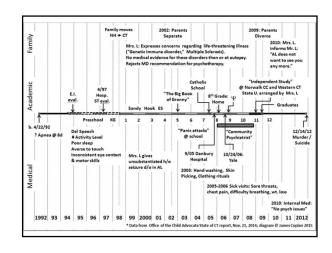
CFRP "shall review the circumstance of the death of a child placed in out-of-home care or whose death was due to unexpected or unexplained causes to facilitate development of prevention strategies to address identified trends and patterns of risk and to improve coordination of services for children and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

Records Reviewed

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

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 ("AL")

- 0-3: Extremely active, poor sleeper, avoided touch, delayed speech; invented own language
- El Eval (~ 32 mo): "Fell well below expectations in socialpersonal development"
- OT eval: Inconsistent eye contact & motor skills
- Neurodevelopmental Eval (age 5)
- Rituals: odd repetitive behavior
- Sensory aversions (touch, texture)
- SIB, Tantrums

OCA Report

Statement of former elementary school classmate

"AL [was] a nice kid who was sort of withdrawn [though] I could tell he was a little off.... AL seemed to get along with everyone, he would interact [with others] but would never engage classmates in conversation. During this school year, I invited all of my classmates over to my house for a birthday party. The one thing that I thought was odd was AL's mother stayed for the entire party."

OCA Report

Email from Mrs. L to Elementary School (1st grade):

"AL is a quiet, considerate child with a tendency to withdraw. He has made tremendous strides in your school system and has benefited from speech therapy. He does, however, tend to 'over focus' on rules and can be very hard on himself as a result. ...I am hoping that next year AL will be placed in a classroom with a more casual feel to it. He responds well to a nurturing environment, and I would like his emphasis to be on learning rather than coping."

OCA Report

"The above communication from Mrs. Lanza indicates that despite AL's compliant behavior, she also characterized him as experiencing stress, including depression and anxiety....Though Mrs. Lanza's communication documents her concerns regarding AL's depression, anxiety, and other social-emotional challenges... there is little in his educational record that echoes or responds to Mrs. Lanza's observations.

Mrs. Lanza's note also begins a pattern of attempts to bend or manage the environment for AL, to help him as she put it much later, 'get through each day.'..."

OCA Report

5th Grade: AL & a classmate author "The Big Book of Granny":

"a very dramatic text, filled with images and narrative relating child murder, cannibalism, and taxidermy...[depicting] a boy who is struggling with disturbing thoughts of extreme violence that seem to have poured out in the form of stories and visual images of a caregiver and child-like character who are alternately victimized by and victimizers of each other..."

OCA Report

"There is intense violence featured in this book, and authors [i.e. the OCA committee] conclude that it was not the sort of creation that most children would even know to invent. Mental health professionals contributing to this report determined that the content of 'The Big Book of Granny' can only be described as extremely abhorrent and, if it had been carefully reviewed by school staff, it would have suggested the need for a referral to a child psychiatrist or other mental health professional for evaluation."

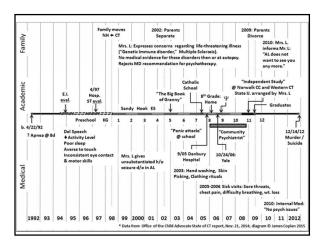
OCA Report – School System

"An appropriate evaluation would have required extended discussion with the child about what the book meant and how it came to be written by encouraging extensive elaboration about what the text revealed regarding the child's thoughts and social-emotional processing.

"The Big Book of Granny" suggests that while in many ways AL appeared to be positively developing, by the age of ten, on some level, he was deeply troubled by feelings of rage, hate, and (at least unconscious) murderous impulses."

OCA Report

"The Big Book of Granny" stands out, to mental health professionals, as a text marked by extreme thoughts of violence that should have signified a need for intervention and evaluation... In the context of special education evaluation and eligibility, consideration of the criteria for Emotional Disturbance would have been appropriate. There is no evidence of communication in any form between the school and AL's parents about this book."



OCA Report

Danbury Hospital Crisis Team

 9/05 –Mrs. Lanza takes AL to the ER of Danbury Hospital for a crisis evaluation. "Mrs. Lanza told hospital personnel that her sole reason for taking AL to the emergency room was to obtain medical permission to allow him to stay home from school indefinitely."

OCA Report Danbury Hospital Crisis Team

"Hospital records described him as "anxious," withdrawn," and "hesitant to be touched." He presented as agitated, hyper-vigilant, and overwhelmed with fear.

"The clinical consultation resulted in diagnoses of Anxiety Disorder, NOS; Rule out Asperger Syndrome; Rule out Autistic Disorder, followed by a discharge diagnosis of Asperger Syndrome and Obsessive Compulsive Disorder.

OCA Report

Danbury Hospital Crisis Team

"The hospital crisis team recommended therapeutic educational placement at the Center for Child and Adolescent Treatment Services . "Mrs. Lanza declined this recommendation, stating that AL would be "better off" at home ...because he was "very comfortable" at home and would not be as anxious

Days later, Mrs. L consults a "community psychiatrist"... who provides a letter stating that AL should "not attend school due to the lack of an appropriate placement" and his "mounting overwhelming anxiety."

Community Psychiatrist

"It is not clear what caused the community psychiatrist to opine that there was no appropriate educational placement. There is no indication as to whether Mrs. Lanza shared Danbury Hospital's recommendations for therapeutic school placement with the community psychiatrist or the IEP team. There is no indication in available treatment or education records that the issue of school placement, therapeutic or otherwise, had ever been explored or even discussed with the school district. Therefore, this statement of the psychiatrist is difficult to interpret."

OCA Report

Community Psychiatrist

"Even more curious was his statement in the same correspondence to district officials:

'[AL] has agreed to achieve competency in all academic subjects at home. At this point tutoring is not needed and could be viewed as counter- productive both academically and emotionally.'

The school district followed up on the psychiatrist's recommendations at an IEP meeting in December 2005 with an offer to evaluate AL....This recommendation was declined by Mrs. Lanza, who stated that evaluations at that time would "not be in [AL's] best interests."

OCA Report

Community Psychiatrist

March 2006: SD sends a note to the psychiatrist: "In order to exempt [AL] from taking the CMTS, we need a letter from you indicating that he is unable to attend school and is medically / emotionally unavailable for homebound instruction for the testing period and the make-up testing period . . . Without this letter, we are mandated to send a certified teacher to [AL]'s house to give him the test."

OCA Report

Community Psychiatrist

"The psychiatrist responded with a faxed note that AL was 'medically/emotionally unavailable to be tested (CMT).' According to the psychiatrist, AL could not and was not receiving home-bound or hospital-based tutoring and he was not attending school at all."

OCA Report

Community Psychiatrist

"...The IEP team did not reconvene until June, 2006...
Though there was a release of information signed by
Mrs. Lanza that permitted the school district to discuss
AL with the community psychiatrist, there is no
documentation in the school record that the district
had a treatment plan for him, or that the district raised
any questions about AL being out of the school for an
entire year....

AL's primary disability was 'to be determined.' The team agreed to defer evaluation due to his extreme anxiety and the psychiatrist's recommendations."

OCA Report

Community Psychiatrist

"...State regulations permit not only homebound instruction, but also hospitalized instruction. In the face of disabilities that were so significant as to apparently justify AL's lack of attendance for the entire school year it does not appear that anyone questioned why, if he was so debilitated, he was never hospitalized or referred for specialized educational placement...

AL's homebound placement was inappropriate and nontherapeutic, and the prolonged acceptance of this educational placement by the school district raises questions about the adequacy of oversight for reliance on such restrictive measures..."

Evaluation by Yale Child Study Ctr: 10/24/06 (9th Grade)

In the fall of 2006, Mr. Lanza seeks help through his Employee Assistance Program to obtain a mental health referral for AL

"Pale, gaunt, and awkward young adolescent standing rigidly with downcast gaze and declining to shake hands....rigid, controlling, and avoidant behaviors ... worries about contamination of grease, dirt, and dust... food related to texture... increasingly socially withdrawn and reclusive.

AL reportedly had not had any psychological testing.

OCA Report

Evaluation by Yale Child Study Ctr: 10/24/06 (9th Grade)

"Beyond the impact of OCD symptoms on himself and his mother, we are very concerned about AL's increasingly constricted social and educational world. Much of emphasis has been on finding curricular level of instruction. Inability to tolerate even minimal interaction with even older more mature classmates will have grave consequences for his future education and social and occupational adaptation unless means of remediation are found. Inability to interact with classmates will prove increasingly deleterious to education..."

OCA Report

Evaluation by Yale Child Study Ctr: 10/24/06 (9th Grade)

"Understandably, AL's parents have gone to great lengths to compensate for AL's hypersensitivities and social difficulties and aversions by providing home-bound instruction. However we believe that there is a significant risk to AL in creating, even with the best of intentions, a prosthetic environment which spares him having to encounter other students or to work to overcome his social difficulties. Having the emphasis on adapting the world to AL, rather than helping him to adapt to the world, is a recipe for him to be a homebound recluse....."

OCA Report

Evaluation by Yale Child Study Ctr: 10/24/06 (9th Grade)

Recommendations: Psych & Speech-Language testing, placement in a therapeutic day school setting, medication, enrollment in a therapy group, and "parental guidance"

10/25/06: "Mrs. Lanza wrote an email to the doctor... She indicated that AL would not agree to any sort of medication management as recommended. She wrote as follows:

Thank you for taking the time to meet with AL yesterday . . . I wanted to let you know that the options you presented are not going to work at this time. I would like to save you any further investment of your time.

OCA Report

Evaluation by Yale Child Study Ctr: 10/24/06 (9th Grade)

Email correspondence from early 2007 demonstrates that *Mr.* Lanza repeatedly contacted school officials to coordinate information sharing between the district, the community psychiatrist and the Yale Child Study Center. Mr. Lanza wrote to the school that the "key" for AL succeeding in his educational goals would be for him to develop "the necessary coping skills," and that the mental health providers were "crucial in such a plan." Mr. Lanza also inquired as to what family services were available pursuant to the IEP and whether those services would be developed separately or would be part of the IEP itself....

OCA Report

Evaluation by Yale Child Study Ctr: 10/24/06 (9th Grade)

...A Newtown school psychologist's evaluation from December, 2006 noted that AL was seen by the Yale Child Study Center and that AL was diagnosed with Asperger's Syndrome, Obsessive Compulsive Disorder and sensory issues. There is no indication in the school records, however, as to whether school personnel actually saw or considered Yale's recommendations for treatment and education planning. The IEP ultimately created by the school and family in 2007 did not reflect the recommendations contained in the Yale Child Study Center report.

SD Psych testing 11/06

WISC-IV, W-J: "AL's ability to sustain attention, concentrate, and exert mental control were in the superior range. AL also displayed a strong ability to attend to and hold information in short-term memory while performing some operation or manipulation with the information. AL demonstrated exceptional auditory working memory and attention skills. However, he would be expected to struggle slightly with comprehending novel information. His relatively low score on the Comprehension subtest included responses to each item but not always with a "socially sensitive" response. There was no discussion of the qualitative nature of these responses..."

OCA Report

SD Psych testing 11/06

Educational classification: "Other Health Impaired."
"It was recommended that AL continue to be eased into regular classroom time as his comfort level increases and anxiety decreases. Desensitization was referenced, with recommendations for small classes, but without any direct therapeutic support....The services offered were essentially 10 hrs of academic tutoring...and a shortened school day..."

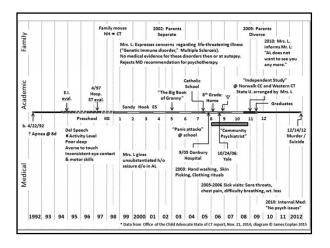
OCA Report

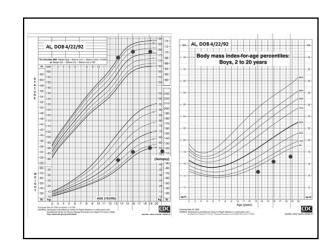
SD Psych testing 11/06

"The required consideration of special factors – 'For students whose behavior impedes his or her learning or that of others, the PPT [Term for IEP team used in Connecticut] has considered strategies, including positive behavioral interventions and supports to address that behavior' - received a response of 'Not Applicable'."

OCA Report

"By this point, there were multiple indicators that AL met statutory-regulatory criteria and applicable guidance for autism spectrum disorders or, alternatively, for emotional disturbance...By not classifying his needs appropriately, attention to AL's severe disabilities focused, as the Yale psychiatrist previously warned, on *curricular issues* rather than on the social and emotional characteristics that were seriously impacting his ability to participate in a regular educational environment..."





Mrs. Lanza

- "Frequently preoccupied with what she felt were her potentially serious and possibly terminal health issues"
- In the summer of 1999 she wrote often to a friend regarding the "group of [medical] experts" she was seeing... Her letters referenced numerous tests, with alternating optimism about her prognosis and concerns that her "diagnosis is not good" and she may have "limited time left." Mrs. Lanza talked about having had enough time to get [Ryan and AL] settled in, but that she may have only "months to live."

OCA Report

Mrs. Lanza

"Mrs. Lanza later told a friend that she was diagnosed with a "genetically flawed autoimmune disorder," but that she intended to be discreet about her diagnosis so as to save loved ones "from unnecessary worry." She asked her friend to keep her condition confidential. She continued to write about experiencing seizures, visiting a neurologist and "being tested, and poked, prodded, injected, and tortured." Mrs. Lanza wrote of additional neurologic problems, telling her friend that she was having "some excruciatingly painful [tests]," and lamenting that her hopes of "any kind of permanent remission [were] gone...."

OCA Report

Mrs. Lanza

"Despite Mrs. Lanza's preoccupation with her health and concerns about her mortality, a review of her medical records from that time do not confirm a significant neurologic disorder, autoimmune disorder, or multiple sclerosis—the latter a diagnosis she sometimes indicated that she had.

A medical record from her July 1999 neurology follow up indicates that all testing was unremarkable. The record notes that Mrs. Lanza was experiencing "significant stress in her life related to her husband." Additional medical testing was recommended along with "psychotherapy for [Mrs. Lanza's] emotional issues."

OCA Report

Mrs. Lanza

- "There is no indication that Mrs. Lanza was provided a terminal diagnosis by doctors at any time... nor did autopsy results confirm the presence of findings consistent with MS
- "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..."

OCA Report

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 (public school, Mr. L)
- "Parentification" of AL: Mrs. L unburdening herself regarding her own worries, with AL trying to reassure her

OCA Report

"While most families of children with autism or mental health disorders collaborate with school and treatment teams ...in some families, other life issues or parental mental health issues take precedence and impede followthrough with educational and clinical recommendations. In the most difficult cases,parents who are conflicted over having the child grow up and become independent can consciously and unconsciously sabotage efforts that would facilitate development....

School districts need to acknowledge that relying solely on parent reports to inform educational plans can have long lasting detrimental effects on a child's education."

"Was Deference to the Family's Decision-Making Appropriate?

...The reluctance to take an adversarial posture with a family that is invested and concerned with their child's welfare can certainly be understood. But educational providers are also mandatory reporters of suspected neglect and if a district has information that the needs of a child are not or cannot be met by his caregiver, these reporters are obligated to bring this to the attention of the child welfare system."

OCA Report

"It is fair to query...whether the Lanzas...needed to be compelled into services and whether this type of action may have arrested AL's deterioration and isolation from the community. Or whether, at a minimum, Mr. Lanza - who did not have the same access or direct knowledge of AL's presentation as Mrs. Lanza--needed to be drawn further into the educational and mental health planning with providers at that time..."

OCA Report

"Would a similar family from a different race or lower socio-economic status in the community have been given the same benefit of the doubt that AL's family was given? Is the community more reluctant to intervene and more likely to provide deference to the parental judgment and decision-making of white, affluent parents than those caregivers who are poor or minority? Would AL's caregivers' reluctance to maintain him in school or a treatment program have gone under the radar if he were a child of color? These questions are meant for reflection, rather than blame..."

OCA Report

Is there a Reluctance to Serve Youths' Social-Emotional Learning Needs in School?

...Social Emotional, developmental, and behavioral health needs are sometimes considered parenthetical to the learning process. It is not uncommon for schools not to have a social worker or other therapeutic support staff in the building. It is also not uncommon for an Individual Education Plan to refer to social-emotional or mental health needs and indicate that those needs are being met in the community by an outpatient provider.

"Siloed Service Systems"

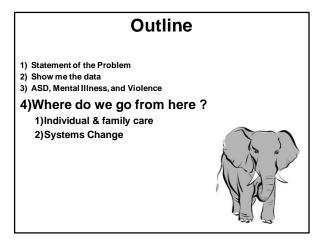
- Primary Care Physicians
- Mental Health Services
- Public Schools

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

OCA Report – School System

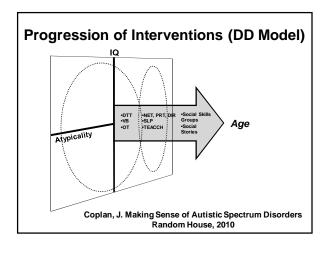
"The school system cared about AL's success but also unwittingly enabled Mrs. Lanza's preference to accommodate and appease AL through the educational plan's lack of attention to social-emotional support, failure to provide related services, and agreement to AL's plan of independent study and early graduation at age 17"

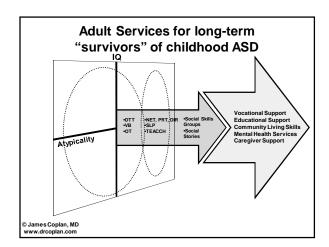


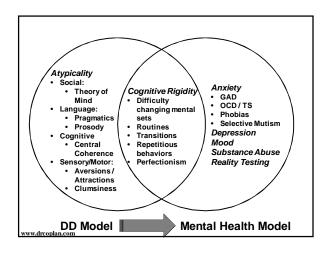
Individual Care

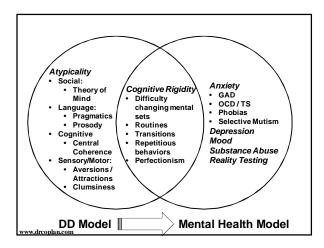
- Not "Co-Morbidity," but Continuum and Metamorphosis
- "Losing the diagnosis" does not = "cure"
- Shift from Developmental Disability model to Mental Health model
- · Need for adult services

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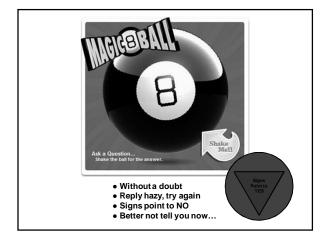


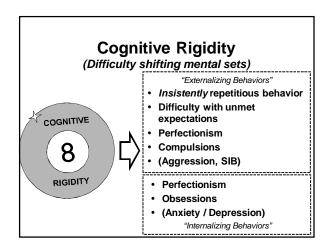




School-Based MH Services

- · Proactively monitor student mental health
 - Don't wait for academic failure or disruptive behavior
 - Positive Behavior Support for Internalizing Behavior





IDEA, Section 614(d)(2)(B)

http://idea.ed.gov/explore/view/p/,root,statute,I,B,614,d

- (B) Consideration of special factors.--The IEP Team shall--
- (i) in the case of a child whose behavior impedes the child's learning or that of others, consider the use of positive behavioral interventions and supports, and other strategies, to address that behavior.

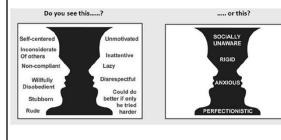


This site was created to provide a "one-stop shop" for resources related to IDEA and its implementing regulations...

- Comment: A few commenters recommended that Sec. 300.324(a)(2)(i) refer specifically to children with internalizing and externalizing behaviors.
- Discussion: We do not believe it is necessary to make the recommended change because Sec. 300.324(a)(2)(i) is written broadly enough to include children with internalizing and externalizing behaviors.
- · Changes: None.

http://idea.ed.gov/explore/view/p/,root,regs,preamble2,prepart2,D,2766

Positive Behavior Support for Internalizing Behavior



SW: ASD, OCD, Anxiety MRN 14-0933

Exam: Perfectionism

S. earnestly attempted the Bender-Gestalt figures, but became overwhelmed, repeatedly erasing and re-erasing. He went so far as to measure the distance between the dots on one of the stimulus cards with his finger, trying to replicate the spacing exactly. "If I can't get something right I get angry with myself... Sometimes I take it out on other people," he confided. 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.

CV

- 13 y.o. boy
- Superior IQ
- Asperger Syndrome
 - Disabling perfectionism
- Generalized Anxiety D/O
- Major Depressive D/O
 - Suicidal Gestures x 2
- Task refusal & SIB when faced w. openended tasks – e.g. language composition

MRN 05-0194

CV

Christopher continues to express symptoms of Asperger Syndrome, Generalized Anxiety Disorder, and Depression. He continues to need intensive mental health services, which he has been receiving from Dr. B., and psychopharmacologic measures (fluoxetine).

MRN 05-0194

CV

At school Christopher needs a *Positive Behavior Support Plan for Internalizing Behavior*. His current FBA is not quite right: He does not engage in crying, hyperventilation, and self-injury "to avoid completing the unpreferred activity" *per se.* Rather, he engages in crying, hyperventilation and self-injury because he has anxiety and perfectionism, and he is pre-emptively *afraid that he won't be able to complete the task perfectly.*What he needs is a behavior plan that promotes *self-tolerance* and *cognitive flexibility.* This is very different from the type of plan drawn up for children who are simply averse to doing work.

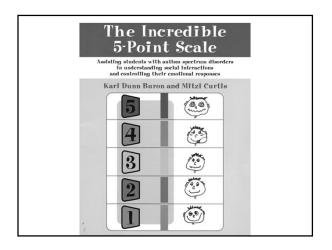
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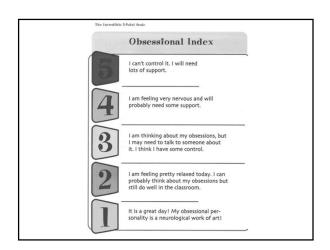
Social Skills Deficit + Cognitive Rigidity

"We are pleased to see that L. has a Positive Behavior Support Plan, but we are dismayed that it does not consider *perfectionism* as an antecedent, in which case L's refusals may not be for the purpose of escape from task *per se*, but to avoid self-criticism for not being able to do a task perfectly.

Liam's Behavior Plan calls for him to recognize the feelings of others, which is fair. By the same token, his Behavior Plan should also require the adults to make an effort to figure out what *Liam* may be feeling – not just react to the surface topography of the behavior."

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





Selective Serotonin Reuptake Inhibitors (SSRIs)

- Primary targets
 - Cognitive Rigidity
 - Anxiety
 - Obsessions (thoughts)
 - Compulsions (behavior)
 - Perfectionism
 - Depression
 - Stereotypies: Probably not
- "Downstream" benefit:
 - — Disruptive Behavior
 - ♠ Quality of Life

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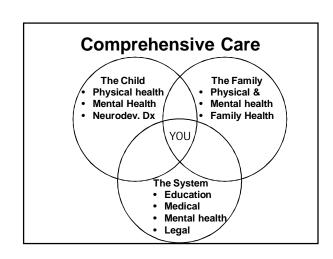
Family Care

- 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

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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



Summary

 ASD has a natural history for improvement over time, insofar as outwardly visible atypical features are concerned (echolalia, stereotypies, etc.), but cognitive limitations (Theory of Mind, Central Coherence) persist

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Summary

- Mental Illness is not "a separate problem."
 Rather, impaired MH is another expression of shared neurobiology
 - Not "co-morbitidy," but continuum and metamorphosis
- Over time, mental health issues present a progressively greater challenge, that may supersede the ASD
- "Losing the diagnosis" of ASD does not mean "cured"

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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

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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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Obstacles

- · Mind-set
 - "That's not my job"
 - Developmental, family-centered
- · Lack of skills
 - Capacity building
- · Cross-Disciplinary collaboration
 - Siloed service systems
 - Confidentiality
 - Different professional orientations
 - Funding
- Stigma

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Thank you