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Neurodevelopmental Pediatrician · Author · Speaker
Making Sense of Autistic Spectrum Disorders
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Beyond DSM5: Achieving the Best Outcome for Children with ASD
James Coplan, MD
Neurodevelopmental Pediatrics of the Main Line, PC
Rosemont, PA



OSPA Fall Meeting, November 7, 2014

Outline

- I. **ASD Defined (and re-defined)**
[Break]
- II. **The Autism Explosion: What it means, and what it doesn't**
[Lunch]
- III. **Behavior Management, Mental Health, and Psychopharmacology**
[Break]
- IV. **Coming Full Circle**

Disclosures

- Dr. Coplan is author of *Making Sense of Autistic Spectrum Disorders: Create the brightest future for your child with the best treatment options* (Bantam-Dell, 2010), and receives royalties on its sale



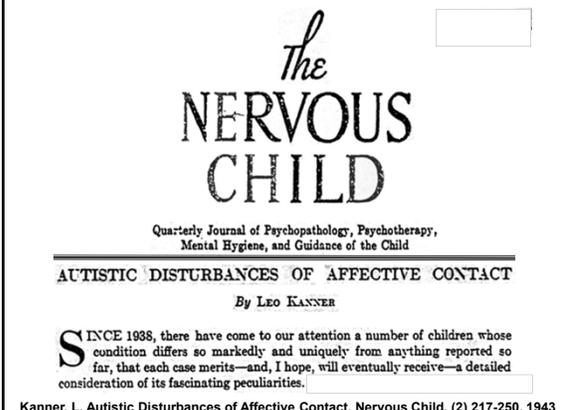
- This presentation will include a discussion of off-label drug use

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- I. **ASD Defined (and re-defined)**
 - A. Leo Kanner revisited
 - B. The changing faces of the DSM
 - C. IQ as a determinant of outcome
 - D. Seeing ASD in 3 dimensions (“The warmer the water, the faster the ice melts”)
 - E. Therapies: Bottom-Up and Top-Down



The
NERVOUS CHILD

Quarterly Journal of Psychopathology, Psychotherapy,
Mental Hygiene, and Guidance of the Child

AUTISTIC DISTURBANCES OF AFFECTIVE CONTACT
By LEO KANNER

SINCE 1938, there have come to our attention a number of children whose condition differs so markedly and uniquely from anything reported so far, that each case merits—and, I hope, will eventually receive—a detailed consideration of its fascinating peculiarities.

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

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
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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- “Withdrawn”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

www.drcoplan.com

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...

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

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”**

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

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Kanner, 1938 → 1943

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

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

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Kanner, 1938 → 1943

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

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

www.drcoplan.com

Kanner, 1938 → 1943

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

Leo Kanner, 1943

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

- **Description: 4 Domains**
 - Social, Language, Repetitious behavior, & Sensory aversions / attractions
- **Attribution: An "inborn disturbance of affective contact"**
- **Progression: Described the *Natural History* of improvement over time (irrespective of treatment)**

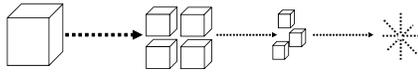
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**Natural History: “The temporal course
a disease from onset to resolution”**
Center for Disease Control & Prevention

ASD has a Natural History

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Over time, the ice melts



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Time Passes.....



1943 → → →

DSM III		
Yr	Event	Comment
1980	DSM-III: First appearance of: •Infantile autism •Autism-residual state: Children who once met criteria for infantile autism but no longer do.	6 mandatory criteria: I. Onset < 30 mo. II. Pervasive lack of responsiveness to other people III. Gross impairment in communication skills IV. Peculiar speech patterns if speech is present V. Bizarre responses to various aspects of the environment VI. Absence of delusions / hallucinations / incoherence

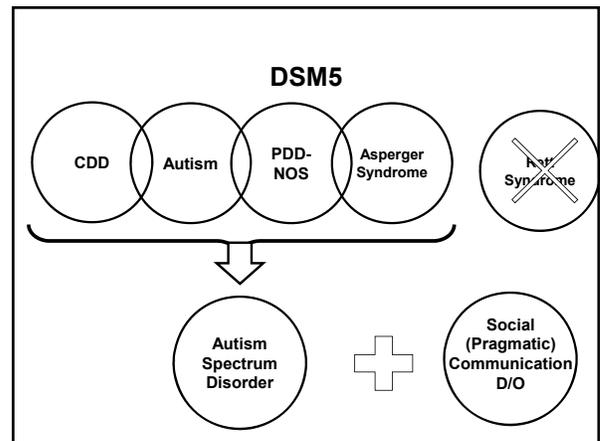
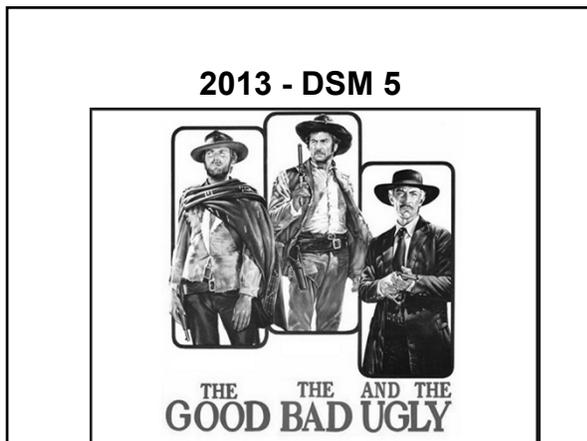
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DSM III-R		
Year	Event	Comment
1987	<p>DSM-III-R: •“Infantile autism” replaced by “Autistic Disorder” •“Autism-Residual State” replaced by PDD-NOS</p>	<p>PDD-NOS encompasses children who <i>never met full criteria for Autism</i>, as well as children who once met such criteria but improved over time.</p>

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DSM IV		
Year	Event	Comment
1994	<p>DSM-IV: •Broader menu for diagnosis •Asperger's Disorder first appears</p>	<p>6 of 16 milder criteria, such as: •Lack of spontaneous seeking to share achievements with other people •Difficulty sustaining a conversation •Lack of varied social imitative play •Persistent preoccupation with parts of objects</p>

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Autism Spectrum Disorder

Clinical Domains: 3 → 2

A. Deficits in Social Communication & Interaction

B. Restricted, Repetitive, Behaviors, Interests, and Activities

DSM5 - ASD

A. “Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive):...”

Social Communication & Interaction

- “Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.”

Social Communication & Interaction

- “Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.”

Social Communication & Interaction

- “Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.”

DSM5 - ASD

B. “Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive)...”

Restricted, repetitive patterns of behavior, interests, or activities

- “Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases)”

Restricted, repetitive patterns of behavior, interests, or activities

- “Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day)”

Restricted, repetitive patterns of behavior, interests, or activities

- Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests)

Restricted, repetitive patterns of behavior, interests, or activities

- “Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain / temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement)”

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

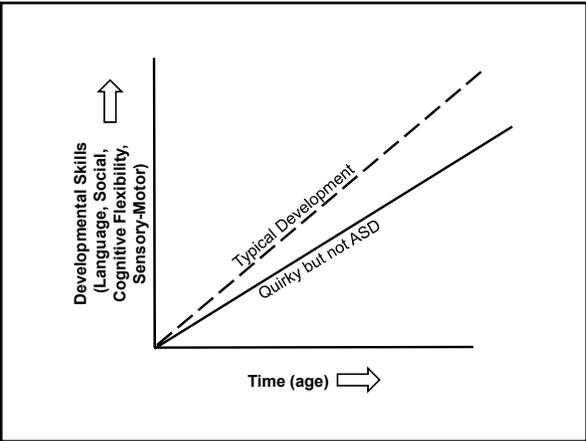
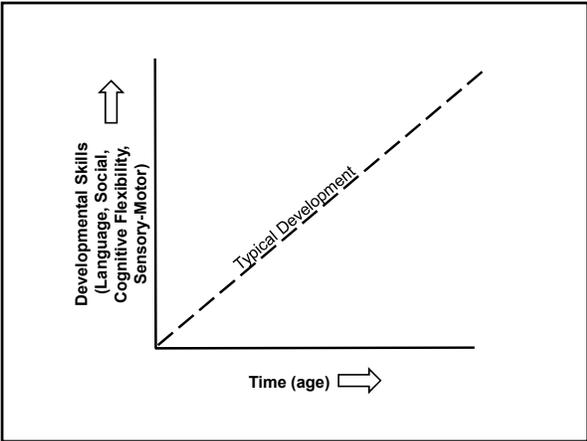
D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

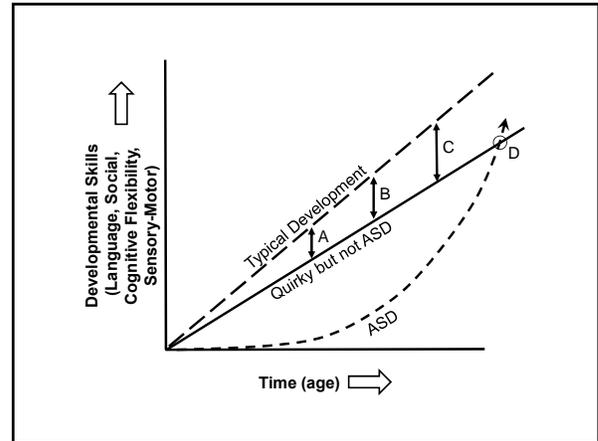
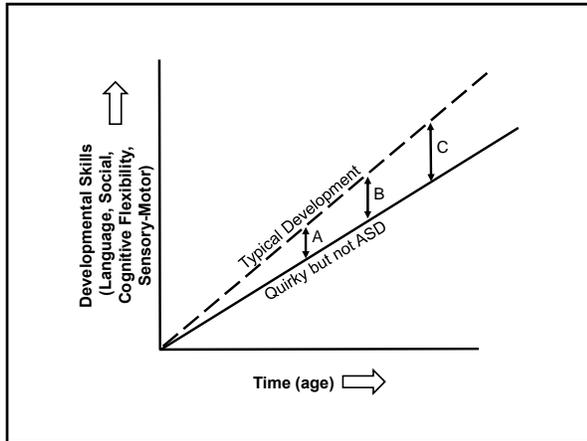
E. These disturbances are not better explained by intellectual disability or global developmental delay.

Growing Into Autism

DSM-5

“Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities....”

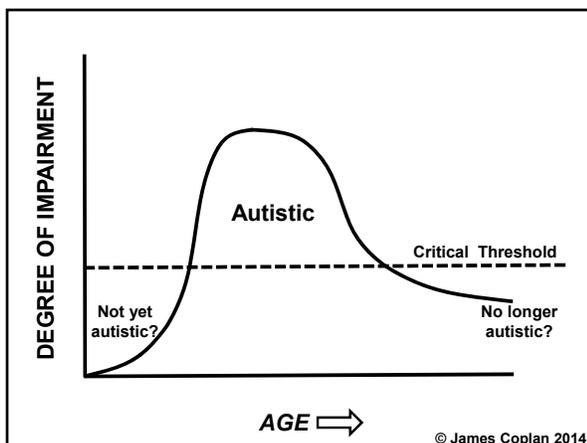




- “Criterion D requires that the features must cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- “Because symptoms change with development and may be masked by compensatory mechanisms, the diagnostic criteria may be met based on historical information, although the current presentation must cause significant impairment.

Prevalence

- “In recent years, reported frequencies for ASD...have approached 1%.... It remains unclear whether higher rates reflect an expansion of the diagnostic criteria of DSM-IV to include subthreshold cases, increased awareness, differences in study methodology, or a true increase in the frequency of autism spectrum disorder.”
 - You're either in or out, and if you're not impaired, you're out --- even if you were “in” when you were younger?
 - This throws the needs of adults with ASD under the bus
 - What about “Broad Autism Phenotype”?



“Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger’s disorder, or PDD-NOS should be given the diagnosis of ASD. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for ASD, should be evaluated for social (pragmatic) communication disorder”

ASD vs. Social (Pragmatic) Communication D/O		
Symptom Domain	Autism Spectrum D/O	Social (Pragmatic) Communication D/O
Social and Language	<ul style="list-style-type: none"> ✓deficits in <i>social-emotional reciprocity</i> ✓<i>nonverbal communication</i>, and ✓<i>maintaining / understanding relationships</i> 	"Deficits in social communication resulting in functional limitations in effective communication, social participation, development of social relationships, academic achievement, or occupational performance"
Restricted, repetitive patterns of behavior, interests, or activities	<ul style="list-style-type: none"> ✓Stereotyped or repetitive motor movements, use of objects, or speech ✓Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal beh. ✓Highly restricted, fixated interests that are abnormal in intensity or focus ✓Hyper- or hyporeactivity to sensory input (at least 2 out of 4) 	Never

ASD vs. Social (Pragmatic) Communication D/O

"Current absence of symptoms would not preclude a diagnosis of autism spectrum disorder, if the restricted interests and repetitive behaviors were present in the past. A diagnosis of social (pragmatic) communication disorder should be considered only if the developmental history fails to reveal any evidence of restricted/repetitive patterns of behavior, interests, or activities"

DSM5

- **The Good**
 - Emphasis on Developmental History, and ability to qualify for a Dx based, in part, on symptoms that may have resolved over time

DSM5

- **The Good**
 - Abnormal sensory processing is now a symptom that counts towards the dx

DSM5

The Bad

- **Lack of awareness of Language as a developmental domain**
 - Combining Language and Social into one domain
 - No mention of pragmatics, apart from impaired socialization
 - Echolalia is listed as a "repetitive behavior"

DSM5

The Bad

- **Lack of awareness of Language as a developmental domain**
 - DSM-IV mischaracterized Asperger syndrome ("No gross delay in language" rather than "relentlessly hyperverbal")
 - DSM5 compounds the error by jettisoning Asperger Disorder

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.

DSM5

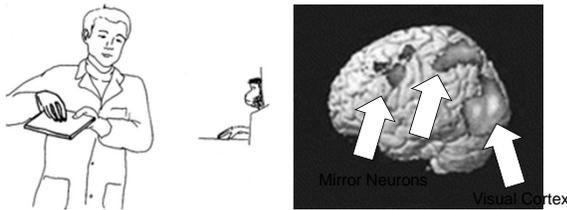
The Bad

- **Lack of awareness of sensory processing and fine motor clumsiness as a developmental domain**

– **Mirror neurons: The basis of motor imitation and empathy?**

- Mostofsky, S.H. and J.B. Ewen, *Altered connectivity and action model formation in autism is autism*. *Neuroscientist*, 2011. 17(4): p. 437-48

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

DSM5

The Bad

- **Lack of 2 sets of criteria**
 - **Research: Restrictive, in order to achieve homogeneity within research sample**
 - **Clinical: Inclusive, in order to assure that nobody who needs services is overlooked**

DSM5

- **The Ugly**
 - **Introduction of Social Pragmatic Language Disorder, and setting it *apart from* (rather than *within*) the Autism Spectrum**

DSM5

- **The Ugly**
 - **In order to get a Dx, one must be *impaired*. "Compensated" ASD is not recognized.**
 - Therapies "**Mask**" rather than "**treat**"
 - **Bring back "ASD, residual state"?**
 - **Mental health issues still present (anxiety, depression, mood, schizophrenia)**
 - **Genetic risk for recurrence still present**

DSM5

The Ugly

- **Up to 10% of children with “high functioning autism” may not meet DSM5 criteria**

	Change From DSM-IV-R	Change To DSM-5
Title	Autistic disorder	Autism spectrum disorder
No. of criteria	12	7
Minimum criteria	6	5
No. of domains	3	2

Helfinstein. JAMA Pediatr. 2013;167(7):608-613. doi:10.1001/jamapediatrics.2013.2168

Molecular Autism 

<http://www.molecularautism.com/series/dsm5>
<http://www.molecularautism.com/content/4/1/13>

Review
Autism in DSM-5: progress and challenges

Fred R Volkmar* and Brian Reichow
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Molecular Autism 2013, 4:13 doi:10.1186/2040-2392-4-13

The electronic version of this article is the complete one and can be found online at:
<http://www.molecularautism.com/content/4/1/13>

Autism in DSM-5: progress and challenges

Fred R Volkmar* and Brian Reichow

- “ASD” as defined in DSM5 might more closely resemble the more classic autism described by Kanner than the broader autism spectrum that might be captured with polythetic criteria...
- *“Despite the name change to Autism Spectrum Disorder, the concept actually proposed is apparently more restricted than the DSM-IV approach”*

The bottom line

- **Most persons with moderate-severe ASD (with or w/o ID) will still meet criteria**
- **Persons with mild ASD and normal IQ are at the greatest risk for exclusion**
- **Evaluation in borderline cases must include a diligent search for early Sx of repetitive behavior**
- **If you’re not impaired, you can’t have ASD (per DSM5)**

THE NEWSPAPER OF THE NATIONAL ASSOCIATION OF SCHOOL PSYCHOLOGISTS
COMMUNIQUE 
SEPTEMBER 2013 VOLUME 41, NUMBER 1

“Implications for School Psychology”
Stephen E. Brock & Shelly R. Hart

“Ultimately, we ask the question as school psychologists: *What does this mean for us?...* The short answer is: Nothing...

The work of school psychologists is, and always has been, *informed* by DSM. DSM has never been a controlling authority....

THE NEWSPAPER OF THE NATIONAL ASSOCIATION OF SCHOOL PSYCHOLOGISTS

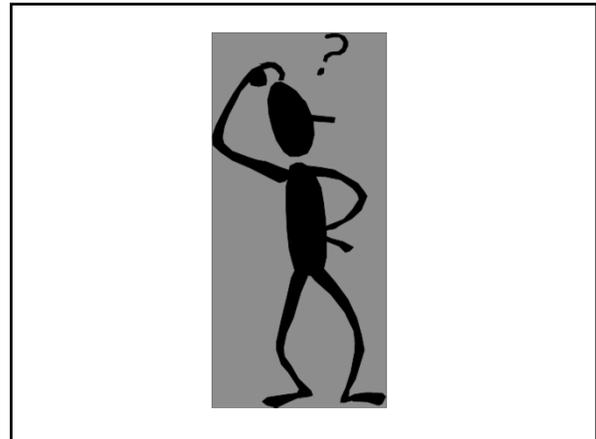
COMMUNIQUE

SEPTEMBER 2013

“The simple presence of a DSM diagnosis for a student we serve can and should direct our attention, but it never should direct our action.

The education codes and regulations that do direct our action (i.e. IDEA) require clear evidence of an adverse effect on educational functioning, and, as a result, some might argue are more restrictive in this setting than DSM*...”

(* Some of us would beg to differ: Anxiety w/o academic failure, e.g.)



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Quantifying severity of ASD, and changes over time

➔

Clinical Domain	Decreasing Atypicality → Increasing Age →		
	Severe / Youngest	Moderate / Older	Mild / Older
<ul style="list-style-type: none"> • Social • Language • Repetitious Behavior • Sensory 			

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

Social Interaction

“Our child is *among* us, but not *with* us.”
Parent of a 4 year old with ASD

www.drcoplan.com

↓

Clinical Domain ↓	Decreasing Atypicality / Increasing Age ⇒		
	Severe / Youngest	Moderate / Older	Mild / Older
1. Social Interaction	<ul style="list-style-type: none"> •No eye contact •No physical affection •Cannot be engaged in imitative tasks 	<ul style="list-style-type: none"> •Intermittent eye contact •Seeks affection “on his own terms” •May invade personal space of others (not true affection) •Engageable in imitative tasks, although with difficulty 	<ul style="list-style-type: none"> •Good eye contact •Shows interest in others, but often does not know how to join in •Easily engaged in imitative activities •Rigid; has difficulty if perceives that rules have been broken •Difficulty with “Theory of Mind” tasks

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↓

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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

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Theory of Mind

Muff

Muff is a little yellow kitten.
She drinks milk.
She sleeps on a chair.
She does not like to get wet.

What is this story about?
How would Muff feel, if you gave her a bath?

•Clean

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Theory of Mind

Camping

Six boys put up a tent by the side of the river. They brought things to eat with them. When the sun went down, they went into the tent to sleep. In the night, a cow came and began to eat grass around the tent. The boys were afraid. They thought it was a bear.

Q: Is this a sad story, a scary story, or a funny story?

- A scary story, because the boys were scared. (PDD-NOS)
- A scary story, because of the bear. (PDD-NOS)
- It's actually not scary, because how could you think a bear is a cow? They make different sounds. (HFA)
- It was a most unusual story, because you don't often find cows in the woods. (Asperger Syndrome)

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Theory of Mind



How does the boy feel?
Why?

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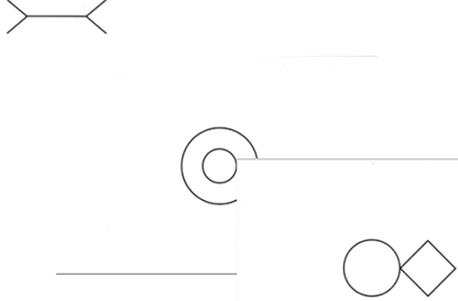
Theory of Mind



Q: How does the boy feel?
A: "I don't know, because I can't see his mouth."

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Bender-Gestalt II



Eye Contact

- 15 y.o. boy, normal IQ, no SDI; referred for eval. of possible reading disability.
- Does not look up after each Bender card.

Q: "Did you know that there are two ways you can tell me you're done: Say 'done,' or look up?"
A: "No, no one ever taught me that."

Eye Contact

Q: How am I supposed to know when you're ready for another card?
A: Because my pencil has stopped moving?

Q: Why is it important to look up after each card?
A: To see if I got the right answer?

Q: When you look up, what does that tell me?
A: That I'm paying attention?



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Language

"My child talks, but he doesn't communicate."
Mother of a 3 year old with autism

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Language Deficits in ASD

- **Pragmatics:** Use of language for the purpose of social interaction
 - Framing
 - Topic maintenance
 - Conversational repair
 - Impaired Pragmatics:
 - Nonverbal
 - Echolalia, delayed echolalia
 - Off-topic responses
 - Person talks “at” rather than “with” partner

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Language Deficits in ASD

- **Prosody:** Tone, Pitch, Volume
 - Stilted
 - Sing-song
 - Robotic
 - Pedantic
 - Overly loud

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Quantifying severity of ASD - 2

Clinical Domain ↓	Decreasing Atypicality / Increasing Age ⇒		
	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	•Echolalia, Delayed echolalia •Verbal Perseveration •Odd Inflection (stilted, sing-song, ↕ volume) •May use stock phrases in an attempt to communicate •Makes use of visual communication modalities (symbol cards; sign language)	•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-believe)

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Quantifying severity of ASD - 2

Clinical Domain ↓	Decreasing Atypicality / Increasing Age ⇒		
	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	•Echolalia, Delayed echolalia •Verbal Perseveration •Odd Inflection (stilted, sing-song, ↕ volume) •May use stock phrases in an attempt to communicate •Makes use of visual communication modalities (symbol cards; sign language)	•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-believe)

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Quantifying severity of ASD - 2

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Language Deficits in ASD: Literal Thinking

- 5 ½ year old boy with ASD and Superior IQ (Verbal Comprehension Index: 146)

Q: “Which is bigger, 9 or 6?”

A: “They are both the same size, but 9 has a loop at the top, and 6 has a loop at the bottom.”

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MRN 10-0681



Repetitious Behavior
“My child has over-attention deficit disorder.”
Father of a 10 year old with autism and perseverative behavior

Quantifying severity of ASD - 3

Clinical Domain ↓	Decreasing Atypicality / Increasing Age ⇒		
	Severe / Youngest	Moderate / Older	Mild / Older
3. Repetitious Behaviors <i>Cognitive</i>	<ul style="list-style-type: none"> •Extreme distress if routines are changed or when required to transition from one task to another •Fascination with odd objects (tags, wheels, fans, etc.) 	<ul style="list-style-type: none"> • 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) 	<ul style="list-style-type: none"> • 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
<i>Motoric</i>	<ul style="list-style-type: none"> •Frequent, intense stereotypical movements (flapping, spinning, toe-walking, finger twiddling) 	<ul style="list-style-type: none"> • Motor stereotypies occasional; may re-emerge when excited 	<ul style="list-style-type: none"> • Motor stereotypies rare or absent

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Quantifying severity of ASD - 3

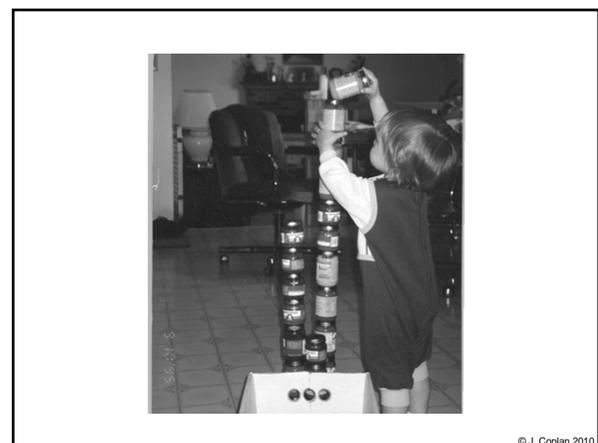
Clinical Domain ↓	Decreasing Atypicality / Increasing Age ⇒		
	Severe / Youngest	Moderate / Older	Mild / Older
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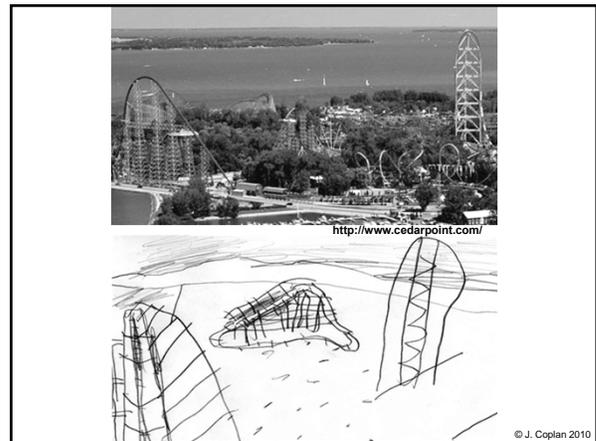
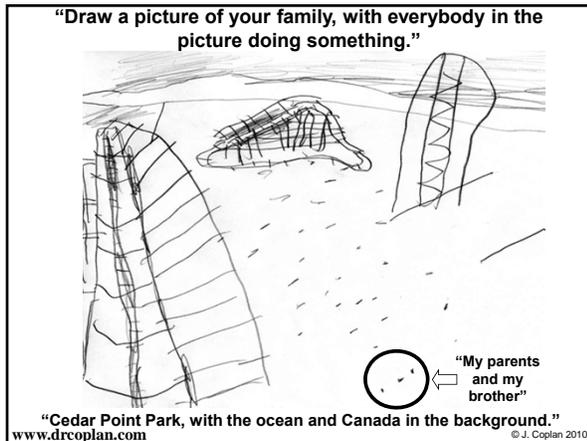
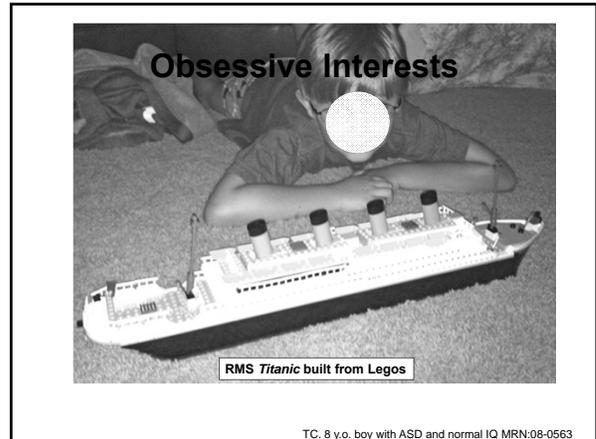
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Central Coherence

- Ability to see "the big picture" rather than a collection of individual elements

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Tasks requiring Central Coherence (in addition to Theory of Mind)

ToM & Central Coherence

The dog.

A little black dog ran away from home. He played with two big dogs. It began to rain. He ran under a tree. He wanted to go home, but he did not know the way. He saw a boy he knew. The boy took him home.

Q: How did the dog get home?
A: By knocking on the door?

DC, 8 10/12 male, ASD & normal NVIQ
MRN: 07-0652

What's happening in this picture?



What's happening in this picture?



“The man is drowning.”

What's happening in this picture?



“The man is swimming, and the car is about to fall on him.”

What's happening in this picture?



A: The man took off his clothes and jumped in the water.
Q: Why did he do that?
A: Because the car was about to crash?

Can you figure out this story from the pictures?





Q: What's happening in this picture?

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Q: What's happening in this picture?
A: The kitten is on the boy's back and is about to eat him.

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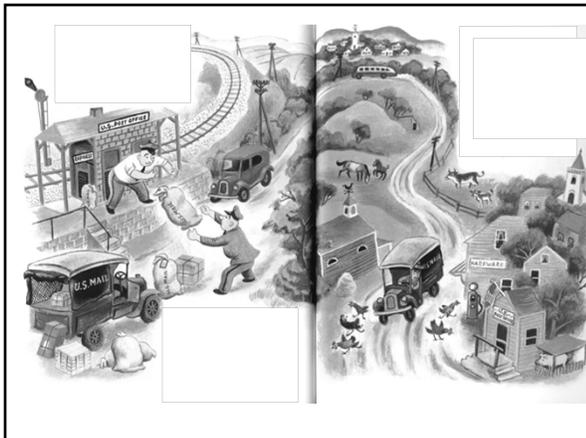
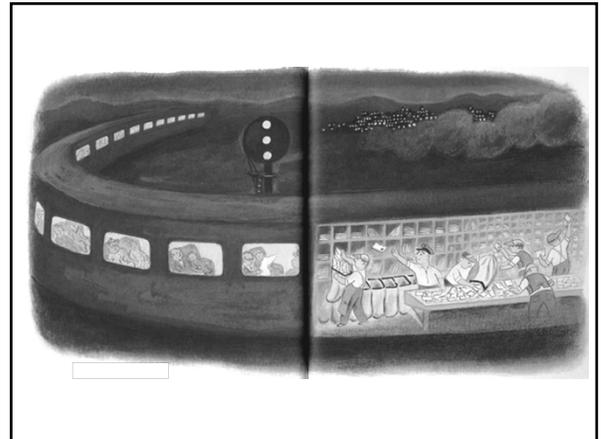
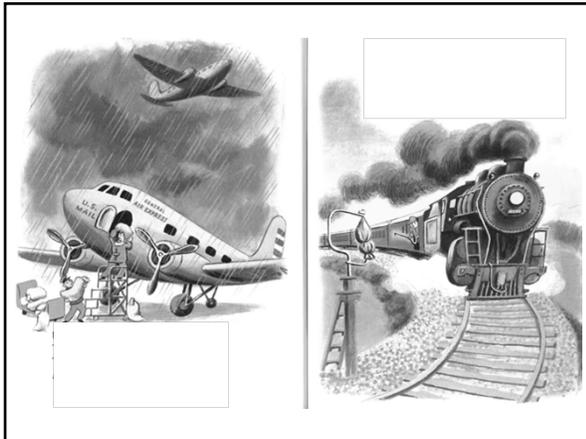
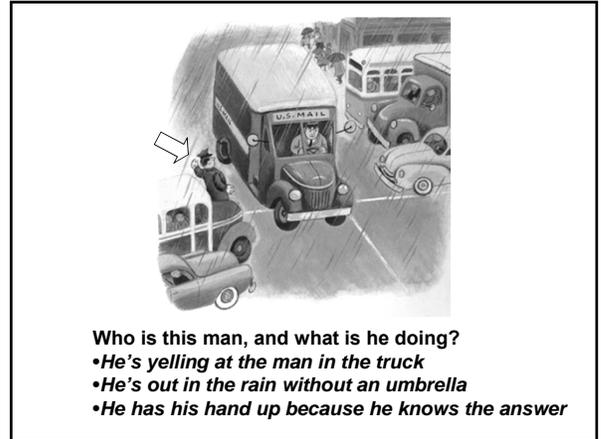
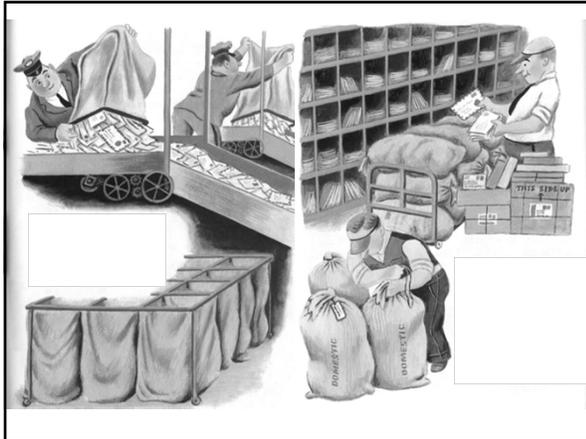


Q: What's happening in this picture?
A: The boy is hoarding animals.



Where is the letter now?







Q: Who is that?
A: A grandmother.

Q: Whose grandmother is she?
A: I don't know.

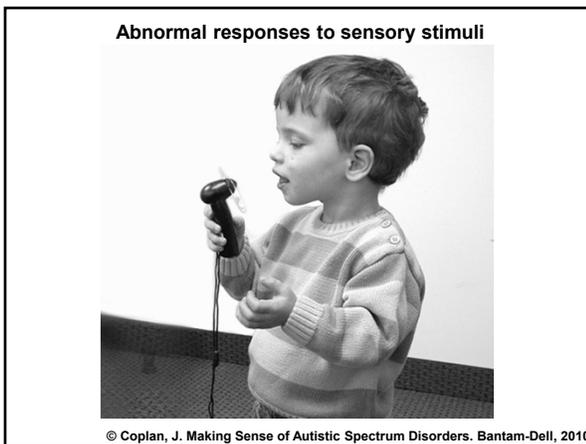
Q: Who sent her the letter?
A: "The policeman?"

Sensory & Motor Processing

Quantifying severity of ASD - 4

Clinical Domain ↓	Decreasing Atypicality / Increasing Age ⇒		
	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: Sniffing •Extreme food selectivity •Pain threshold •Fears: Heightened / blunted	Same, but diminishing intensity	Same, but diminishing intensity

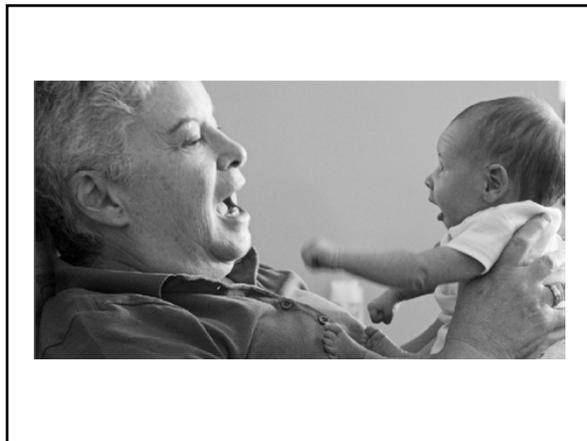
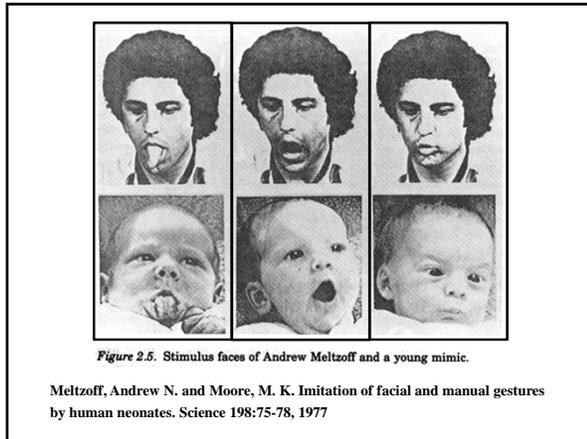
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Mirror Neurons: The Missing Link?

"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



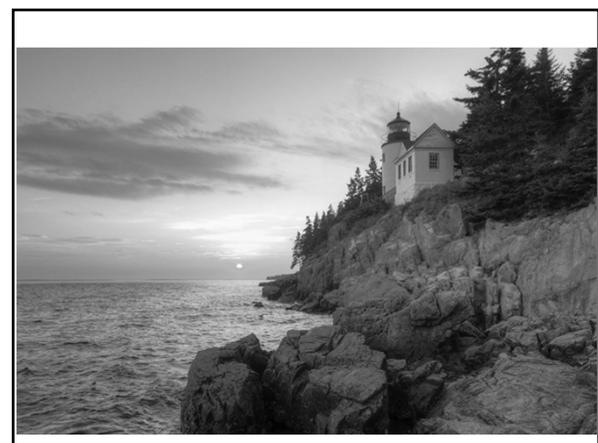
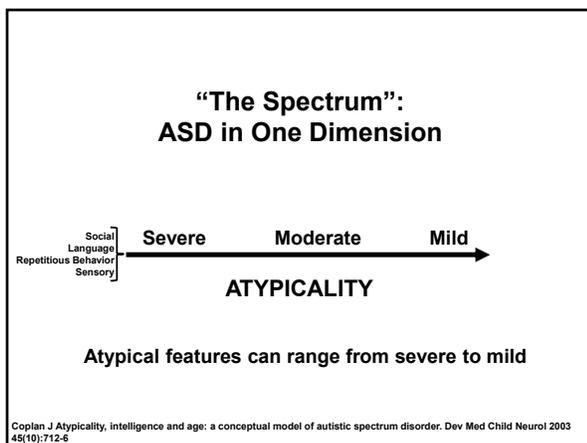
Altered Connectivity and Action Model Formation in Autism Is Autism

The Neuroscientist
17(4) 437-448
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DOI: 10.1177/1073858410392381
<http://nss.sagepub.com>
SAGE

Stewart H. Mostofsky¹ and Joshua B. Ewen²

Figure 1. Brain regions associated with praxis and imitative function

“Children with autism place a greater than normal reliance during motor learning on their own proprioception while discounting visual consequences in the extrinsic world”



Outline

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 - A. Leo Kanner revisited
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Influence of IQ on Prognosis

- “In terms of scholastic progress, social competence, and work opportunities, the child’s IQ level is as influential as the presence of autism.”*
- 1973-2005: > 10 studies; >1000 subjects (reviewed in Coplan, 2010, Appendix II)

* Bartak, L. and M. Rutter. Differences between mentally retarded and normally intelligent autistic children. Journal of Autism & Childhood Schizophrenia, 1976. 6(2): p. 109-20

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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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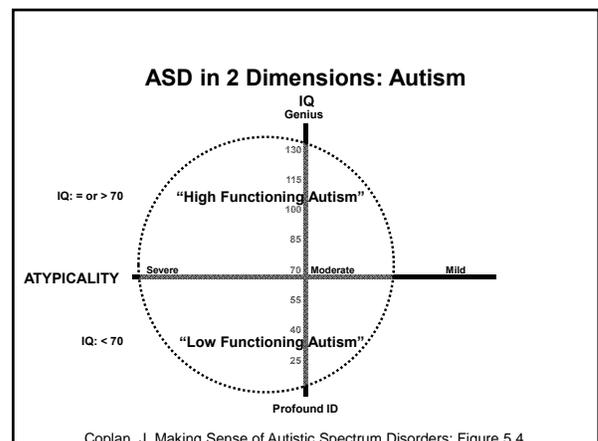
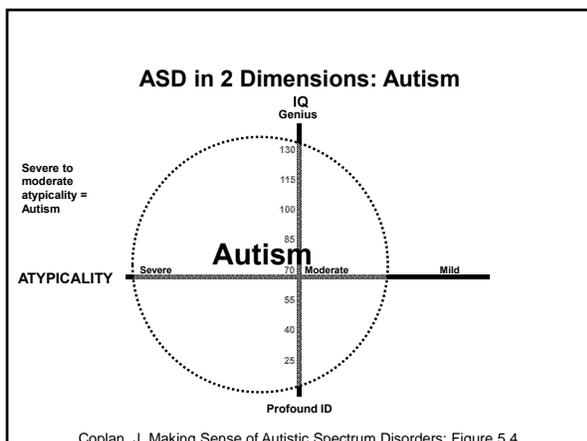
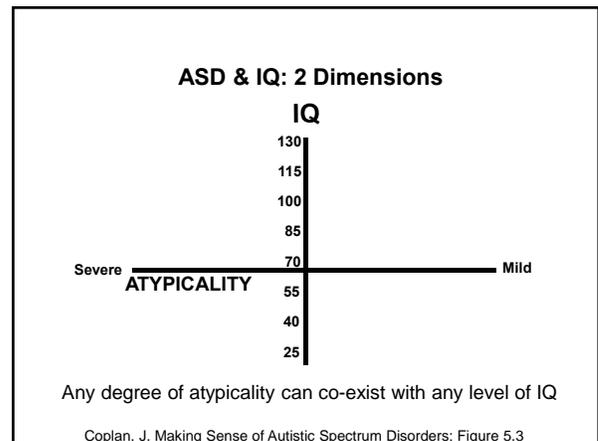
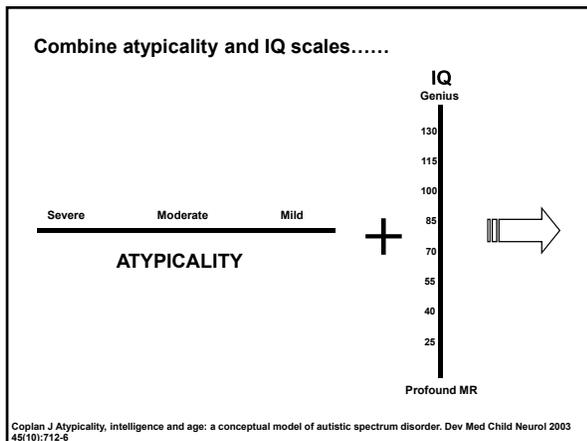
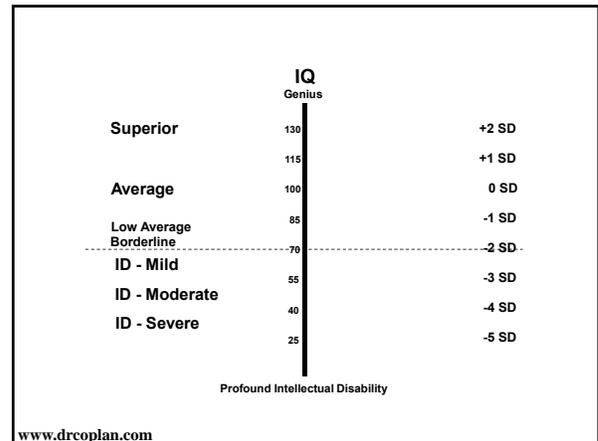
Play

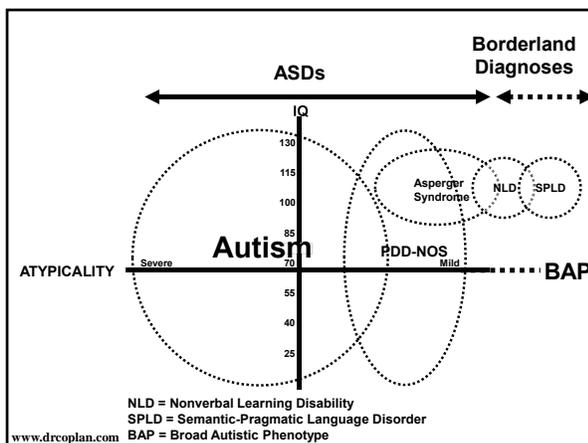
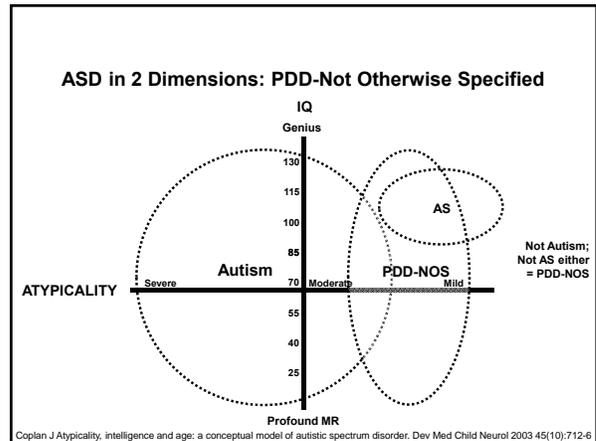
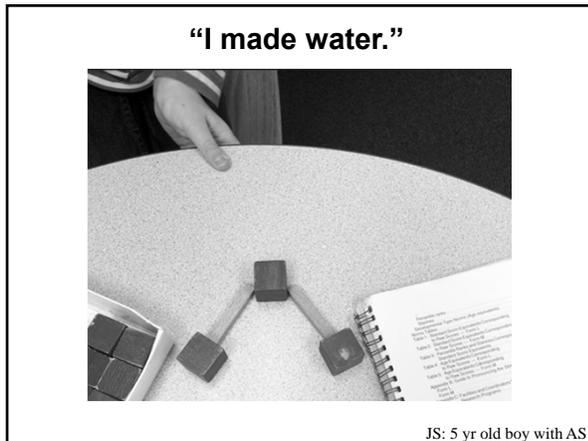
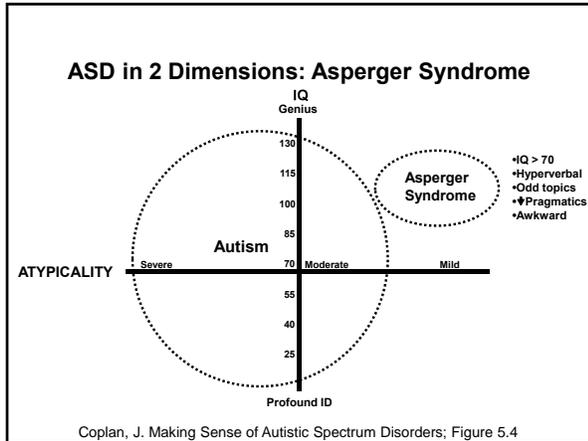
- Midline hand play (3 mo)
- Banging & Mouthing (7 - 9 mo)
- Casting (12 mo)
- Tools (crayon) ~ 14 mo
- Cause & Effect (14 to 16 mo & up)
- Imitative Play (24 mo)
- Imaginative Play (36 mo)
- Rule-based Play (48 mo)

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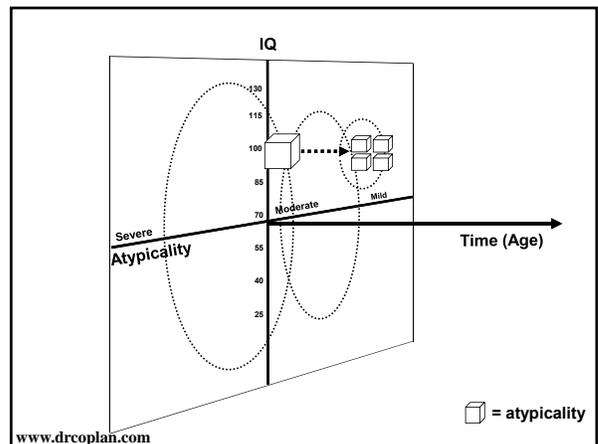
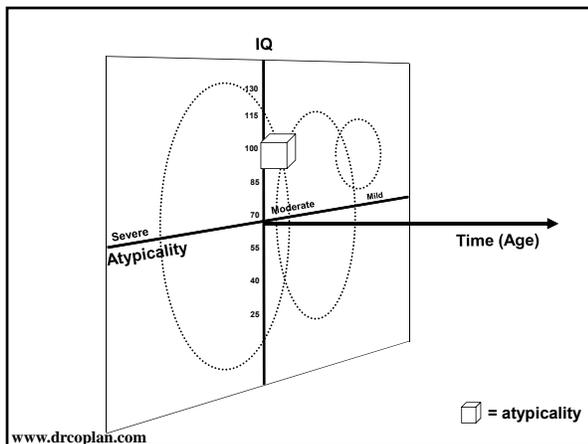
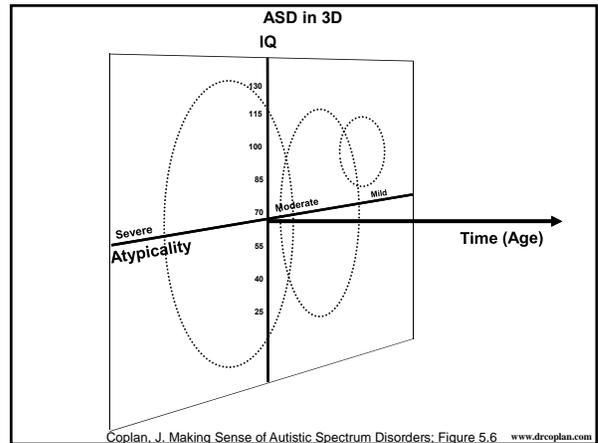
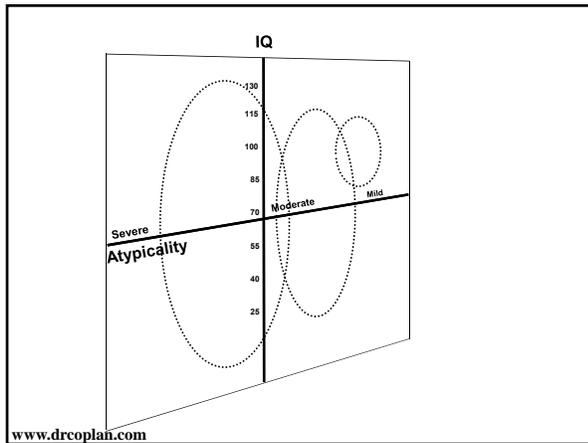
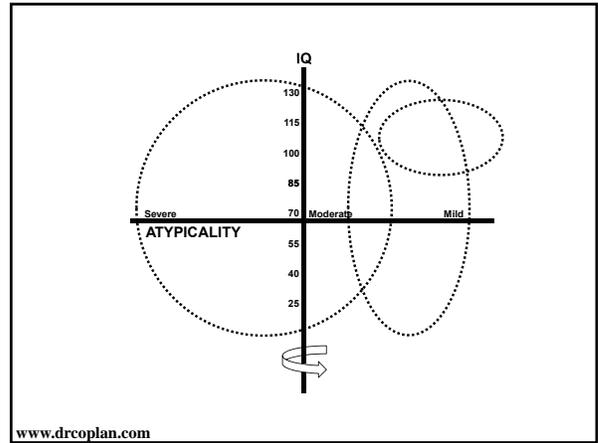
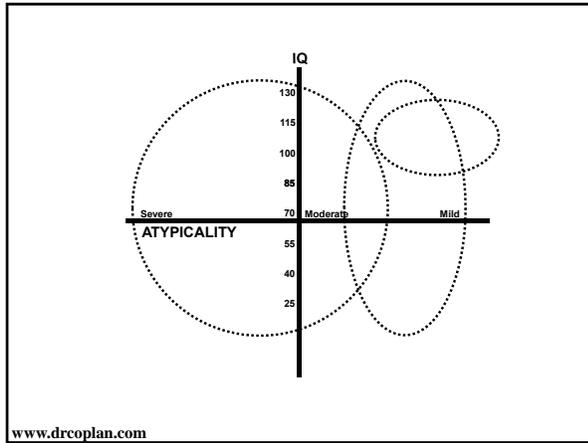
Cognitive & Academic Profile in ASD

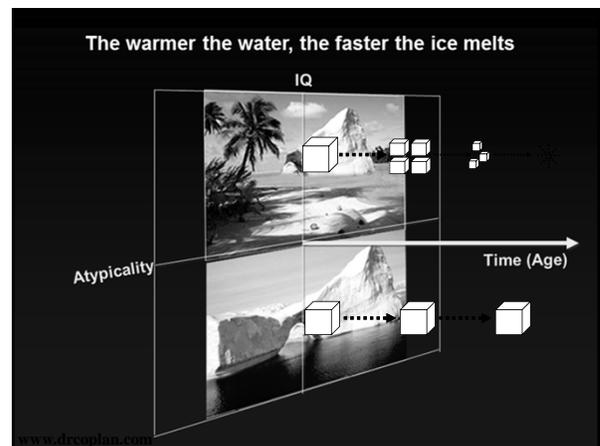
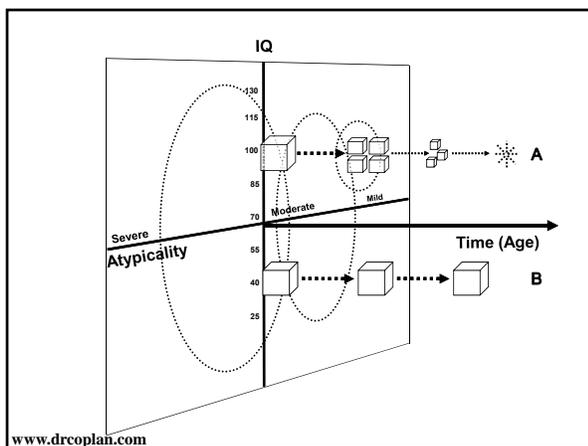
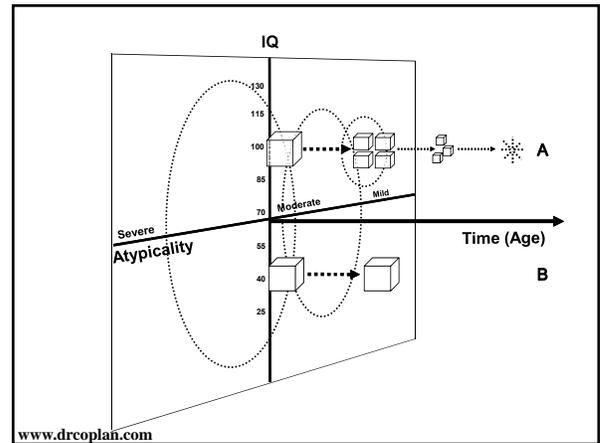
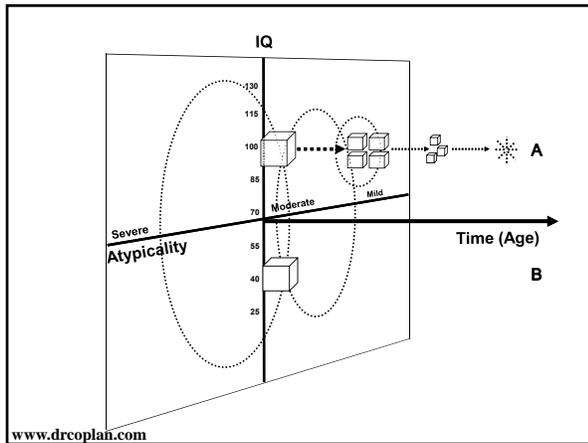
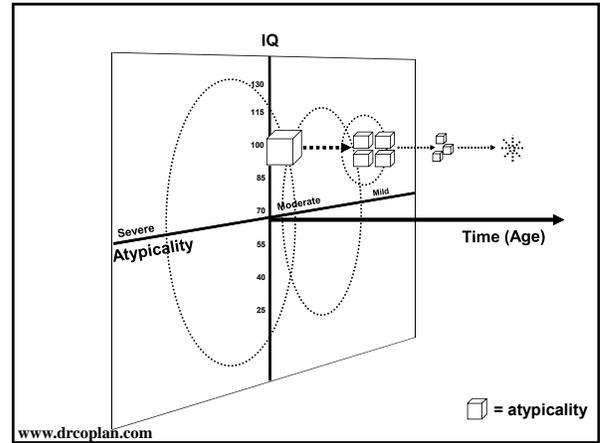
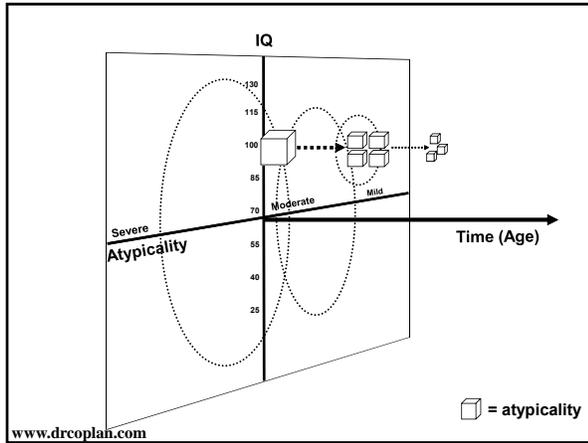
<p>Weaker</p> <p>Fluid Verbal Intelligence</p> <ul style="list-style-type: none"> • WISC: <i>Comprehension</i> • Reading comprehension (>2G) • Oral pragmatics <p>Often</p> <ul style="list-style-type: none"> • Executive Dysfunction <ul style="list-style-type: none"> • Working Memory Index • Processing Speed Index <p>[Obsessive Mentation and/or Anxiety can mimic ADD]</p> <p>BASC: Anxiety, Attention, Atypicality, Withdrawal (look for differences between raters)</p>	<p>Stronger</p> <p>Crystallized Verbal Intelligence</p> <ul style="list-style-type: none"> • WISC: <i>Information, Vocabulary</i> • Reading comprehension <2G • Pseudoword decoding <p>Non Verbal Intelligence</p> <ul style="list-style-type: none"> • WISC: <i>BD, Matrices</i>
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- ### 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)
- www.drcoplan.com



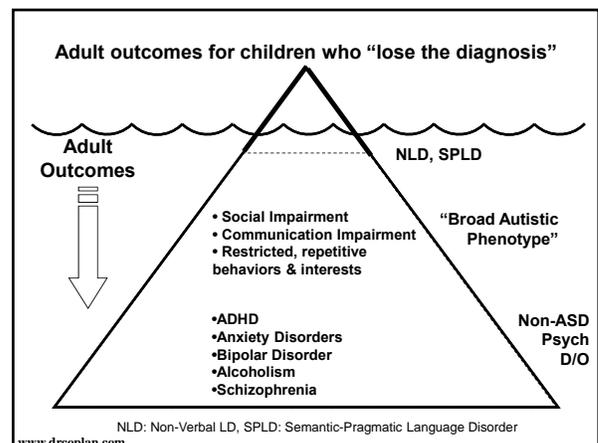
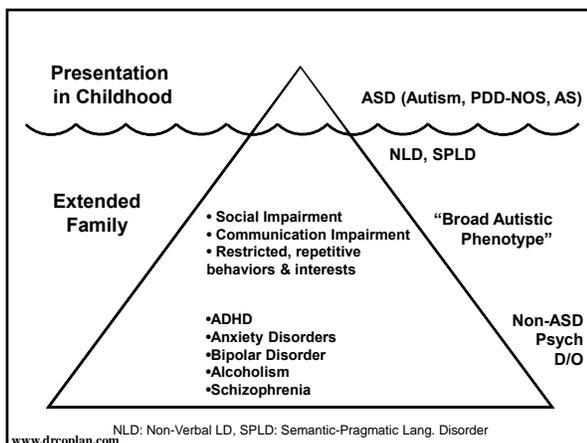
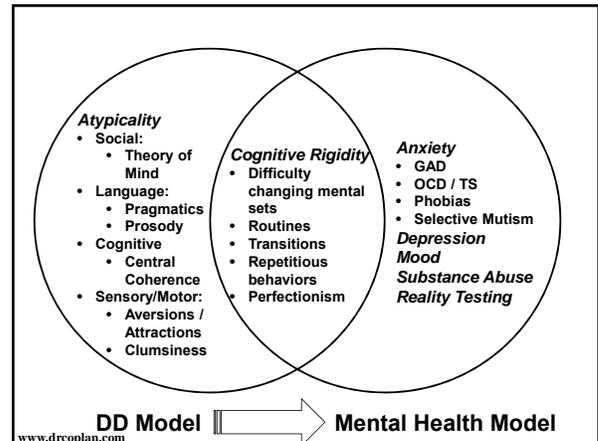
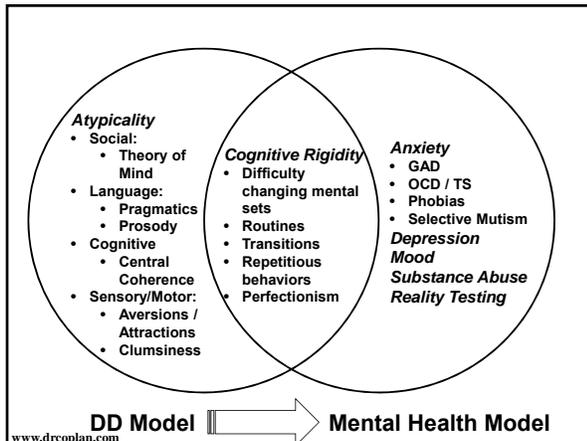




Adult outcome

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

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Summary

- **ASD: 4 domains (Kanner)**
 - Social
 - Language
 - Repetitious behavior
 - Sensory

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Summary

- **Natural History is for improvement over time, regardless of intervention**
- **Long-term outcome is driven by the joint impact of IQ and degree of atypicality**

Coplan, J., Counseling parents regarding prognosis in autistic spectrum disorder. Pediatrics, 2000. 105(5): p. E65

Summary

- **“Losing the diagnosis” does not = “cure”**
- **Shift from Developmental Disability model to Mental Health model**
- **Need for adult services**

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Summary

- **3D “map” of ASD + IQ + Time:**
 - **Facilitates:**
 - Tracking child’s progress over time
 - Selecting best therapy at any given point in time
 - Anticipating future needs (prognosis)
 - Accounts for differences in outcome
 - Accounts for ↑ prevalence of children with Dx
 - Serves as a benchmark for intervention research (Is the child “more better” than would have been the case based on natural history alone?)

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Interventions: Issues

- **Lack of controlled studies**
 - What is the best therapy?
 - How much therapy is “enough”?
 - How much progress is due to therapy, and how much to natural history of ASD?
- **Therapeutic dogmatism**
 - The blind men and the elephant

THE BLIND MEN AND THE ELEPHANT
(Traditional Indian folk tale)

It was six men of Indostan,
To learning much inclined,
Who went to see the Elephant,
(Though all of them were blind,)
That each by observation
Might satisfy his mind.

The First approached the Elephant,
And happening to fall
Against his broad and sturdy side,
At once began to bawl:
"God bless me!-but the Elephant
Is very like a wall!"

The Second, feeling of the tusk,
Cried "Ho! what have we here
So very round and smooth and sharp?
To me 't is mighty clear
This wonder of an elephant
Is very like a spear!"

The Third approach the animal,
And, happening to take
The squirming trunk with in his hands,
Thus boldly up and spake:-
"I see," quoth he, "the Elephant
Is very like a snake!"

The Fourth reached out his eager hand,
And felt about the knee;
"What most this wondrous beast is like
is mighty plain," quoth he;
"'T is clear enough the Elephant
Is very like a tree!"

The Fifth, who chanced to touch the ear,
Said "Even the blindest man
Can tell you what this resembles most:
Deny the fact who can,
This marvel of an Elephant
Is very like a fan!"

The Sixth no sooner had begun
About the beast to grope,
Than, seizing on the swinging tail
That fell within his scope,
"I see," quoth he, "the Elephant
Is very like a rope!"

And so these men of Indostan
Disputed loud and long,
Each in his own opinion
Exceeding stiff and strong,
Though each was partly in the right,
And all were in the wrong!

Clever Stories of Many Nations, Rendered in Rhyme
John Godfrey Saxe, 1865



Clever Stories of Many Nations, Rendered in Rhyme
John Godfrey Saxe, 1865

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Therapeutic Dogmatism

(Six Blind Men and the Elephant)

Is ASD:

- a sensory processing disorder...
- a language disorder...
- a social disorder...
- a behavioral disorder...
- a learning disorder...
- a neurological syndrome...?

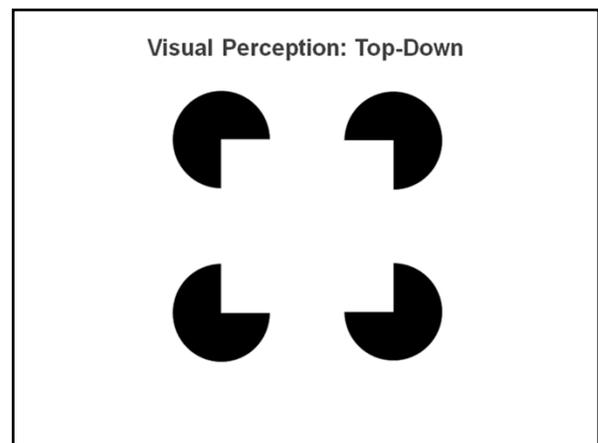
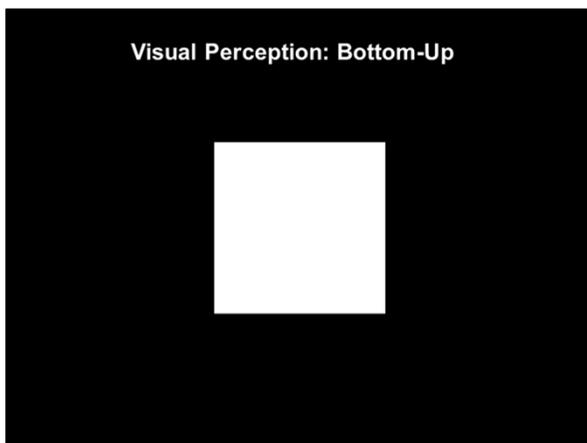
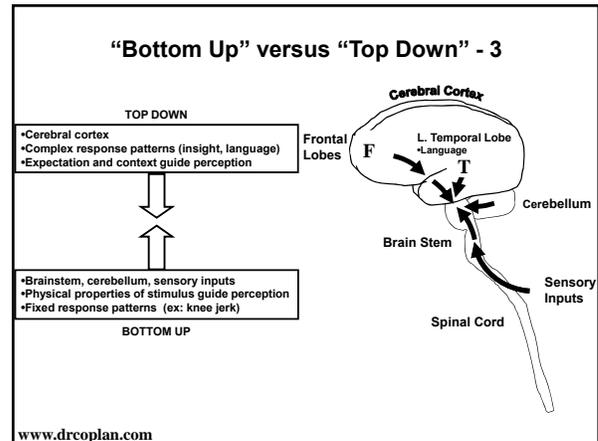
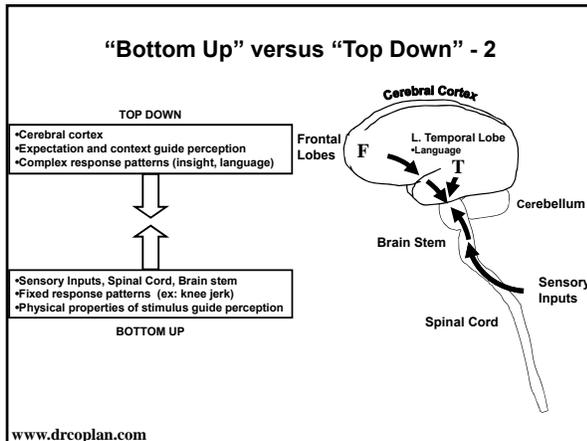
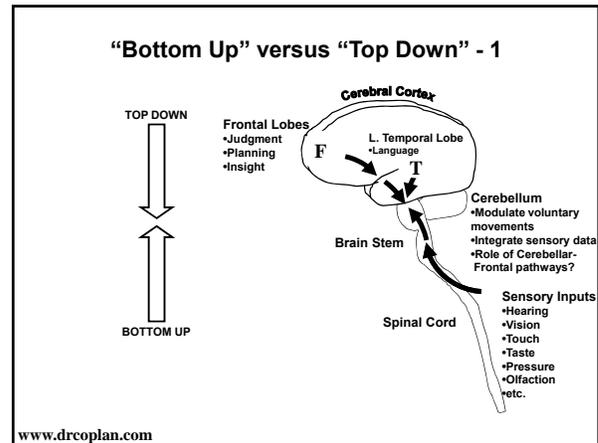
Answer: All of the Above (and More)

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Therapies for ASD: A Modest Proposal

- Therapies for ASD should be matched to the natural history of ASD itself
 - *As the child’s symptoms evolve, so should the forms of therapy*
 - *It’s not a matter of right vs wrong; It’s a matter of what & when*

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Language: Bottom-Up vs Top Down
(Literal meaning, vs. Context)

“The chicken is ready to eat.”

www.drcoplan.com



“The chicken is ready to eat.”

www.drcoplan.com

Cognitive Orientation of Therapy

Top-Down ↓

- Concept-driven
- Learner-directed
- Focus on complex linguistic & social skills
- Explicit understanding is a goal
- Strategizing by child is required

↕

- Therapist and child work as partners
- Works on foundation and target skills
- Explicit understanding may be a goal
- Strategizing by child may be required

↑

Bottom-Up

- Stimulus-driven
- Therapist-directed; learner initiation is minimal
- Focus on foundation skills (attending, reciprocating)
- Explicit understanding is not a goal
- Strategizing by child is not required

Therapy Goals

Top Down ↓

Top-down therapies
teach concepts

Cognitive Orientation of Therapy

↑

Bottom Up

Bottom-up therapies
shape behavior

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Moving from One Stage to the Next

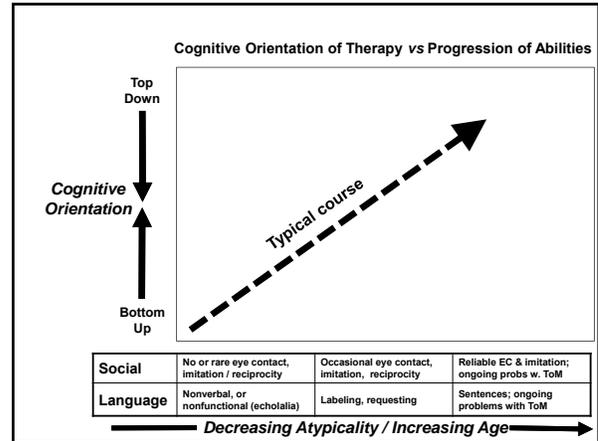
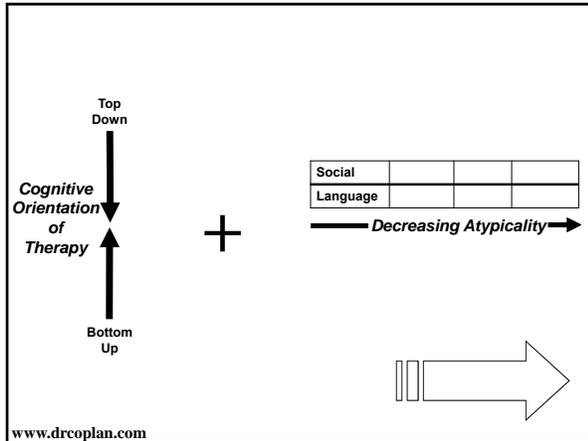
- Social Reciprocity**
 - Attending to others
 - Imitation of others
 - Initiation of interaction with others

Degree of Atypicality

	Severe	Moderate	Mild
Social	No or rare eye contact, No social reciprocity (imitation; initiation)	Occasional eye contact & social reciprocity	Reliable EC & reciprocity; Ongoing problems with Theory of Mind (personal space, rules, etc.)
Language	Nonverbal, or nonfunctional (Echolalia, delayed echolalia)	Labeling, requesting; +/- commenting, reciprocating	Commenting, reciprocating; Ongoing problems with Theory of Mind (humor, make-believe, fibbing, etc.)

← Decreasing Atypicality →

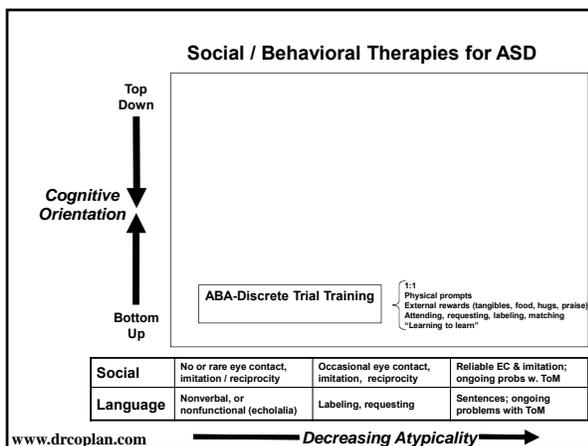
www.drcoplan.com



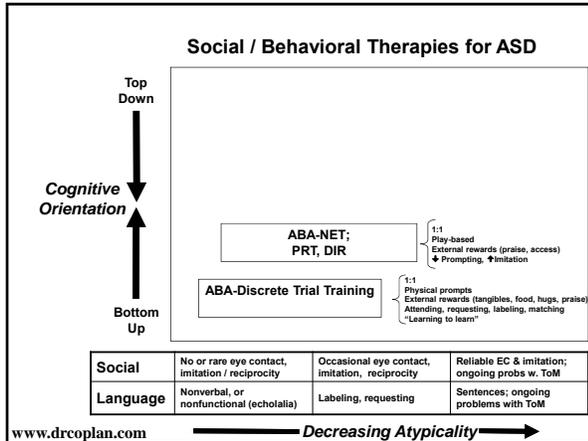
Social and Behavioral Therapies

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- Applied Behavior Analysis – Discrete Trial Training (ABA-DTT)**
- **Therapist-driven**
 - 2:1 ➔ 1:1
 - Physical prompts ➔ Verbal prompts
 - Initiation by child = 0
 - **Rewards: External**
 - Food, tangibles, hugs, praise
 - **Goals: Attending, matching, labeling**
 - **Meta-goal: “Learning to learn”**
- www.drcoplan.com



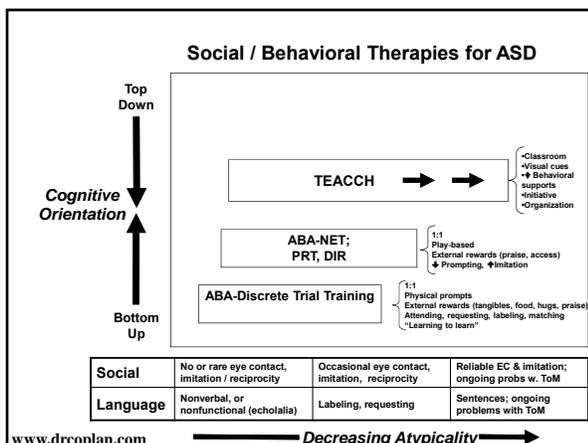
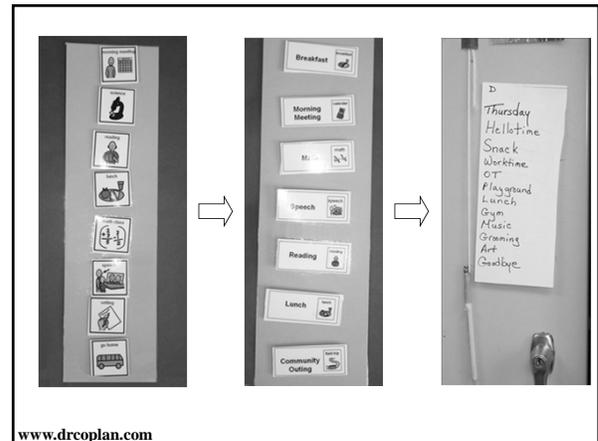
- ABA-Natural Environment Training (NET); Pivotal Response Treatment (PRT) Floor Time (DIR)**
- **Child-driven / Play-based**
 - Therapist playfully obstructs child’s activities
 - **Rewards: Internal**
 - Child regains access to desired object or activity
 - **Goals:**
 - ↓ Prompting by adult
 - ↑ Initiation with adult
- www.drcoplan.com



TEACCH
(Treatment and Education of Autistic and related Communication-handicapped Children)

- **Classroom-based**
- **Make expectations clear & explicit**
- **Visual cues**
 - Environmental organization
 - Visual schedules
- **Teacher available if child gets stuck**
- **Goals: Initiative, organization**

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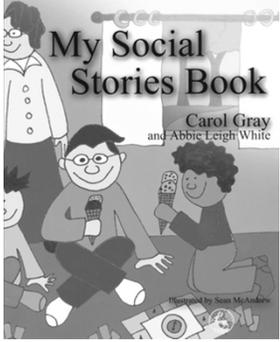
Social Skills Training

- **Recognize the thoughts & feelings of others ("Theory of Mind")**
- **Narrative**
 - Social Stories™
 - Social Skills Picture Book
 - Many others....
- **Interactive**
 - Social Skills Groups

www.drcoplan.com

“Will my friend use my toys?”

“A friend is coming to my home. My friend knows I have toys. My friend is hoping to have a turn playing with my toys. I may let my friend play with my toys for a short time. This is called sharing my toys. My friend knows my toys belong to me. He knows my toys stay with me when we are finished playing. Someday, my friend may share his toys with me.”



My Social Stories Book
Carol Gray and Abbie Leigh White

The Social Skills Picture Book
Jed Baker, PhD

- Enables child to see the thoughts of others, by clever use of “thought bubbles”



www.drcoplan.com

Therapies for ASD

- **Social Skills Groups**
 - Structured interaction with peers
 - Emphasis on language pragmatics & social interaction (sharing, turn-taking, empathy, co-operation, social “rules of the road”)
 - Usually run by Speech Language Pathologist, OT, Special Ed Teacher, or other trained child development specialist

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Social / Behavioral Therapies for ASD

Cognitive Orientation

Top Down

Bottom Up

1:1 → Small group
Perspective-taking
Role-playing
Social context

**Social Stories
Social Skills Groups**

TEACCH → →

- Classroom
- Visual cues
- Behavioral supports
- Initiative
- Organization

1:1
Play-based
External rewards (praise, access)
↓ Prompting, ↑ Imitation

**ABA-NET;
PRT, DIR**

1:1
Physical prompts
External rewards (tangibles, food, hugs, praise)
Attending, requesting, labeling, matching
“Learning to learn”

ABA-Discrete Trial Training

Social	No or rare eye contact, imitation / reciprocity	Occasional eye contact, imitation, reciprocity	Reliable EC & imitation; ongoing probs w. ToM
Language	Nonverbal, or nonfunctional (echolalia)	Labeling, requesting	Sentences; ongoing problems with ToM

www.drcoplan.com **Decreasing Atypicality** →

Language Function / Language Therapies

Cognitive Orientation

Top Down

Bottom Up

- Use of language: Social
 - Conversation
 - Humor
 - Fibbing
 - Make-Believe
- Meaning is context-dependent
 - “The chicken is ready to eat”
- Use of language: Instrumental (obtain goal)
 - “Want chip”
- Meaning is invariant
 - “Touch square”

www.drcoplan.com

Language Therapy Philosophies

- **Behaviorism**
 - ABA-Discrete Trial Training (DTT)
 - Verbal Behavior (VB)
- **Traditional speech therapy**
- **Social Skills Groups**

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Behaviorism

- All behavior is the result of prior experience
- Behaviorists deny the existence of “understanding,” “thought,” “intuition,” etc.
 - Johnny says “I want an apple” not because “he knows what it means,” because the last 1000 times he emitted that behavior, he received an apple.
- The focus of behavioral therapy is to *shape behavior* (not to impart understanding)

ABA-DTT: Receptive

- Tacting (“Touch square”)
 - 2:1 ratio initially
 - Full physical prompt ➔ Faded
 - External rewards (edibles, hugs, etc.)
- Meta-Goals
 - Attending to the therapist
 - Following verbal instructions
 - Discrimination within sets

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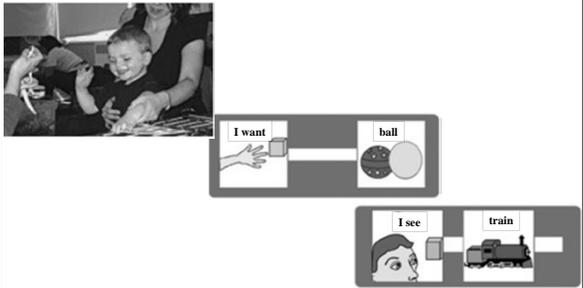
Discrete Trial Training: Expressive

- Manding (Picture Exchange)
 - 2:1 ratio initially
 - Full physical prompt ➔ Faded
- No verbalization required
- May enhance speech; data weak
- Requires cards / board / computer

www.drcoplan.com

Picture Exchange

Picture Exchange Communication System (PECS)
Pyramid Educational Products, Inc.



www.drcoplan.com <http://www.pecusa.com/pecs.php>

Language Therapies ASD

Top Down

↓

Cognitive Orientation

↑

Bottom Up

DTT: Tacting, Picture Exchange

Social	No or rare eye contact, imitation / reciprocity	Occasional eye contact, imitation, reciprocity	Reliable EC & imitation; ongoing probs w. ToM
Language	Nonverbal, or nonfunctional (echolalia)	Labeling, requesting	Sentences; ongoing problems with ToM

www.drcoplan.com **Level of Function** ➔

Verbal Behavior (VB)

- Begin immediately with focusing on the child’s interests
 - a. Gain control of “Echoic function” (verbal imitation)
 - b. Pair the child’s utterance with a desired object
 - c. Requesting (“manding” for desired items)
 - Picture Exchange or Sign if nonverbal
- Then move on to:
 - a. Verbal labeling of objects (“tacting”)
 - b. Object matching by form, function & class
 - c. “Intraverbal behavior”



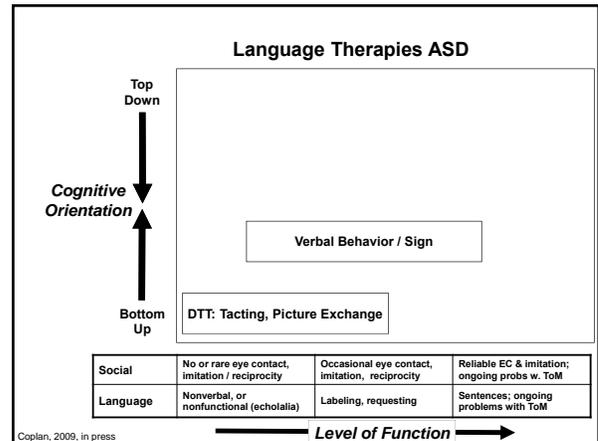
SIGN

- **Pro's**
 - Easier to learn than speech
 - Enhances speech development
 - Can be taught hand-over hand
 - Children with ASD frequently rely on H-O-H
 - Does not require cards, boards, etc.
- **Con's**
 - Does require physical dexterity
 - Does require others to know Sign

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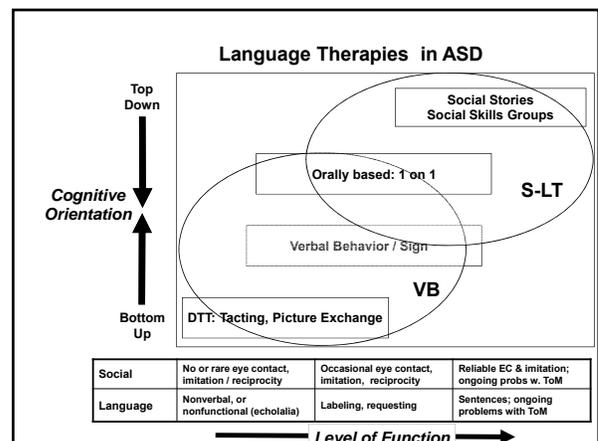
Augmentative Communication Devices

KS. 18; profound ID & Autism; MRN 05-0092



Traditional Speech-Language Therapy

- 1-on-1 ➔ Pair with peer ➔ Small Group
- Often play-based
- Eclectic; no single method
- Requires child to attend and imitate
- Goals: Instrumental ➔ Social



Behaviorism

“The analysis of skills for the purpose of diagnosis and treatment planning is linguistically based. This is handicapping because, despite linguistic information from the assessment, the therapist lacks the functional analysis of verbal behavior needed to effect *behavior change*, which is the *sole aim of therapy*.” (Emphasis added)

Esch, LaLonde, and Esch. Speech and language assessment: A verbal behavior analysis. SLP-ABA, (5):2, 2011

Behaviorism

“With all his (VB) training, I still think he sometimes doesn’t understand what is being asked of him.”

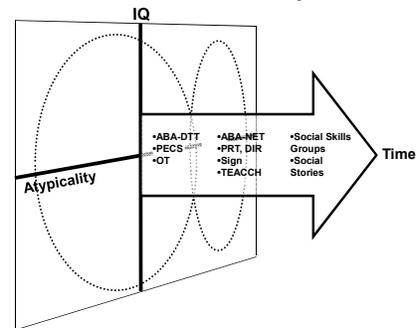
Mother of a 5 year old boy with mild ASD and normal nonverbal abilities. (MRN 09-0623)

Sensory-Based therapies for ASD

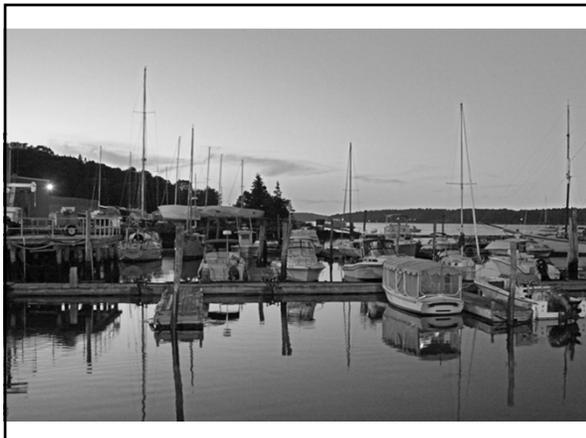
- OT / Sensory Integration Therapy
 - “Sensory Diet”
 - Desensitize to aversive stimuli
 - Use sensory-seeking behaviors to enhance cognitive/behavioral function (claimed)
 - Mirror neurons: The missing link between bottom-up and top-down therapies? (proprioceptive awareness → consciousness)

Coplan, 2008, in press

Progression of Interventions Follows the Natural History



www.drcoplan.com



Outline

- I. ASD Defined (and re-defined)
[Break]
- II. The Autism Explosion: What it means, and what it doesn't
[Lunch]
- III. Behavior Management, Mental Health, and Psychopharmacology
[Break]
- IV. Coming Full Circle

The ASD “Explosion”

- Are we in an epidemic?
- If so:
 - Is there a smoking gun?
 - Are there preventive or therapeutic measures?
- If not:
 - Where did all these kids come from?
 - Where are the “missing” adults?

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Incidence, Prevalence, and Scientific Illiteracy

- Incidence
- Prevalence
- Epidemic
- “Explosion”

Incidence = *Rate*

- The number of new cases of a disorder, over a specified period of time, in a defined population (“How fast am I going?”)
 - New cases of Influenza / 100,000 persons / wk
 - New cases of ASD / 100,000 children / yr
 - Incidence of ASD =
 - Birth rate of newborns who will have ASD +
 - Rate of autistic regression among children

Incidence = Rate of occurrence of new cases



Epidemic = ↑↑Incidence

Prevalence = *Proportion*

- The percent of the population that is affected, at one point in time (“How full is my tank?”)
 - The % of people with the Flu
 - The % of people with ASD
 - We do not know the true prevalence of ASD. What we know is the number of children being served with a *diagnosis* of ASD.

Prevalence = % of population affected



“Explosion” = ↑↑Prevalence



Prevalence can go Up or Down, independently of Incidence

- Criteria for defining a “case”
- Ascertainment methods
- Duration of illness
- Mortality Rate

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Scientific Illiteracy

<http://www.bloomingtonalternative.com/node/10276>
'Autism and the Indiana Environment Blog'
 by Steven Higgs
 January 3, 2010

The CDC ... revealed the gist of its autism findings in October, after a study in the journal *Pediatrics* said its incidence had reached 1 in every 91 children. (**FALSE**)

CHANGING THE COURSE of AUTISM
 A SCIENTIFIC APPROACH FOR PARENTS AND PHYSICIANS
 BRYAN JEPSON, M.D. with JANE JOHNSON

FALSE **TRUE**

EVIDENCE-BASED MEDICINE SHOWS THAT:

- Autism is epidemic (1 in 150 children has been diagnosed).
- Autism is a medical disease, not a psychological disorder.
- Autism affects other body organ systems besides the brain.
- Autism is treatable; children are recovering.

Centers for Disease Control and Prevention
MMWR Morbidity and Mortality Weekly Report
 Surveillance Summaries / Vol. 61 / No. 3 March 30, 2012

Prevalence of Autism Spectrum Disorders — Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008

TABLE 2. Estimated prevalence* of autism spectrum disorders (ASDs) per 1,000 children aged 8 years, by sex and race/ethnicity — Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008

Site	Total no. with ASDs	Sex				Male-to-female prev ratio [†]
		Total [‡]	Male	Female		
Total	337,093	3,820	11.3 (11.0-11.7)	18.4 (17.7-19.0)	4.0 (3.7-4.3)	4.6

11.3 cases / 1000 children = 1 in 88

March 30, 2012 **PREVALENCE**

AUTISM SOCIETY
 Improving the Lives of All Affected by Autism

Dear James,

Today the Centers for Disease Control and Prevention released its latest report that estimates 1 in every 88 U.S. children has autism. While there is no agreement or proven reasons for this increase the Autism Society believes we must address the issues important to those living with autism today.

The increasing incidence of autism should serve as an urgent call to address a critical issue facing society: individuals and families living with autism need support and services. These CDC statistics are a clear call that the need for services has never been greater. If society does not answer that call, particularly as the population grows, more and more individuals will not receive the help they desperately need.

Scientific Illiteracy, or Willful distortion of the facts?

Why it matters

- **If we are really in an epidemic:**
 - Is there a smoking gun?
 - Immunizations
 - Mercury
 - Other?
 - Is there a cure or preventive measure?

Known causes of ↑ Prevalence of children with a Dx of ASD*

- Broadening diagnostic criteria
- Broadening Federal service & reporting requirements
- Diagnostic substitution
- Broadening ascertainment methods

* Not the same as a true ↑ in prevalence itself

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Relationship between *diagnostic criteria* and prevalence

What is the prevalence of “Tall Stature”

- If the cutoff for “Tall” = 7 feet?
- If the cutoff for “Tall” = 6 ft 10”
- If the cutoff for “Tall” = 6 ft 6”
- If the cutoff for “Tall” = 6 ft
- Etc.....

Relationship between atypicality and IQ

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DSM Criteria and the ASD Explosion

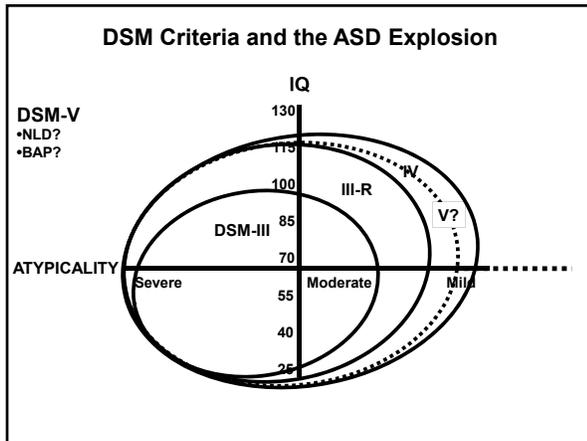
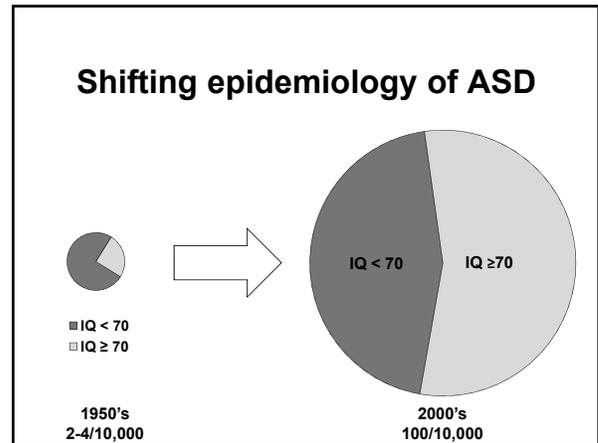
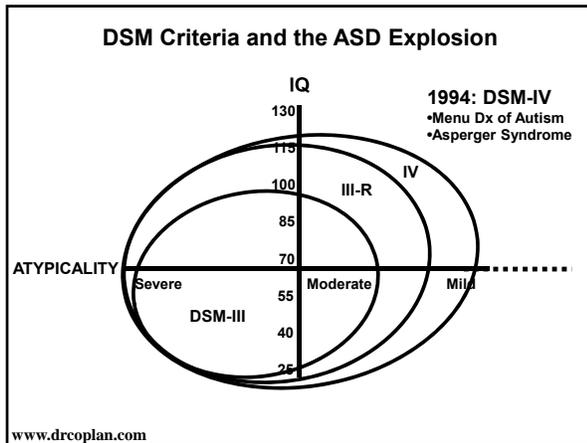
1980: DSM-III
• infantile autism
• Autism, Residual State

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DSM Criteria and the ASD Explosion

1987: DSM-III-R
• PDD-NOS replaces Autism, Residual State

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- ### Known causes of ↑ prevalence of children with a Dx of ASD
- Broadening diagnostic criteria
 - Broadening Federal service & reporting requirements
 - Diagnostic substitution
 - Broadening ascertainment methods
- www.drcoplan.com

Changes in Federal Law - 1

Year	Event	Comment
1975	Congress enacts Public Law 94-142: Education for All Handicapped Children (EAHC)	First Federal law requiring the States to provide free and appropriate public education (FAPE) to "all children >5 yrs old, regardless of disability"

But.....

- ### "Handicapping Conditions" (PL 94-142; 1975)
- Mentally Retarded
 - Learning Disabled
 - Speech impaired
 - Hearing / Vision Impaired
 - Seriously emotionally disturbed
 - Orthopedically impaired
 - Multi-handicapped
 - Other health impaired
- Where is autism?*

Changes in Federal Law - 2

Year	Event	Comment
1986	PL 99-457: Early Intervention Amendments to PL 94-142	<ul style="list-style-type: none"> •Extends FAPE to children age 3-5, mandated to take effect by 1991 (Section 619, Part B) •Creates Early Intervention for children 0-3 (Section 619, Part H).

Where is autism?

Changes in Federal Law - 3

Year	Event	Comment
1990	Congress Amends PL 94-142 again (PL101-476)	<ul style="list-style-type: none"> •Renamed <i>Individuals with Disabilities Education Act (IDEA)</i> •Includes Autism & Traumatic Brain Injury (TBI) as “eligible disabilities” under the scope of the law

Prior to 1990, according to Federal regulations, **Autism did not exist.**

Changes in Federal Law - 4

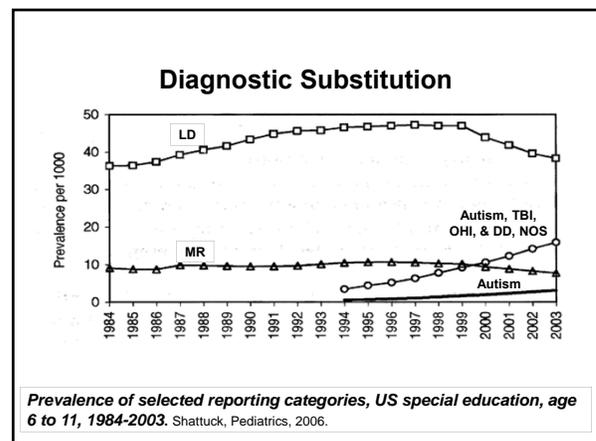
Year	Event	Comment
1991	US Department of Education, Office of Special Education Programs (OSEP) requires reporting of autism by the States, starting in 1992.	<ul style="list-style-type: none"> • Coincides with implementation of Part B (3 to 5 yr olds) & Part H (birth to 3) of PL 99-457

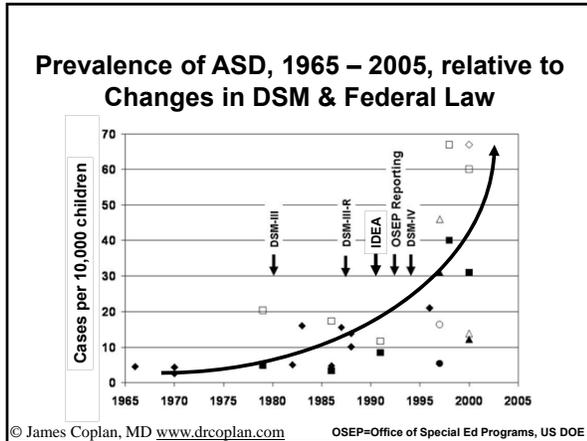
- ### Impact of Federal Law & Regulations
- EI & 3 to 5 Services begin: 1986
 - Autism recognized as a fundable D/O: 1990
 - Re-classification of children already in the system (diagnostic substitution)
 - Correct classification of new children with autism entering the system
 - Reporting autism to US DOE required: 1992
- www.drcoplan.com

Trends in autism prevalence:

Diagnostic Substitution Revisited
H. Coo, et al. J. Autism & Devel Disord 2008; 38(6): 1036-1046

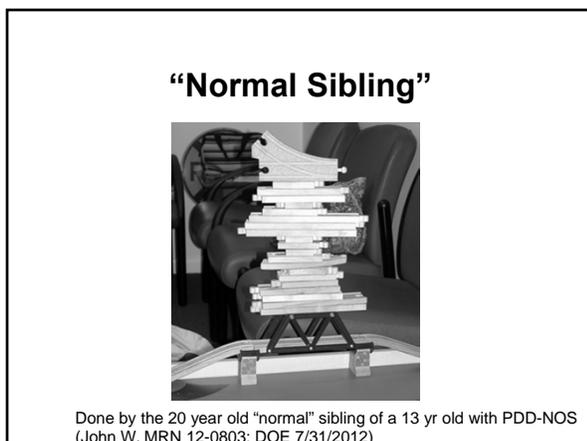
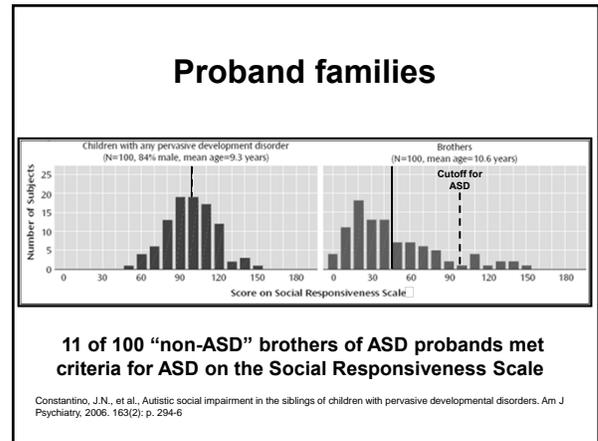
- Result:
 - “Diagnostic substitution...accounted for one third of the increase in the administrative prevalence of autism from 1996 to 2004 based on BC special education data”



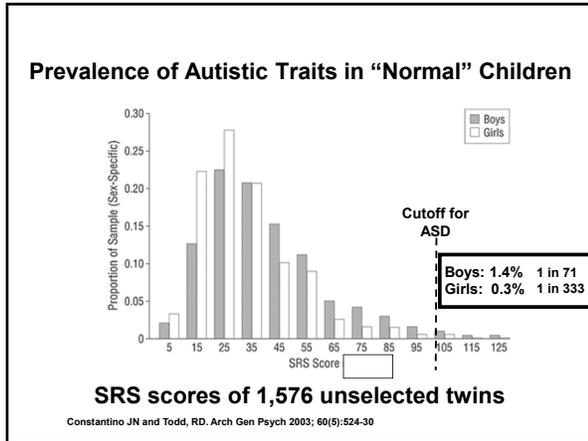


- ### Ascertainment Methods for ASD
- **Old: Count already-identified cases**
 - School data
 - Medical clinics
 - **New: Search for unrecognized cases**
 - Proband families
 - Population Screening
 - **Ascertainment Bias**

- ### “Proband”
- **The first member of a family to be diagnosed with a given condition**
 - **“Proband families” = relatives of the child first diagnosed with ASD**



- ### Population Screening
- **Subjects**
 - Missouri Twin Study
 - 788 twin pairs, age 7-15
 - No identified developmental disorder
 - **Methods**
 - Social Responsiveness Scale (SRS); mother = informant (97%)
- Constantino JN and Todd, RD. Arch Gen Psych 2003; 60(5):524-30

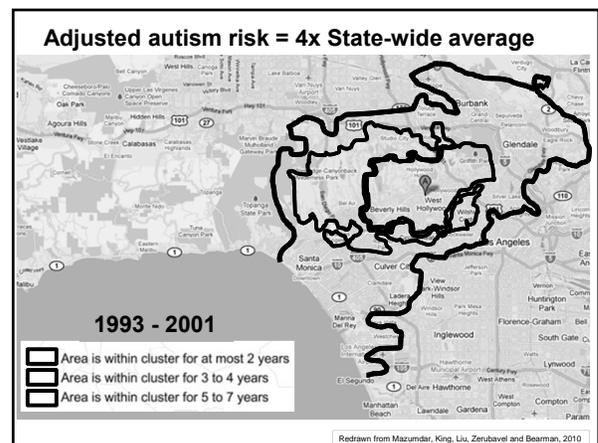
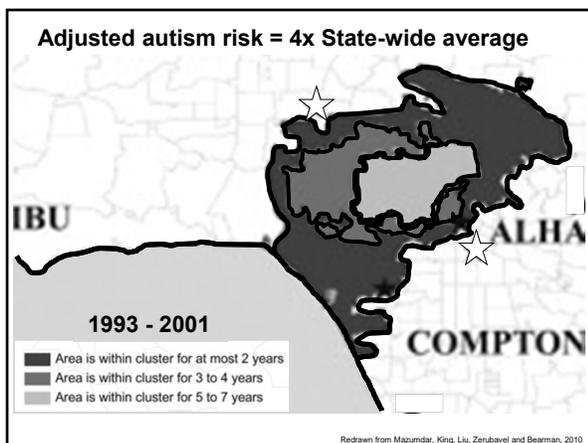
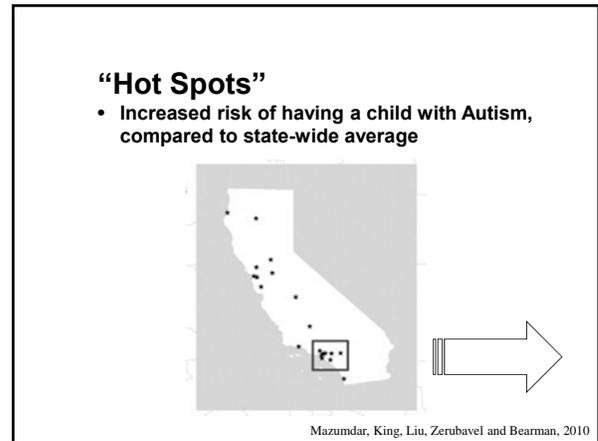


Ascertainment Bias

- **Differential ascertainment**
 - By race
 - By geographic region
 - By socioeconomic status

The spatial structure of autism in California, 1993–2001

Health & Place
Volume 16, Issue 3, May 2010, Pages 539-546
Soumya Mazumdar, Marissa King, Ka-Yuet Liu, Noam Zerubavel and Peter Bearman
Institute for Social and Economic Research and Policy Columbia University, New York, NY, USA



Following the money

- \$ earmarked for children with ASD
- Pressure to classify children with borderline symptoms as ASD in order to access to services
 - Improved recognition of children with mild ASD, or
 - Artificial ↑ in number of children with autism diagnosis?

Monday, April 30, 2012 | Like | Follow @disabilityscoop | 10.2K followers | About

disabilityscoop The Premier Source for Developmental Disability News

Lawmakers Want More Autism Training For Teachers
<http://www.disabilityscoop.com/2012/04/30/lawmakers-autism-training/15493/>
 April 30, 2012

A bill introduced in Congress would establish a five-year federal grant program to allow school districts to team with universities and nonprofits to train general education teachers and other school staff to best support students with autism. ...Under the bill, the program would be available in school districts where at least 10 percent of special education students have an autism diagnosis....

Where have all the adults gone?

- If we are not in an epidemic, where are all the adults with ASD?
 - Today’s adults were Dx’d 30-50 yrs ago
 - Severe atypicality
 - IQ < 70
 - Natural History of ASD (improve w. time)
 - Diagnostic tools in adults (new!)
 - Screening in adults (new!)

Ascertainment of ASD in adults

- There is no agency tracking developmental data on adults
 - Census Bureau?
 - Social Security?
 - Selective Service?
 - IRS?

“Missing” adults: NHS Survey



Autism Spectrum Disorders
in adults living in households
throughout England

Report from the Adult Psychiatric
Morbidity Survey 2007

<http://www.ic.nhs.uk/pubs/asdpsychiatricmorbidity07>

NHS Survey 2007



- National sample of survey of adults living in the community
- Excludes persons in residential care
- Therefore, under-counts adults with severe disability

<http://www.ic.nhs.uk/pubs/asdpsychiatricmorbidity07>

NHS Survey 2007

Phase 1
•Autism Quotient (20-Item Screen)
•N=2,854

↓

Phase 2
•ADOS (Autism Diagnostic Observation Schedule)
•N=618

↓

Prevalence of ASD: 1 %
 ⇒ •Male: 1.8% (1 in 56)
 ⇒ •Female: 0.2% (1 in 500)

<http://www.ic.nhs.uk/pubs/asdpsychiatricmorbidity07>

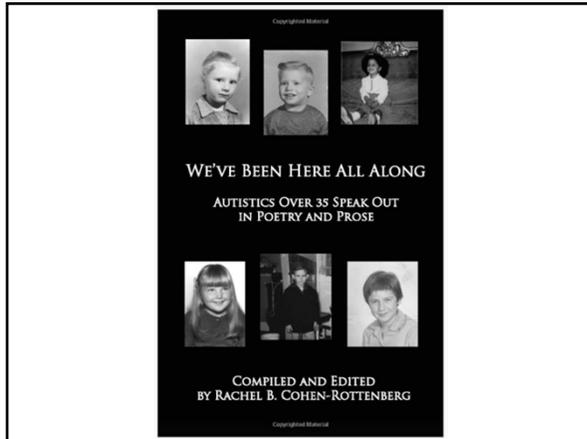
NHS Survey 2007

Prevalence of ASD (ADOS 10+), by age

All adults	2007		
	Age group		
	16-44	45-74	75+
	%	%	%
ASD (ADOS score of 10+) ^a	1.1	0.9	0.8

Prevalence x Age: Not statistically significant

<http://www.ic.nhs.uk/pubs/asdpsychiatricmorbidty07>



Summing up....

The ASD “Explosion”

- Service load is definitely increasing, but unclear if true prevalence has changed
- ↑ Prevalence of children getting ASD diagnosis
 - Broader definitions (DSM III, III-R, IV). Impact of DSM V?
 - US Dept of Education recognition of autism (1990)
 - Federal service & reporting requirements (1992)
 - Funding & services tied to Dx of ASD creates pressure to get the Dx
- Confounding variables
 - Racial and Geographic disparities in apparent prevalence
 - Higher SES → higher chance of Dx
- No proof of an epidemic (↑ Incidence)

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You cannot get a speeding ticket for having a full tank of gas.

INCIDENCE (epidemic)

PREVALENCE (“explosion”)

Implications

- **Beware of any arguments that rest on the claim that we are in an epidemic**
 - Allegations as to cause
 - Promises of cure

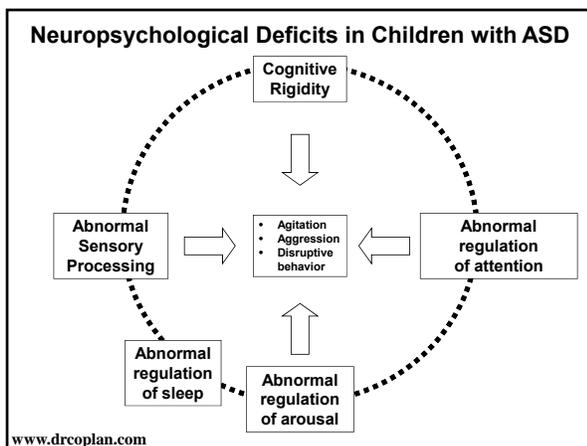
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Outline

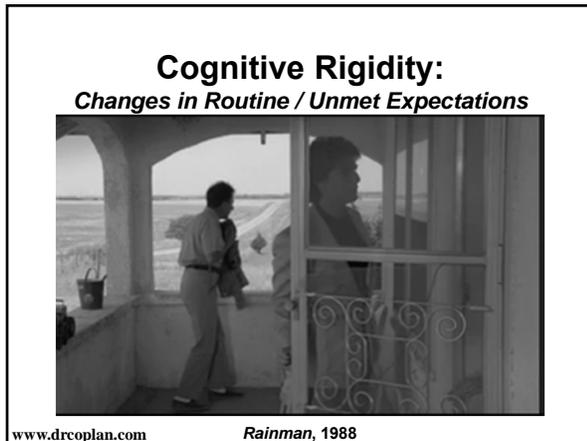
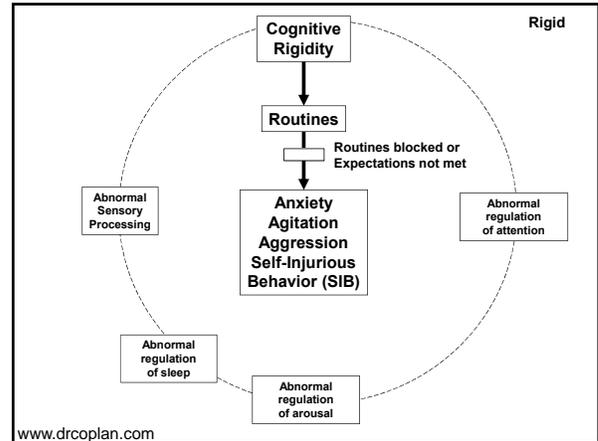
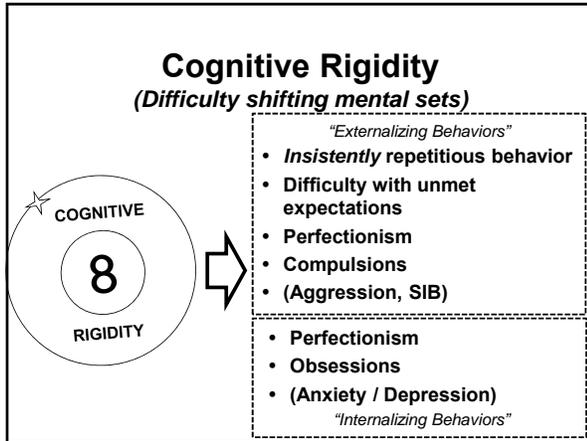
- I. **ASD Defined (and re-defined)**
[Break]
- II. **The Autism Explosion: What it means, and what it doesn't**
[Lunch]
- III. **Behavior Management, Mental Health, and Psychopharmacology**
[Break]
- IV. **Coming Full Circle**

Outline

- I. **ASD Defined (and re-defined)**
[Break]
- II. **The Autism Explosion: What it means, and what it doesn't**
[Lunch]
- III. **Behavior Management, Mental Health, and Psychopharmacology**
 - A. Neuropsychology of ASD
 - B. Beyond FBA
 - C. Mental Health in ASD
- IV. **Coming Full Circle**



- Without a doubt
- Reply hazy, try again
- Signs point to NO
- Better not tell you now...

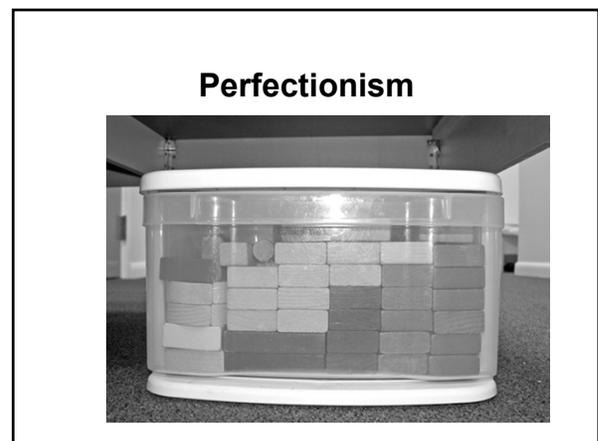
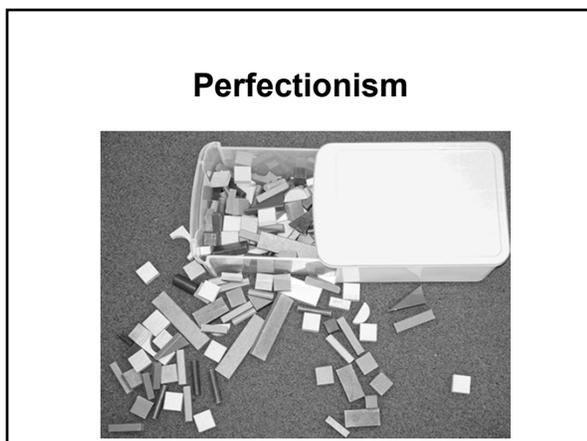


Cognitive Rigidity → Anxiety → Disruptive Behavior

“Our son experiences extreme anxiety when what he anticipates isn’t what happens...When we know a change is coming we can prepare him, but those we can’t anticipate are still very upsetting for him...The switch flips in his mind, and it’s out of his control.”

6 y.o. boy with ASD, anxiety, and normal nonverbal IQ

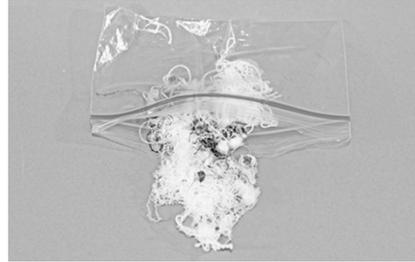
MRN 12-0782



Perfectionism



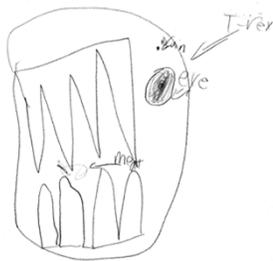
Compulsions



Joseph F: 15 y.o. boy Asperger Syndrome

MRN: 05-0096

Anxiety

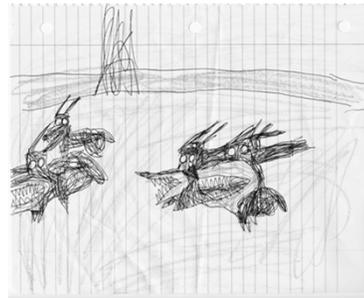


RM: 9 y.o. boy: ASD, normal IQ, anxiety d/o, disruptive behavior.
Mother: Anxiety D/O; PGM hoarding & OCD

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MRN: 10-0642

Anxiety

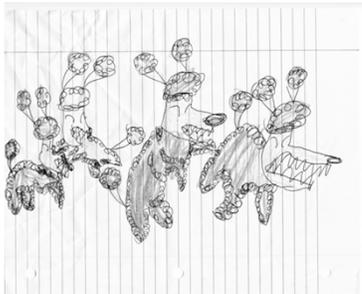


RD. 7 y.o. F, nl IQ, PDD-NOS & Anxiety. Father: GAD

www.drcoplan.com

MRN: 07-0427

Anxiety



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

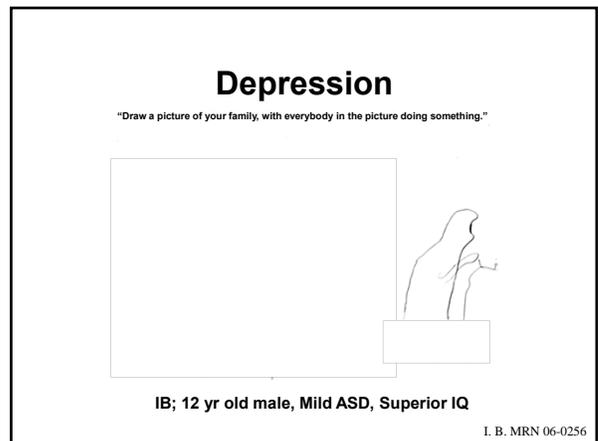
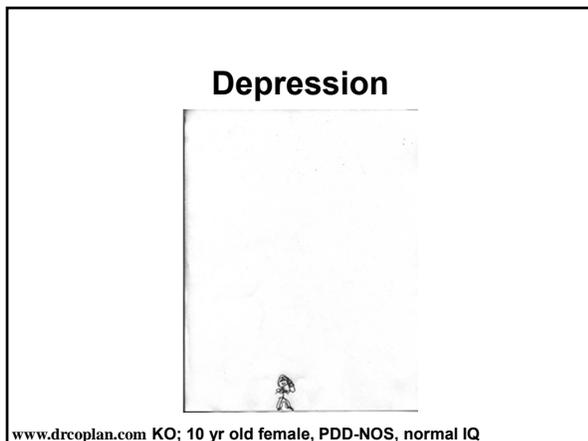
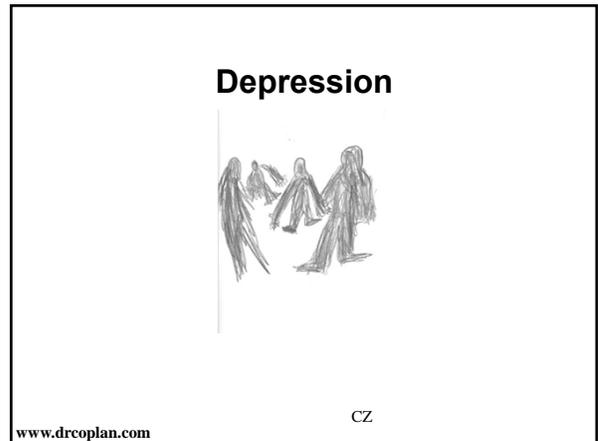
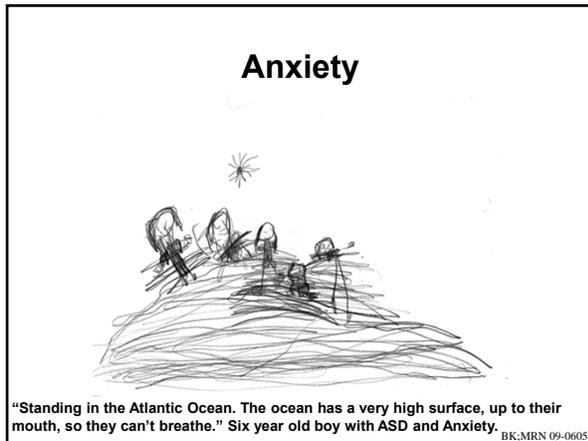
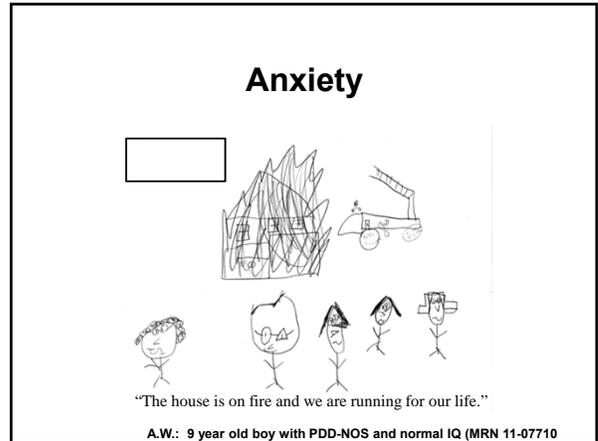
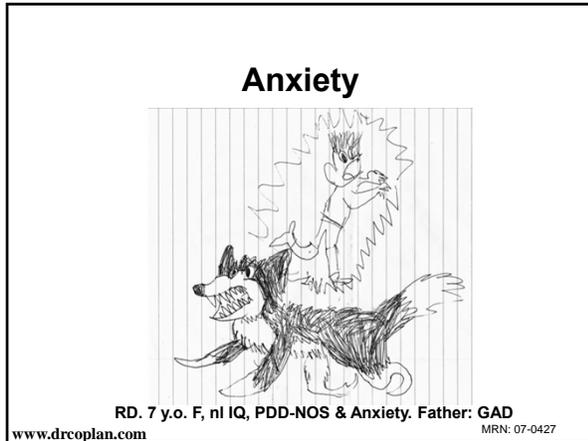
www.drcoplan.com

MRN: 07-0427

Anxiety



RD. 7 y.o. F, nl IQ, PDD-NOS and Anxiety. Fa: GAD
R.D. MRN 07-0427



Depression

"Draw a picture of your family, with everybody in the picture doing something."

IB; 12 yr old male, Mild ASD, Superior IQ

I. B. MRN 06-0256

Depression

"Draw a picture of your family, with everybody in the picture doing something."

IB; 12 yr old male, Mild ASD, Superior IQ

I. B. MRN 06-0256

Depression

"Draw a picture of your family, with everybody in the picture doing something."

Me watching TV My sister on her computer My father washing the car My mother cooking

IB; 12 yr old male, Mild ASD, normal IQ

I. B. MRN 06-0256

Depression (& Perseveration)

Standard Score: 123

IB; 12 yr old male, Mild ASD, normal IQ

I. B. MRN 06-0256

Anxiety, Perfectionism, and Self-Injurious Behavior

Standard Score: 138

A.D. : 9 y.o. girl with ASD (my MRN: 06-0227)

Throughout the session, "Alice" delivered a steady stream of self-deprecating comments, calling herself "stupid," or perseveratively asking if she was "fat." During the Bender, she anxiously and angrily twisted the eraser off the tip of the pencil, while declaring "Why do I keep making stupid mistakes?" As her stress level rose, she escalated to slapping herself, and then punching herself in the face.

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

<http://idea.ed.gov/explore/view/pl/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.

ED.gov U.S. Department of Education
Promoting educational excellence for all Americans

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

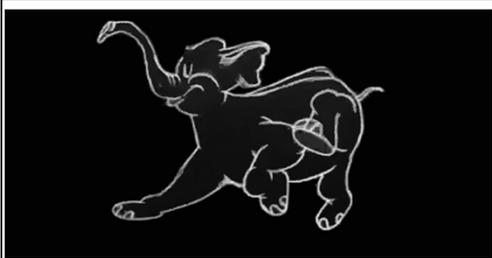
- **Comment:** A few commenters recommended that Sec. 300.324(a)(2)(i) refer specifically to children with *internalizing and externalizing behaviors*.
- **Discussion:** We do not believe it is necessary to make the recommended change because Sec. 300.324(a)(2)(i) is written broadly enough to *include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

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

IDEA

- **As a practical matter, however:**
 - “Behavior” is tacitly interpreted to mean “Externalizing” behavior
 - “Impedes Learning” is equated with academic failure
 - The opportunity to intervene before internalizing behavior erupts into externalizing behavior is lost

How do you kill a blue elephant?



Shoot it with a blue elephant gun.

How do you kill a pink elephant?



How do you kill a pink elephant?



Hold it by the trunk until it turns blue, then shoot it with a blue elephant gun.

The Story of Billy’s Box - 1

(or, why it’s important to ID internalizing behavior)

- 8 y.o. boy with ASD and normal Nonverbal IQ
- Severe tantrums at school
- Antecedents:
 - TRANSITIONS
- Function?
 - Not attention, escape, access
 - “Biological” (i.e. “just part of his ASD”)?

The Story of Billy's Box - 2

(or, why it's important to ID internalizing behavior)

Q: "Billy – You're always getting in trouble at school. What's going on?"

A: "I'm afraid that if I hand in my work, I'll never get a chance to go back and make it perfect."

The Story of Billy's Box - 3

(or, why it's important to ID internalizing behavior)



"Put your papers in the box, and we promise you will be able to go back later and work on them some more, if you want to."

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...."

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

Social Skills Deficit + Cognitive Rigidity

"L's IEP includes a Positive Behavior Support Plan, with goals that focus on compliance, and awareness of the feelings of others."

Specific target behaviors include "Refusal to comply with task," "Time off task," and "Making noises." The "Perceived Functions" of these behaviors are listed as "Escape from work, self-stimulation, sensory, and attention-seeking."

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

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."

L'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 L. 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

Not seeing the vase

(ignoring internalizing behavior)

"We caution against the use of the word "stubborn" to characterize Ryan's classroom behavior. Ryan's task avoidance and non-adherence to teacher instruction reflect cognitive rigidity and anxiety, rather than "stubborn" behavior. Re-framing his actions will lead to more appropriate intervention, placing the focus on anxiety management and cognitive flexibility, rather than "compliance."

www.drcoplan.com

RH; MRN: 11-0717; 7 y.o. male;
Anxiety D/O & Mild Atypicality

Positive Behavior Support Plan for Internalizing Behavior

- **Staff Awareness**
- **Visual Schedules**
 - What am I supposed to be doing *do now*?
 - What am I supposed to do *next*?
- **Relaxation Techniques**
 - Mental Imagery
 - Isometrics
 - Deep Breathing
 - “Break” cards
- **Cognitive Behavioral Therapy (CBT)**
- **SSRIs**

www.drcoplan.com

Not seeing the vase (ignoring internalizing behavior)

ASSESSMENT SUMMARY:

Antecedents to the behavior of concern	Behavior of concern	Consequences maintaining the behavior of concern	Perceived function of the behavior of concern
Denied Access Task demand (individual) Social situations (competitive)	Tantrum (4 levels) Level of Tantrums: 1. Isolation tantrum: eloping from adults or from the classroom/assigned area, not responding or refusing staff prompting 2. Low Frustration tantrum: clenching fists, stomping feet, grunting, whining, crumpling/bending objects, or crying. 3. Physical tantrum: aggression is defined	anxiousness entering into regular education classroom increased academic standards difficulty maintaining focus on instructor and tasks limited time frames for task completion increased expectations for written work	To gain Attention To avoid, escape, or postpone academic tasks/expectations

www.drcoplan.com MW; MRN 06-0211

Seeing the vase (recognizing internalizing behavior)

ASSESSMENT SUMMARY:

Antecedents to the behavior of concern	Behavior of concern	Consequences maintaining the behavior of concern	Perceived function of the behavior of concern
Denied Access Task demand (individual) Social situations (competitive)	Tantrum (4 levels) Level of Tantrums: 1. Isolation tantrum: eloping from adults or from the classroom/assigned area, not responding or refusing staff prompting 2. Low Frustration tantrum: clenching fists, stomping feet, grunting, whining, crumpling/bending objects, or crying. 3. Physical tantrum: aggression is defined	anxiousness entering into regular education classroom increased academic standards difficulty maintaining focus on instructor and tasks limited time frames for task completion increased expectations for written work	To gain Attention To avoid, escape, or postpone academic tasks/expectations

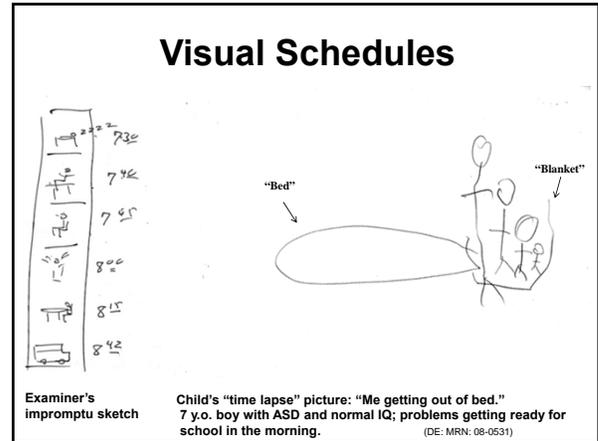
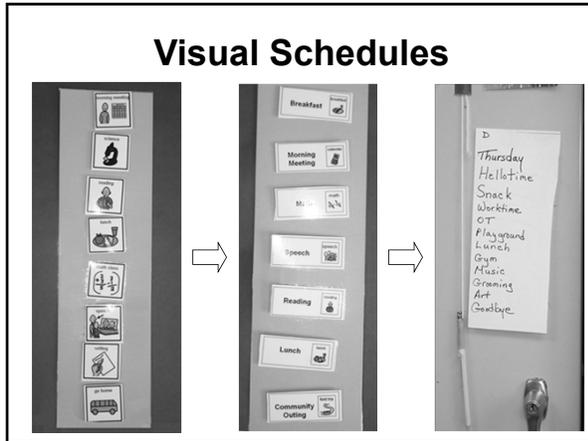
Antecedents	Behaviors	Consequences	Perceived Function
Anxiety Perfectionism Fear of Failure	Tantrums Eloping Task Refusal	Temporary <i>reduction</i> in anxiety via task avoidance	Avoidance of self-blame for not completing the task perfectly

www.drcoplan.com MW; MRN 06-0211

Positive Behavior Support Plan for Internalizing Behavior

- **Staff Awareness**
- **Visual Schedules**
 - What am I supposed to be doing *do now*?
 - What am I supposed to do *next*?
- **Relaxation Techniques**
 - Mental Imagery
 - Isometrics
 - Deep Breathing
 - “Break” cards
- **Cognitive Behavioral Therapy (CBT)**
- **SSRIs**

www.drcoplan.com



Positive Behavior Support Plan for Internalizing Behavior

- **Staff Awareness**
- **Visual Schedules**
 - What am I supposed to be doing *now*?
 - What am I supposed to do *next*?
- **Relaxation Techniques**
 - Mental Imagery
 - Isometrics
 - Deep Breathing
 - "Break" cards
- **Cognitive Behavioral Therapy (CBT)**
- **SSRIs**

www.drcoplan.com

The Incredible 5-Point Scale

Assisting students with autism spectrum disorders
in understanding social interactions
and controlling their emotional responses

Kari Dunn Buron and Mitzi Curtiss

The image shows a 5-point scale with five levels. Each level has a number in a box and a corresponding face showing increasing levels of distress from neutral to angry. The faces are: 5 (neutral), 4 (slight frown), 3 (frown), 2 (wide frown), 1 (angry).

The Incredible 5-Point Scale

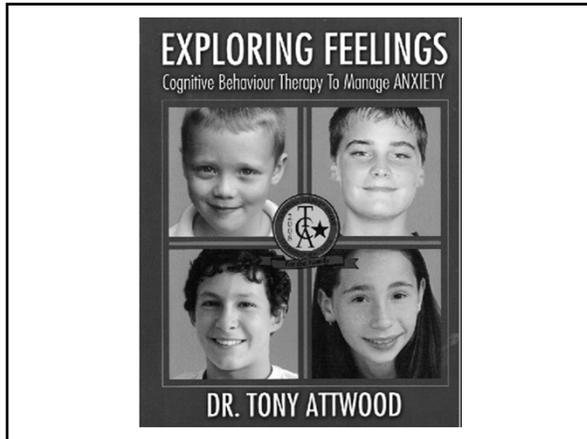
Obsessional Index

The image shows an Obsessional Index scale with five levels. Each level has a number in a box and a corresponding description of the student's level of control over their obsessions. The levels are: 5 (I can't control it, I will need lots of support.), 4 (I am feeling very nervous and will probably need some support.), 3 (I am thinking about my obsessions, but I may need to talk to someone about it. I think I have some control.), 2 (I am feeling pretty relaxed today. I can probably think about my obsessions but still do well in the classroom.), 1 (It is a great day! My obsessional personality is a neurological work of art!).

My Calming Sequence

Sometimes my worries are way too big! I can stop, squeeze my hands and take a deep breath. I can also rub my head and rub my legs. This can help me to stay calm.

The image shows a calming sequence grid with five levels. Each level has a number in a box and three icons representing different calming techniques: a face with eyes closed, hands being squeezed, and legs being rubbed. A downward arrow is on the left side of the grid.



Positive Behavior Support Plan for Internalizing Behavior

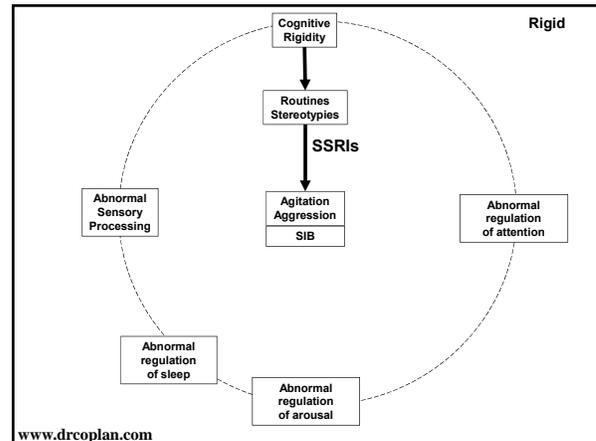
- Staff Awareness
- Visual Schedules
 - What am I supposed to be doing *now*?
 - What am I supposed to do *next*?
- Relaxation Techniques
 - Mental Imagery
 - Isometrics
 - Deep Breathing
 - “Break” cards
- Cognitive Behavioral Therapy (CBT)
- SSRIs

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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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SSRIs in ASDs

- Side Effects
 - Activation
 - Hyperactivity
 - Irritability
 - Insomnia
 - Agitation
 - Uncommon or irrelevant
 - GI dysfunction
 - Sexual dysfunction
 - “Black Box” warning (suicidal mentation)

www.drcoplan.com

Selective Serotonin Reuptake Inhibitors (SSRIs)

Generic Name	Brand Name	Comment
Fluoxetine	Prozac	• The first selective SRI
Fluvoxamine	Luvox	
Sertraline	Zoloft	• May be less activating
Citalopram	Celexa	• Prolonged QT interval
Escitalopram	Lexapro	• Prolonged QT interval
And others...		

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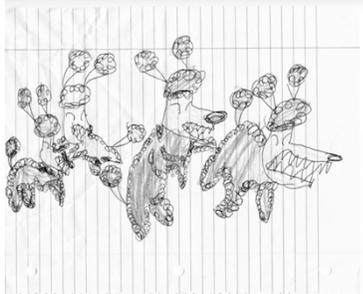
★

Pharmacotherapy for anxiety disorders in children and adolescents

Ipser JC, Stein DJ, Hawkrigde S, Hoppe L. Cochrane Database of Systematic Reviews 2009, Issue 3.

- **Studies reviewed: 22 RCTs/ 2,519 participants**
 - Short-term (average 11 wks)
 - Mean age 12 yrs
 - **Drugs studied (versus placebo)**
 - SSRIs :15 (fluoxetine 6, fluvoxamine 2, paroxetine 3, sertraline 4)
 - SNRIs: 5, (clomipramine 3), venlafaxine 2)
 - Benzodiazepines: 2: (alprazolam 1, clonazepam 1)
 - Tricyclic antidepressants: 1 (desipramine)
- **Meta-analysis**
 - Response rate: Medication 59%; Placebo 31%
 - 7.3% of subjects treated with SSRIs withdrew bec/o side effects
 - "The overwhelming majority of evidence of efficacy was for the SSRIs, with the most evidence in paediatric OCD"

Anxiety



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

www.drcoplan.com MRN: 07-0427

Anxiety after Rx with CBT & Escitalopram

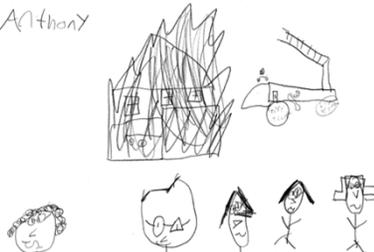


RD. 9 y.o. F, nl IQ, PDD-NOS & Anxiety. Father: GAD

www.drcoplan.com MRN: 07-0427

Anxiety

Anthony



"The house is on fire and we are running for our life."

A.W.: 9 year old boy with PDD-NOS and normal IQ (MRN 11-07710)

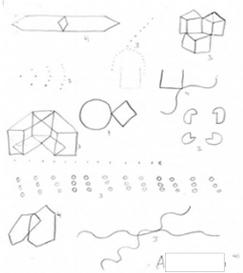
Fluoxetine 10 mg/d



A.W.: 9 year old boy with PDD-NOS and normal IQ (MRN 11-07710)

Anxiety, Perfectionism, and Self-Injurious Behavior

Standard Score: 138



A.D. : 9 y.o. girl with ASD (my MRN: 06-0227)

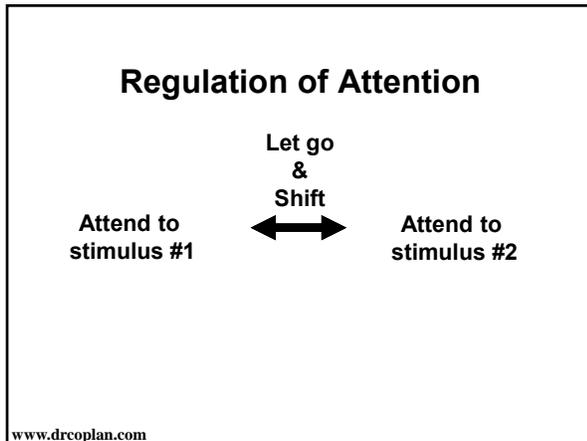
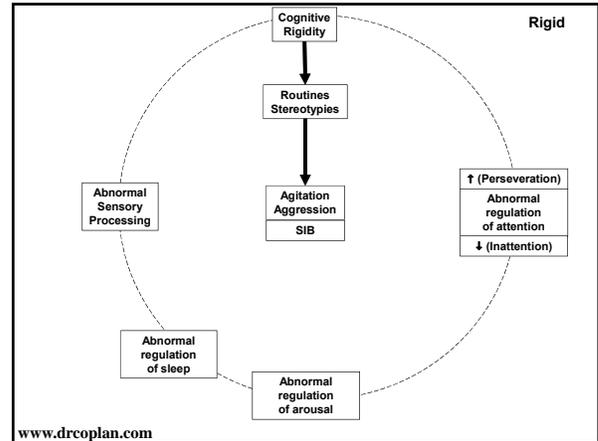
Throughout the session, "Alice" delivered a steady stream of self-deprecating comments, calling herself "stupid," or perseveratively asking if she was "fat." During the Bender, she anxiously and angrily twisted the eraser off the tip of the pencil, while declaring "Why do I keep making stupid mistakes?" As her stress level rose, she escalated to slapping herself, and then punching herself in the face.

Cognitive Rigidity

“I haven’t been ‘fired’ or told that I was ‘the worst mom ever’ in a month! ... Our son has been more adaptable. He has not had a meltdown in a month. (He has come close – but we managed or problem-solved, to come back from the cliff.)”

Mother of an 8 y.o. with ASD and normal IQ, 4 wk after starting SSRI

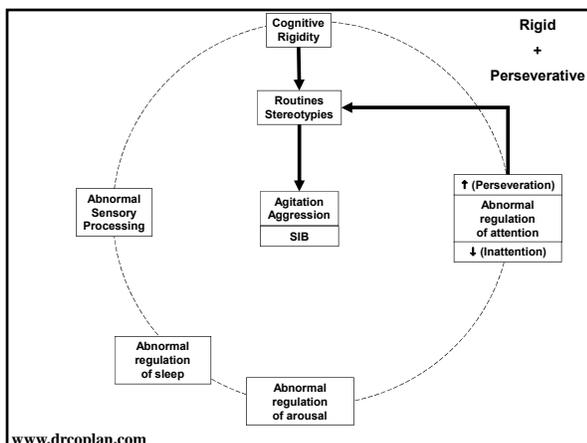
MRN 10-0701



Abnormal Regulation of Attention - 1

- **Perseveration**
 - Inability to “Let go and shift”
 - Gets “stuck”
 - “Overattention Deficit Disorder”
- **Compounds the effects of cognitive rigidity**

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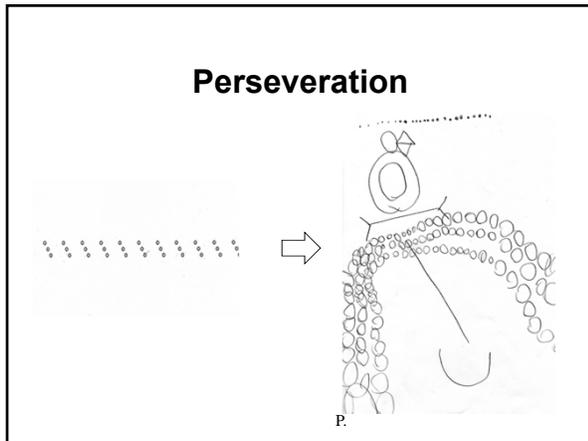
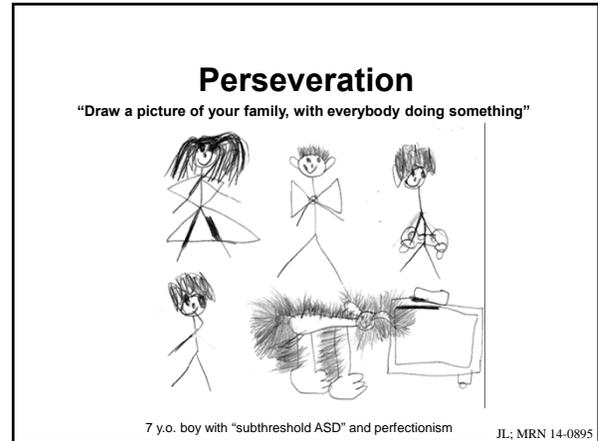
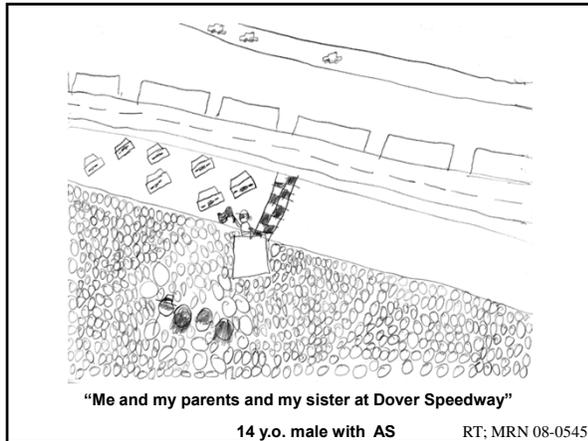


Perseveration

“Draw a picture of your family, with everybody doing something”

“We are going into the Grand Hyatt”

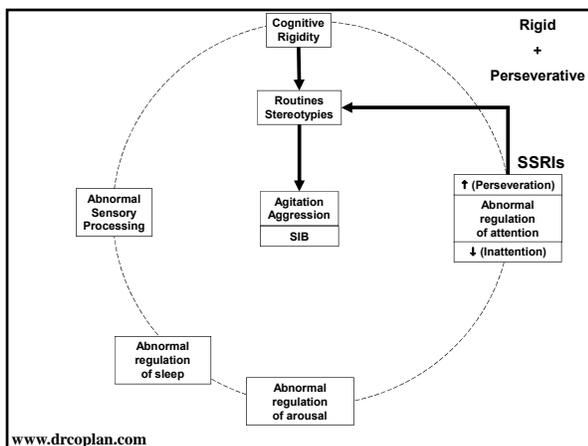
Wm W; 10 y.o. male; ASD & Anxiety; MRN 12-0827



Abnormal Regulation of Attention (Perseveration)

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

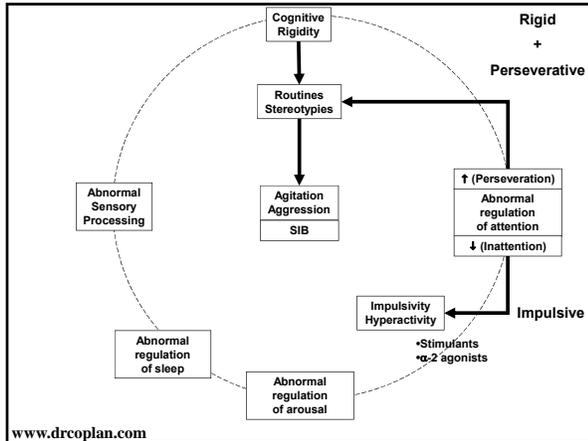
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Abnormal Regulation of Attention - 2

- **Inattention**
 - Inability to focus
 - Impulsive
 - Distractible

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Inattention

- **Interventions**
 - Limited stimuli
 - Short work periods
 - **Medication**
 - Stimulants (may ↑ anxiety / rigidity / agitation; “unmask” tics)
 - alpha-2 agonists

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Stimulants, NRI's

Generic Name(s)	Brand Name(s)	Comment
Amphetamine		FDA Schedule II
Dextroamphetamine	Dexedrine, Dextrostat	FDA Schedule II
Dextroamphetamine + amphetamine	Adderall	FDA Schedule II
Methylphenidate	Concerta, Ritalin, Metadate	FDA Schedule II
Dexmethylphenidate	Focalin	FDA Schedule II
Atomoxetine, Attentin	Strattera	Norepinephrine reuptake Inhibitor (NRI), not FDA Schedule II

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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

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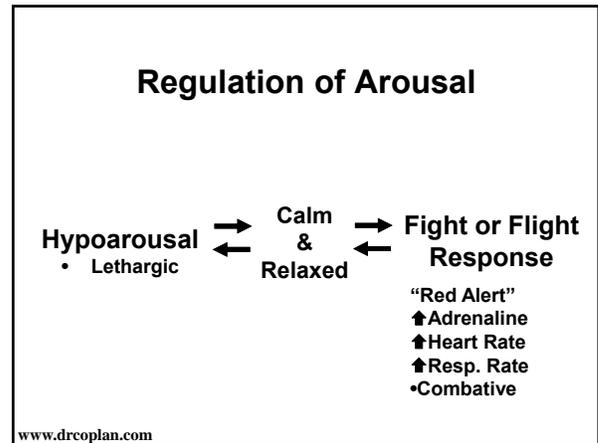
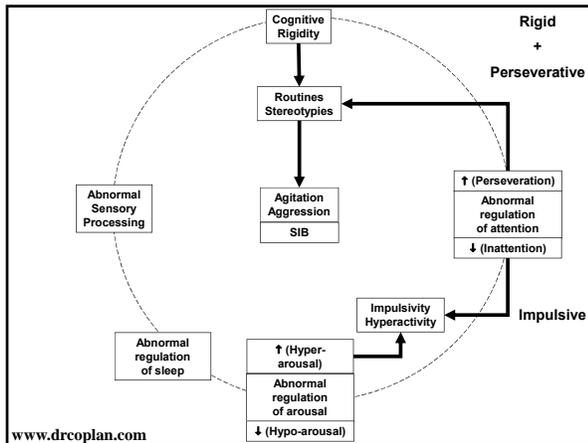
Alpha-2 Agonists

<p>Benefits</p> <ul style="list-style-type: none"> • ↓ Agitation • ↓ Hyperactivity • ↑ Attention Span • No exacerbation of anxiety / rigidity 	<p>Side Effects</p> <ul style="list-style-type: none"> • Sleepiness: Common • Emotional Lability (crying) - occasional • Hypotension (low BP) - rare
--	--

Clinical Pearl

- **Beware of Cognitive Rigidity masquerading as ADHD**
 - Perseveration on inner stimuli: “Inattentive”
 - Perfectionism:
 - “Problems w. task completion”
 - (Or: Task avoidance!)
 - Anxiety:
 - “Rushes through work”
 - “Out of seat behavior”

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Dysregulation of Arousal & Mood

- "We feel like we're walking on egg shells"

"He is so hard to calm down when he gets upset....His emotional thermostat doesn't work"

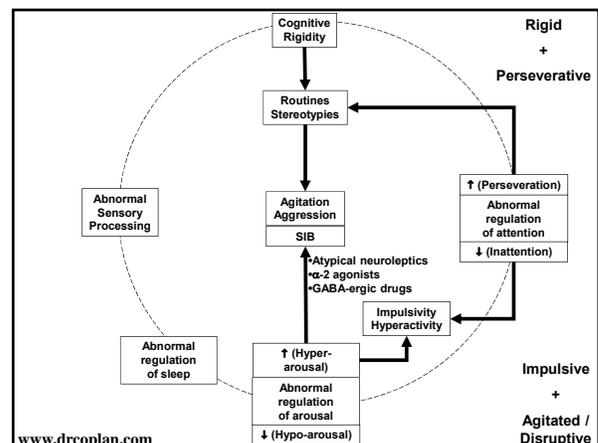
Parent of an 8 year old with ASD

F. O. MRN 06-0208

Arousal & Mood

"A. seems to be struggling with his emotions... can vary from pleasant interaction that can quickly turn to... aggression. Always wants to act his own way & tries to intimidate staff and peers. Level of agitation is unpredictable... aggression, mood swings..."

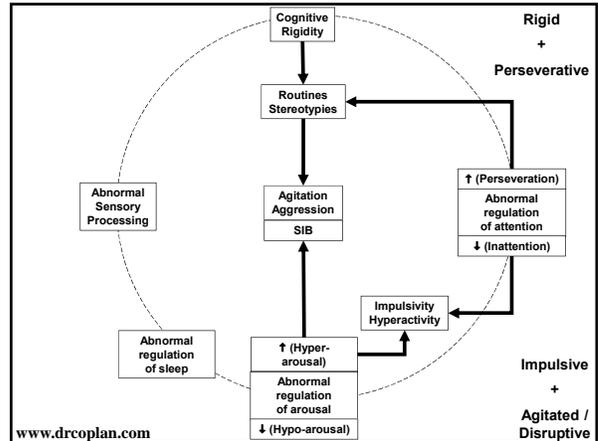
AF: 10 yr old boy with mild ASD and cognitive skills ranging from average to mild ID. MRN 07-0472



Atypical Neuroleptics

Generic Name	Brand Name	Comment
Aripiprazole	Abilify	<ul style="list-style-type: none"> • Relatively less risk of weight gain • FDA approved for Rx of ASD
Clozapine	Clozaril	<ul style="list-style-type: none"> • Bone marrow suppression
Olanzapine	Zyprexa	<ul style="list-style-type: none"> • Greater risk of weight gain
Quetiapine	Seroquel	<ul style="list-style-type: none"> • Greater sedation
Risperidone	Risperdal	<ul style="list-style-type: none"> • Greater risk of weight gain • FDA approved for Rx of ASD
Ziprazidone	Geodon	Relatively less risk of weight gain

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Regulation of Sleep - 1

- **Melatonin**
 - Brain hormone
 - ↓ Metabolic rate (Heart, Temp)
 - “You’re sleepy now”
- **Suppressed by light**
 - 24 hr cycle
 - Seasonal cycle

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Regulation of Sleep - 2

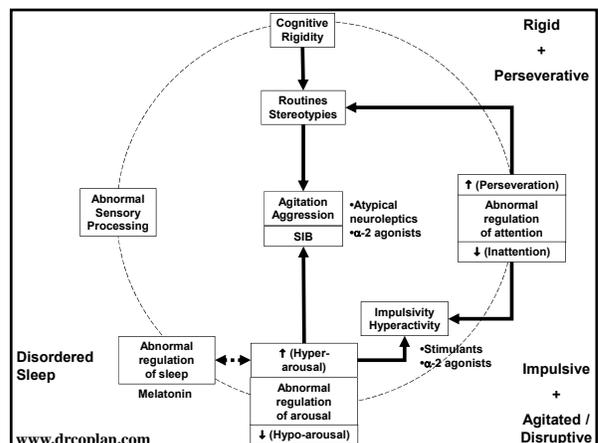
- **Abnormal melatonin cycling**
 - Primary disorders of sleep
 - Blindness
 - ASD
- **Symptoms**
 - Delayed onset of sleep
 - Shortened duration / frequent waking

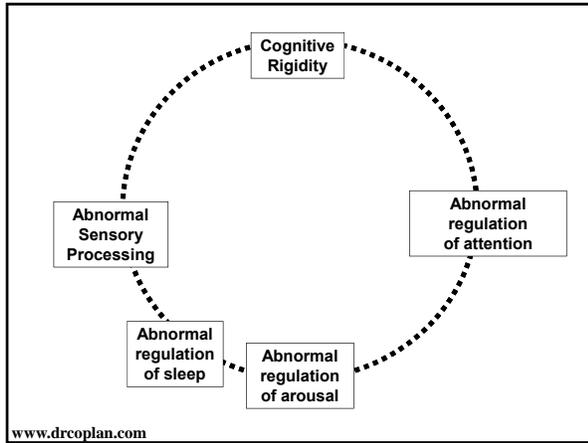
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Regulation of Sleep - 3

- **Shared genetic control**
 - Regulation of sleep
 - Regulation of arousal
- **Family history of sleep disorder**

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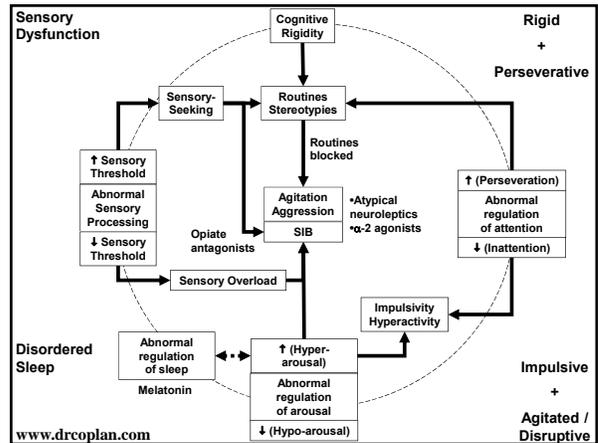


Sensory Processing

- **Subjective Properties**
 - Familiar / Unfamiliar
 - Pleasant / Unpleasant
 - Strong / Weak
 - Internal / External
- **Sensory Input → Self-awareness**
- **Mirror Neurons → Empathy**

Mostofsky, S. and J. Ewen, *Altered Connectivity and Action Model Formation in Autism Is Autism*. Neuroscientist, 4/15/2011

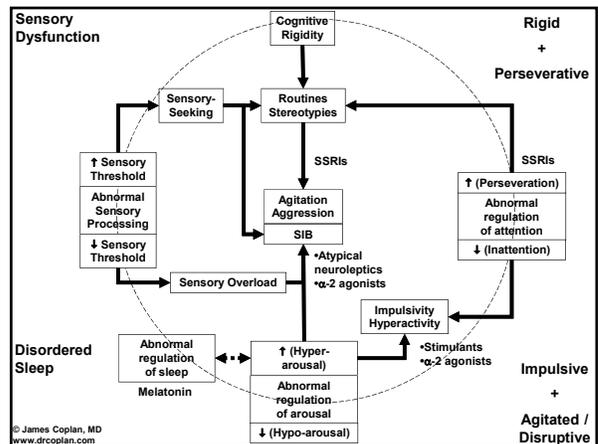
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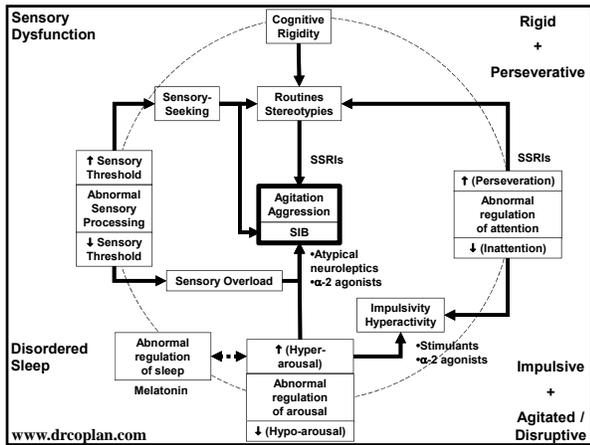


The whole is greater than the sum of its parts

Max Wertheimer

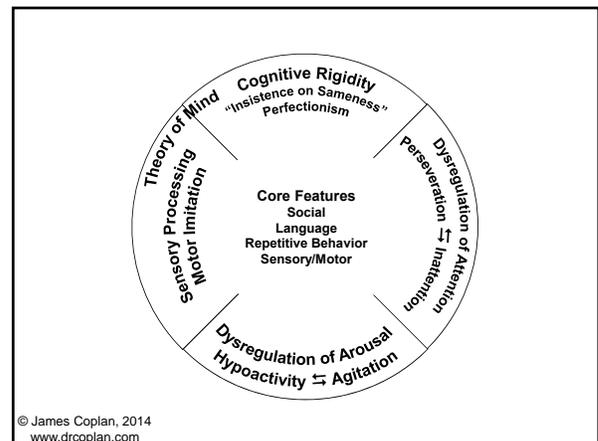
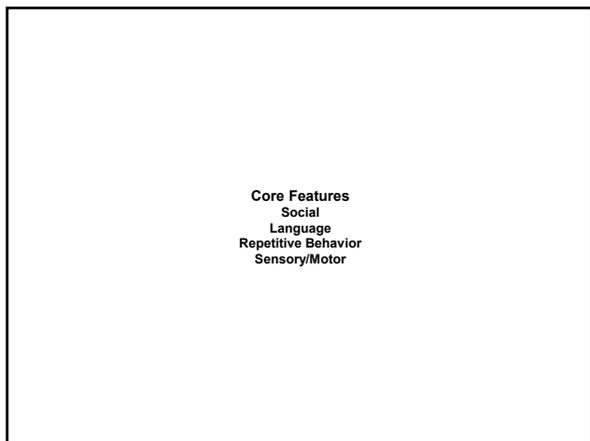
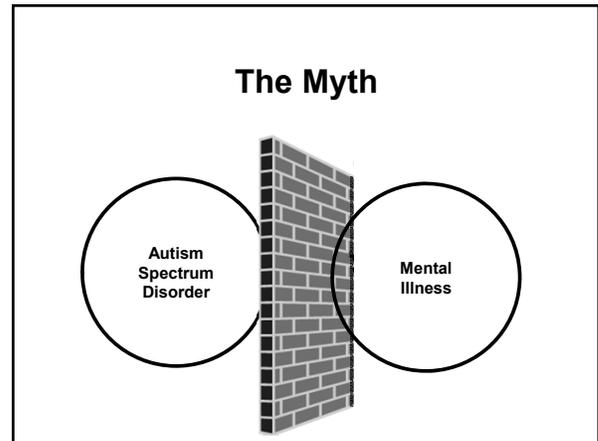
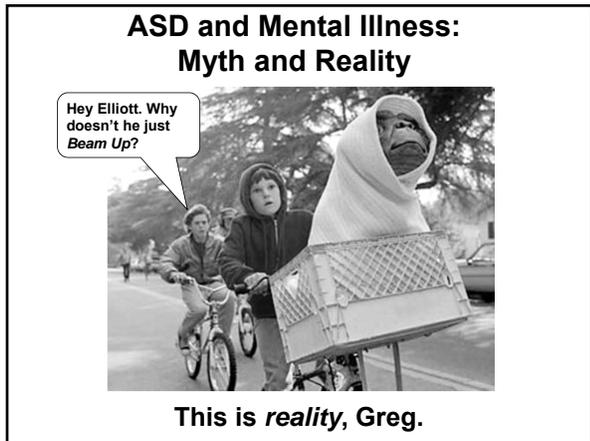
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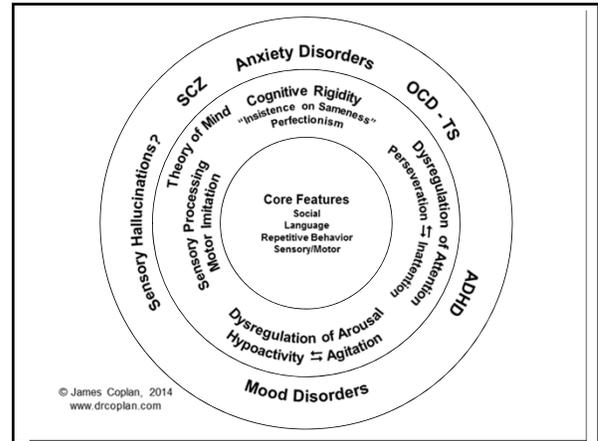
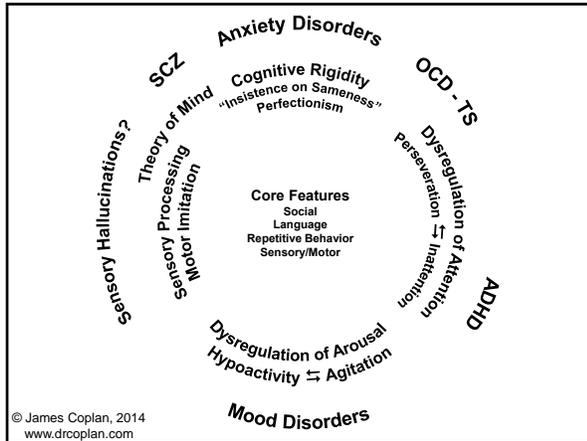




Outline

- I. ASD Defined (and re-defined)
[Break]
- II. The Autism Explosion: What it means, and what it doesn't
[Lunch]
- III. Behavior Management, Mental Health, and Psychopharmacology
 - A. Neuropsychology of ASD
 - B. Beyond FBA
 - C. Mental Health in ASD
- IV. Coming Full Circle





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 (%)*	
	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"

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

<http://medical-dictionary.thefreedictionary.com/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

“Is Schizophrenia on the Autism Spectrum?”

King & Lord, 2011

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

“Is Schizophrenia on the Autism Spectrum?”

King & Lord, 2011

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

“Is Schizophrenia on the Autism Spectrum?”

King & Lord, 2011

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

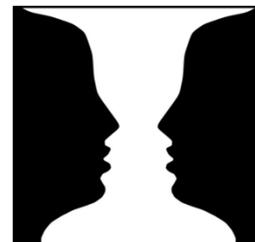
Theory of Mind

- Realization that other people have an internal mental & emotional state, different from one’s own
- Ability to gauge the internal mental & emotional state of others
 - Able to infer motives & predict behavior of others
 - Empathy
 - Humor

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Central Coherence

- The ability to see the big picture



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Q: What's happening in this picture?

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



Q: What's happening in this picture?
A: The boy is hoarding animals.

What's happening in this picture?



What's happening in this picture?

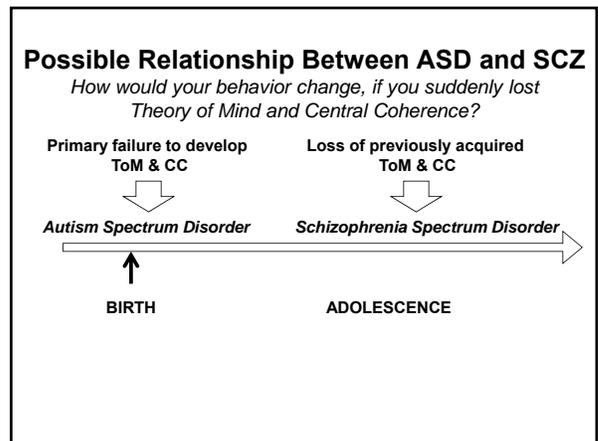


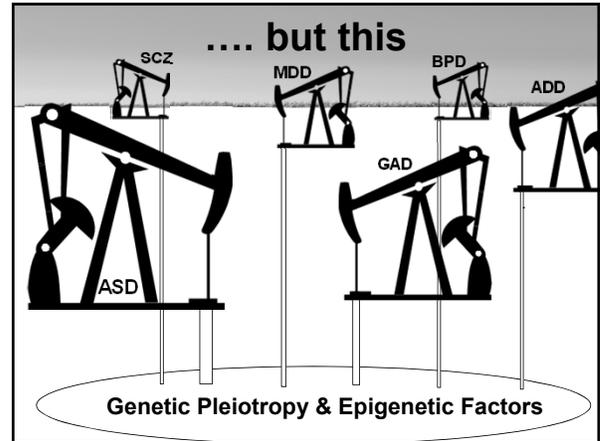
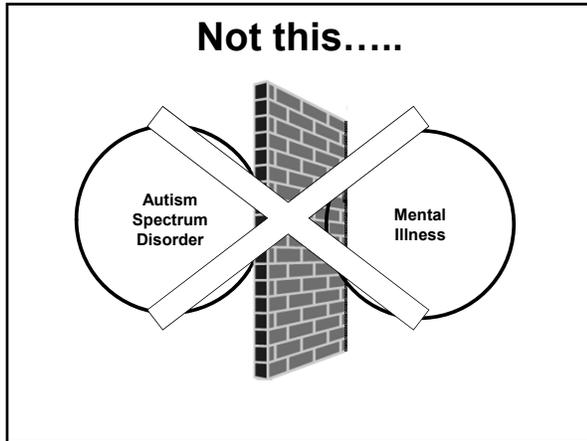
Two strangers got into the house and are handing out newspapers.

What's happening in this picture?

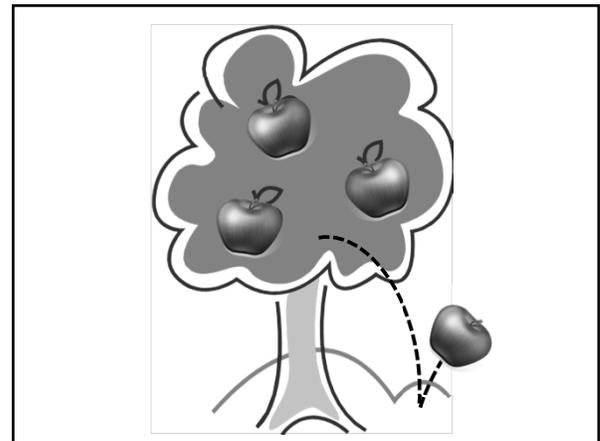


"They are stealing the children."





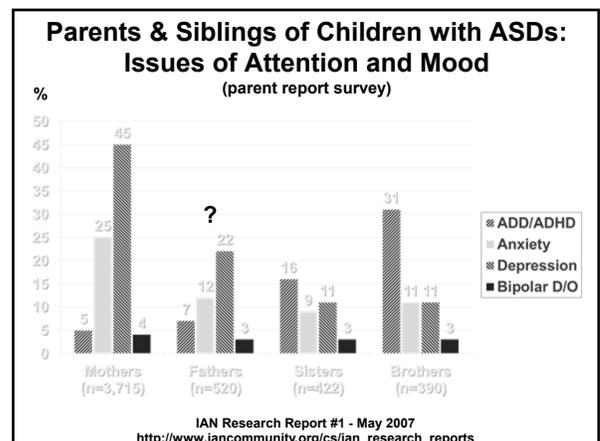
- Outline**
- I. ASD Defined (and re-defined)
 - II. The Autism Explosion: What it means, and what it doesn't
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 - A. Parental Mental Health-The elephant in the room
 - B. Losing the diagnosis-a good thing?
 - C. Service Needs beyond HS
 - D. Future directions



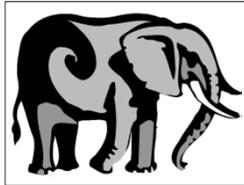
Kanner, 1943

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.



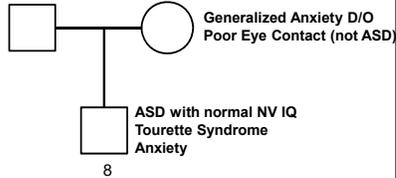
The Elephant in the Room



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

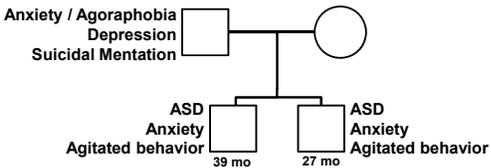
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TS, Anxiety, ASD



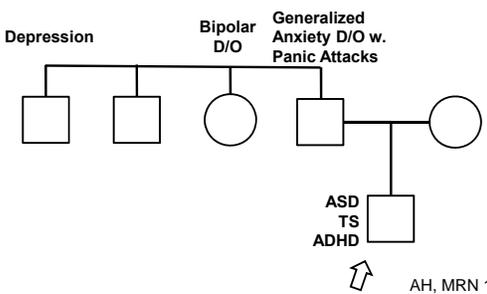
S.W.; MRN 08-0485

Anxiety, Depression, ASD, Agitation



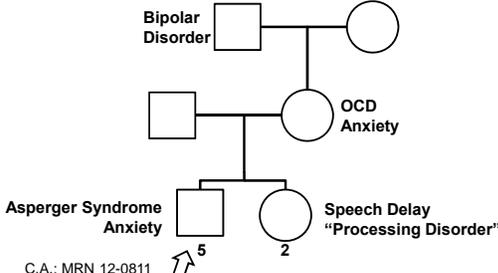
MRN 12-0815
MRN 13-0876

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



AH, MRN 13-0887

BPD, OCD, Anxiety, AS



C.A.; MRN 12-0811

Severe mood problems in adolescents with autism spectrum disorder

Simonoff, E., et al., Journal of Child Psychology and Psychiatry, 2012. 53(11): p. 1157-1166

- **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. 1157-1166

Results

- **High SMP: 24 (26%)**
 - Predictors of High SMP:
 - Emotional & behavioral problems at age 12
 - Autism severity (by parent report)
 - Maternal GHQ: *“The current analyses suggest a specific relationship between maternal affective symptoms and SMP in offspring”*
 - Not predictors:
 - Full Scale IQ
 - Adaptive function

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

Subjects

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

Results

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

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.

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.

© James Coplan, 2013. www.drcoplan.com

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**

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Danger Signs

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

Vignette #1

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

Vignette #2

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

School-Based MH Services

- **Proactively monitor student mental health**
 - Don’t wait for academic failure or disruptive behavior
 - Positive Behavior Support for Internalizing Behavior
 - Embed MH services within schools
 - Who owns the problem of family mental health?

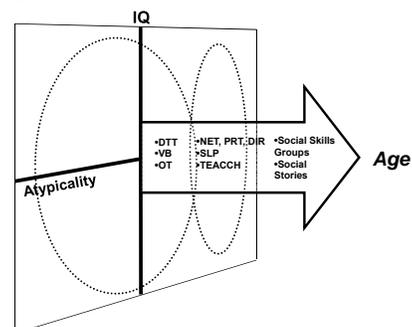
Family Function: Resources

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

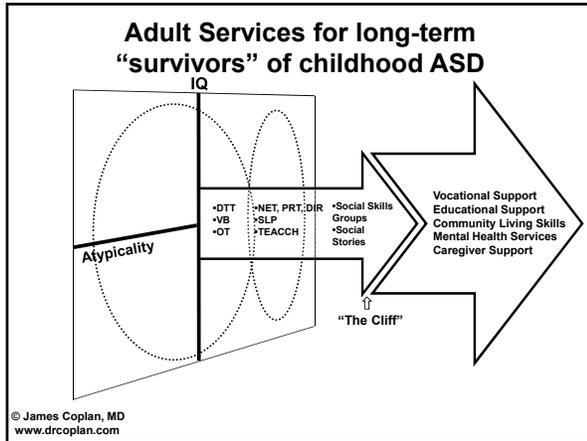
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Progression of Interventions (DD Model)



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



After HS – What?

- **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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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

Dr Sarah Cassidy PhD ¹, Paul Bradley MRCPsych B, Janine Robinson DClinPsy B, Carrie Allison PhD B, Meghan McHugh BSc B, Prof Simon Baron-Cohen PhD 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

Methods:

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

[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)

THE LANCET Psychiatry

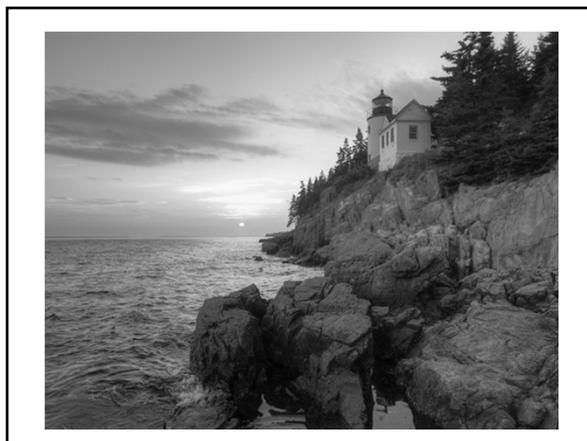
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Dr Sarah Cassidy PhD ¹, Paul Bradley MRCPsych B, Janine Robinson DClinPsy B, Carrie Allison PhD B, Meghan McHugh BSc B, Prof Simon Baron-Cohen PhD B

Results (98% response rate):

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

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



Summary

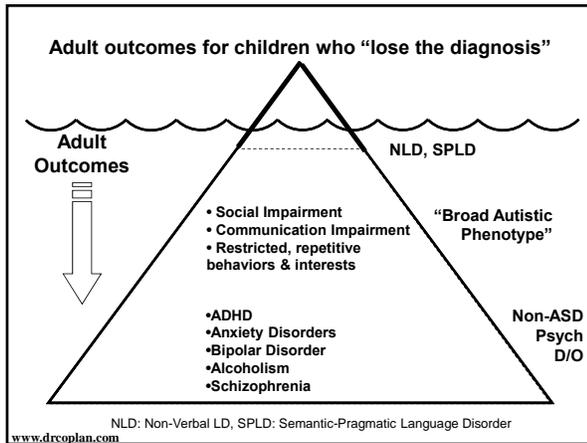
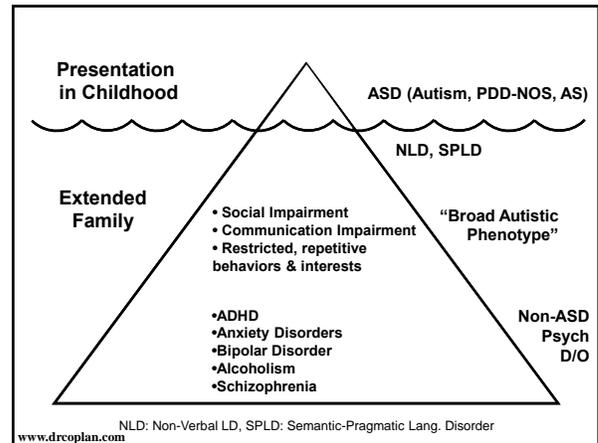
- **ASD: 4 domains (DSM5 notwithstanding)**
- **Social**
 - Theory of Mind
- **Language**
 - Pragmatics
 - Prosody
- **Repetitive behavior**
 - Cognitive Rigidity
 - Stereotypies
- **Abnormal sensorimotor processing**
 - Mirror Neurons: Where mind and body come together

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Summary

- ASD has a natural history for improvement over time, insofar as outwardly visible atypical features are concerned (echolalia, stereotypies, etc.), but cognitive & behavioral patterns persist
- IQ is the single biggest driver of prognosis
- “Losing the diagnosis” does not mean “cured”

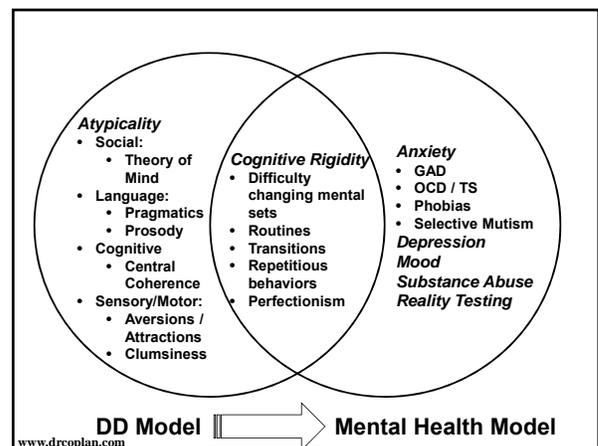
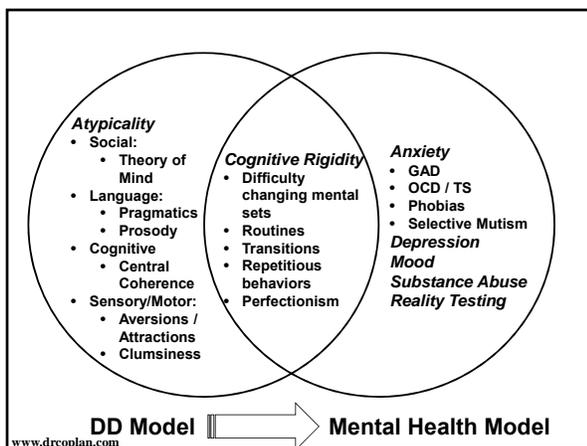
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Summary

- Mental illness is not “a separate problem.” Rather, impaired MH is another expression of shared neurobiology
- Over time, mental health issues present a progressively greater challenge, that may supersede the ASD

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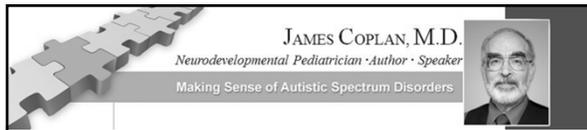
Summary

- **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**
- **Educational community's role in delivery of mental health services?**
- **Barriers**
 - Hard to shift mental sets
 - Fear, Stigma
 - Lack of suitable training
 - Institutional inertia / turf



JAMES COPLAN, M.D.
Neurodevelopmental Pediatrician · Author · Speaker
Making Sense of Autistic Spectrum Disorders

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Thank you