ASD in 3D:Autism Spectrum Disorders across the Lifespan

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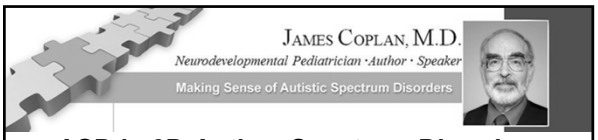

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Colin J. Condron, MD - Care of the Sick Child Conference
November 13-15, 2013

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Disclosures

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

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

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Topics

- Core features of ASD
- Co-Morbidity
- Etiology
- Epidemiology (the "explosion")
- Prognosis (the "Natural History")
- Developmental / Educational Interventions
- Behavior Management & Medication
- Quackery
- Family Matters
- Transition to Adulthood / Long-term issues

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Topics

- ➢ Core features of ASD
- ➢ Co-Morbidity
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- Epidemiology (the "explosion")
- ➢ Prognosis (the "Natural History")
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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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Topics

- Core features of ASD
- Co-Morbidity
- Prognosis
- Transition to Adulthood / Long-term issues

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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.
- Clinical Features:
  - Impaired socialization
  - Idiosyncratic language
  - Repetitious behaviors
  - 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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Impaired Socialization "In his own little world"

Age: 22 months. Nonverbal. CARS=44.

www.drcoplan.com MRN 11-0741

Difficulty with eye contact

Q: "How does the boy feel?"

MRN: 10-0681

Difficulty with eye contact

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

MRN: 10-0681

Idiosyncratic Language

- Echolalia
- Delayed Echolalia
- Pronoun Reversal
- Odd inflection

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Repetitious Behaviors

- Rigid Routines
- Stereotypies
- Lining up / spinning objects

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Unusual sensory responses

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

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Kanner, 1938 → 1943

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

www.drcoplan.com

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

www.drcoplan.com

Kanner, 1938 → 1943

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

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

www.drcoplan.com

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

www.drcoplan.com

Kanner, 1971

- Deceased: 1
- Lost to follow-up: 2
- Institutionalized: 5
- Living on work farm: 1
- Living at home: 2
  - BA degree / bank teller
  - Sheltered workshop / machine operator

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Kanner's contributions

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

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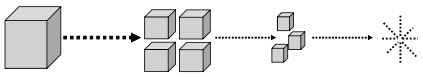
Over time, the ice melts



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Quantifying severity of ASD, and changes over time

Clinical Domain	Decreasing Atypicality→ Increasing Age→		
• Social • Language • Repetitious Behavior • Sensory	Severe / Youngest	Moderate / Older	Mild / Older

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1. Social Interaction

"Our child is *among* us, but not *with* us."

Parent of a 4 year old with ASD

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Clinical Domain ⇓	Decreasing Atypicality / Increasing Age ⇒		
	Severe / Youngest	Moderate / Older	Mild / Older
1. Social Interaction	•No eye contact •No physical affection •Cannot be engaged in imitative tasks	•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	•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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Clinical Domain ⇓	Decreasing Atypicality / Increasing Age ⇒		
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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**
  - **Fibbing**
  - **Make-believe**

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Theory of Mind

How does the boy feel?
Why?

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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.

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

•***A scary story, because the boys were scared.*** **(PDD-NOS)**
•***It was a most <u>unusual</u> story, because you don't often find cows in the woods.*** **(Asperger Syndrome)**

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Theory of Mind

www.drcoplan.com

2. 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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Language Deficits in ASD

"Draw a picture of your family: *Mommy, Daddy, Riley, You*."

MRN 06-0299

www.drcoplan.com

3. 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 *Cognitive*	•Extreme distress if *routines* are changed or when required to *transition* from one task to another •Fascination with odd objects (tags, wheels, fans, etc.)	• Same, but with diminishing level of distress; able to accept verbal preparation for changes in routine • Complex repetitious play (lining up objects, memorizes numbers, letters, etc)	• May demonstrate conscious awareness of preference for routines; easier to self-modulate •Play remains repetitious, but repetitive quality is more subtle; preoccupation with arcane topics •Problems with Central Coherence
Motoric	•Frequent, intense stereotypical movements (flapping, spinning, toe-walking, finger twiddling)	• Motor stereotypies occasional; may re-emerge when excited	• Motor stereotypies rare or absent

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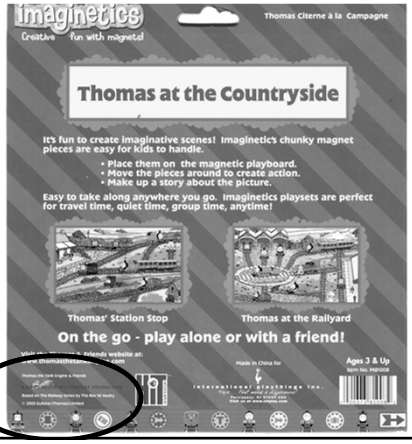
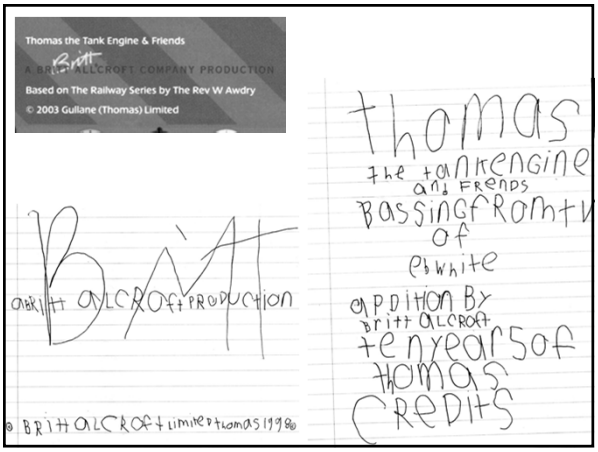
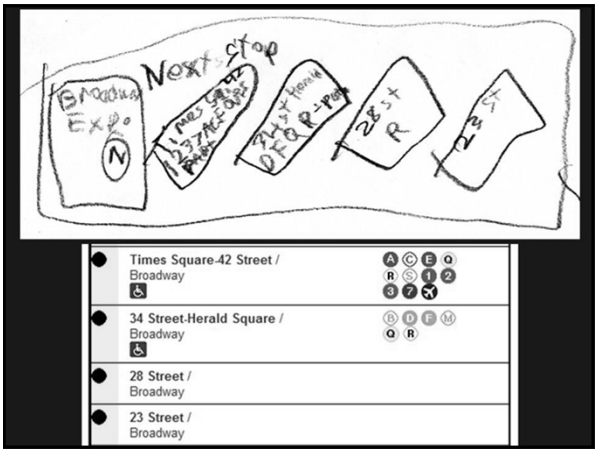
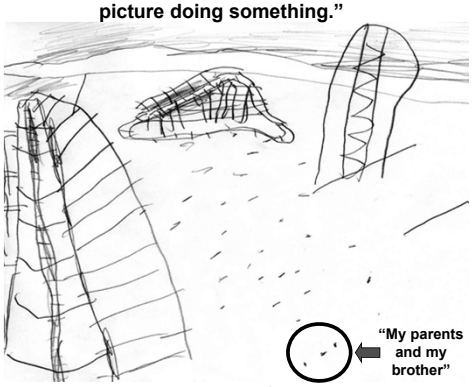




9 y.o. with ASD and normal intelligence (lives in Philadelphia, not NYC) MRN 06-0211



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



"Cedar Point Park, with the ocean and Canada in the background."

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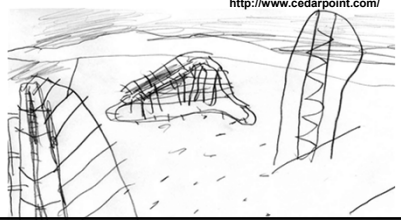
http://www.cedarpoint.com/



Central Coherence

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

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

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?***

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?

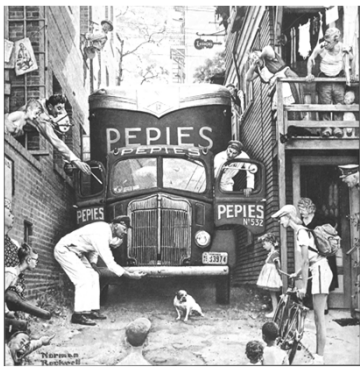
What's happening in this picture?

"The girl is screaming."

What's happening in this picture?

"That girl is trying to steal the other girl's book."

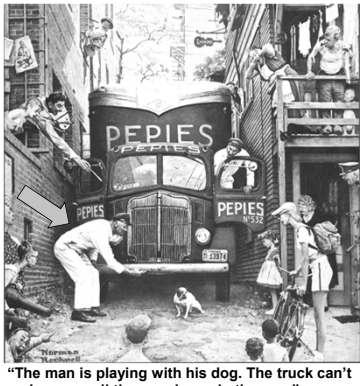
What's happening in this picture?



What's happening in this picture?

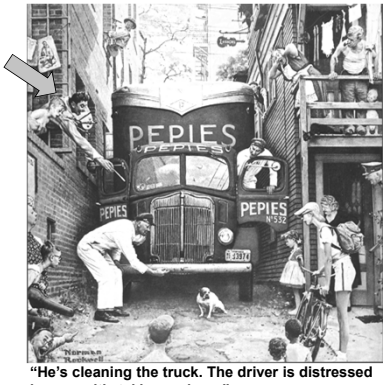
"The man is trying to fix the truck."

What's happening in this picture?



"The man is playing with his dog. The truck can't go because all the people are in the way."

What's happening in this picture?



"He's cleaning the truck. The driver is distressed because it's taking so long."

13-0833

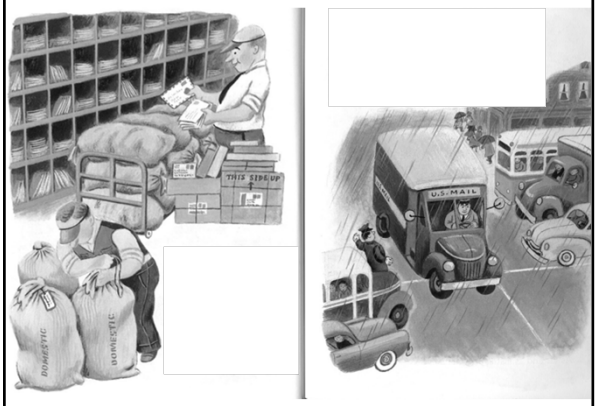
Can you figure out this story from the pictures?

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

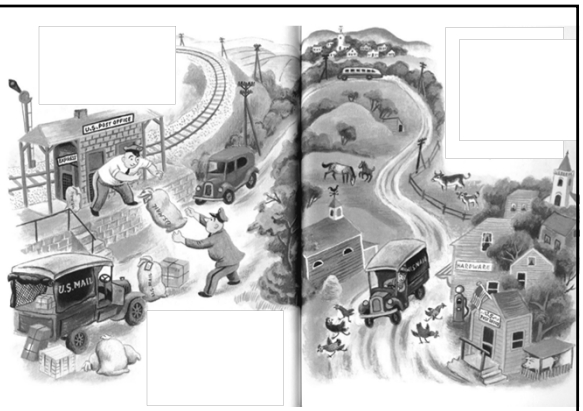
Q: What's happening in this picture?
A: ***The boy is hoarding animals.***

Q: What's this?
A: ***It's a rectangle with a triangle and an X on it.***

Where is the letter now?



Who is this man, and what is he doing?
- ***He's yelling at the man in the truck***
- ***He's out in the rain without an umbrella***
- ***He has his hand up because he knows the answer***



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?"*

4. 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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Abnormal responses to sensory stimuli

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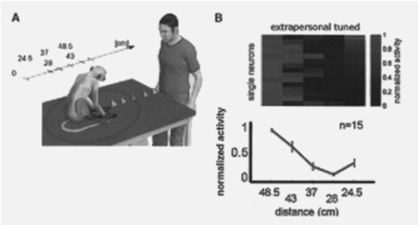
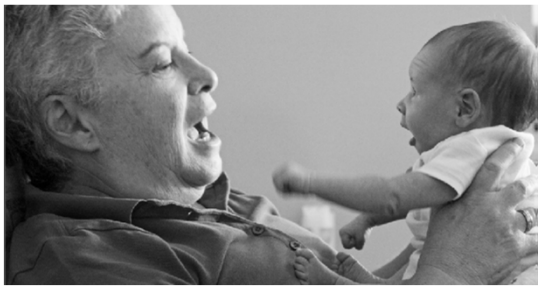
Mirror Neurons: The Missing Link?



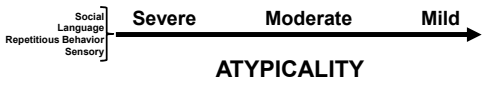
Caggiano et al Science 17 April 2009. Mirror Neurons Differentially Encode the Peripersonal and Extrapersonal Space of Monkeys

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

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



"The Spectrum": ASD in One Dimension



- **Atypical features can range from severe to mild**
- **ASD has a natural h/o improvement over time**

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Topics

- **Core features of ASD**
- ➢ **Co-Morbidity**
- **Prognosis**
- **Transition to Adulthood / Long-term issues**

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Co-Morbidity

- **Developmental**
  - **Cognitive Delay**
- **Neuropsychiatric**
  - **Anxiety**
  - **Depression**
  - **Agitation**

Atypicality vs Delay

- ***Delayed:*** **Behavior would be normal in a younger child**
  - **Ex: Pulling to stand at 18 months; normal tone & reflexes**
  - **Ex: Babbling in a 24 month old**
- ***Atypical:*** **Behavior would be abnormal at any age**
  - **Ex: Spasticity & hyperadduction**
  - **Ex: Reciting TV commercials but not saying "mama" or "dada"**

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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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Problem-Solving

1" Cubes

- **Takes one: 6 m**
- **Transfers: 7 m**
- **Bangs two: 9 m**
- **Takes three: 10-12 m**
- **Copies**
  - **14 m**
  - **18 m**
  - **24-27 m**

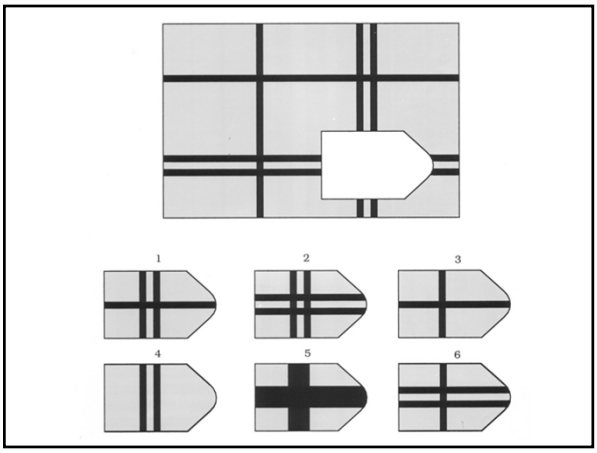
- **Builds:**
  - **30-36 m**
  - **3 1/2 yr**
  - **4 yr**
  - **5 yr**
  - **6 yr**

Problem-Solving

Crayon

- **Mouths: < 9 m**
- **Makes marks 10-12 m**
- **Scribbles p demo: 14 m**
- **Scribbles spont: 16 m**
- **Alternates from stroke to scribble: 22 m**
- **24-27 m**

- **Draws:**
  - **30-36 m**
  - **3 1/2 yr**
  - **4 yr**
  - **5 yr**
  - **6 yr**



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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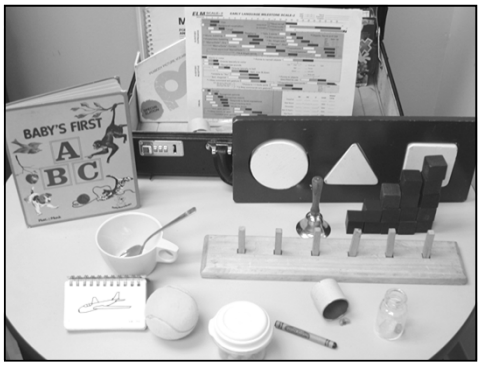

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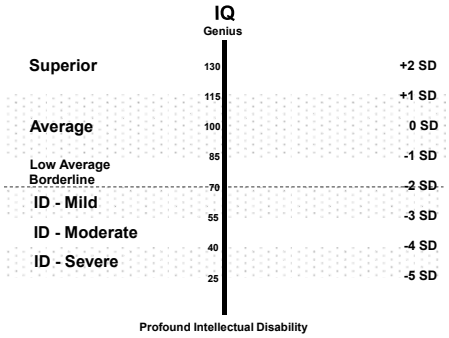

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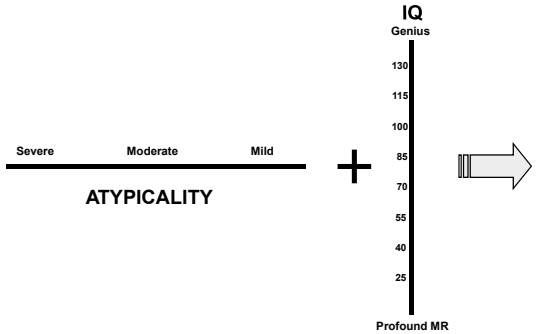
Combine atypicality and IQ scales……



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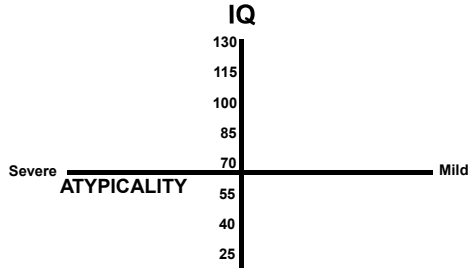
ASD & IQ: 2 Dimensions



- Any degree of atypicality can be accompanied by any level of intelligence

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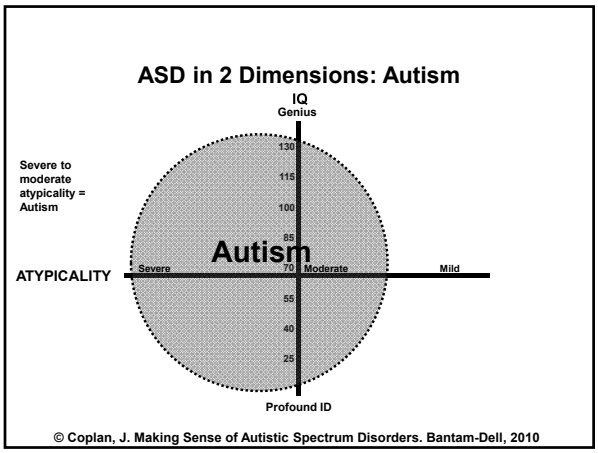
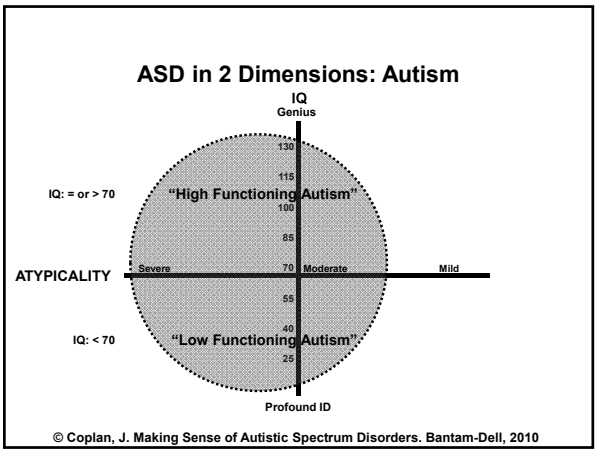
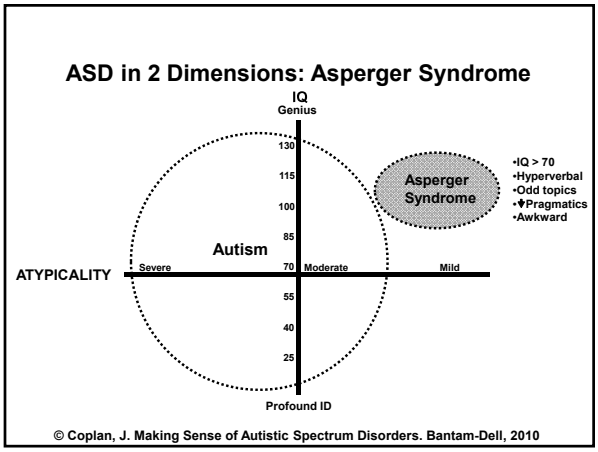

ASD in 2 Dimensions: Autism
IQ
Genius
Severe to moderate atypicality = Autism
Autism
ATYPICALITY
Severe
Moderate
Mild
130
115
100
85
70
55
40
25
Profound ID
© Coplan, J. Making Sense of Autistic Spectrum Disorders. Bantam-Dell, 2010


ASD in 2 Dimensions: Autism
IQ
Genius
IQ: = or > 70
"High Functioning Autism"
ATYPICALITY
Severe
Moderate
Mild
IQ: < 70
"Low Functioning Autism"
130
115
100
85
70
55
40
25
Profound ID
© Coplan, J. Making Sense of Autistic Spectrum Disorders. Bantam-Dell, 2010


ASD in 2 Dimensions: Asperger Syndrome
IQ
Genius
Asperger Syndrome
•IQ > 70
•Hyperverbal
•Odd topics
•⬇Pragmatics
•Awkward
Autism
ATYPICALITY
Severe
Moderate
Mild
130
115
100
85
70
55
40
25
Profound ID
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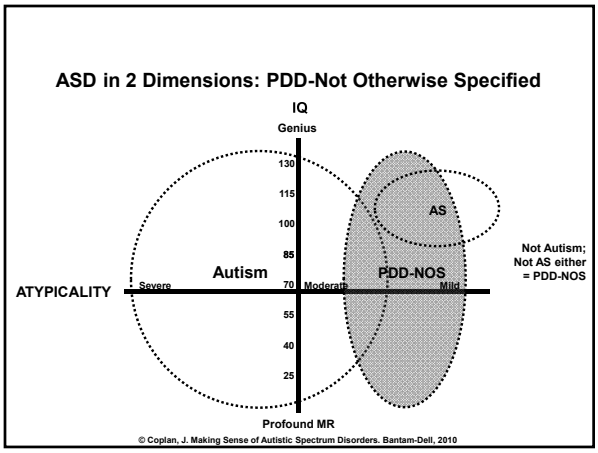
ASD in 2 Dimensions: PDD-Not Otherwise Specified
IQ
Genius
AS
Not Autism; Not AS either = PDD-NOS
Autism
PDD-NOS
ATYPICALITY
Severe
Moderate
Mild
130
115
100
85
70
55
40
25
Profound MR
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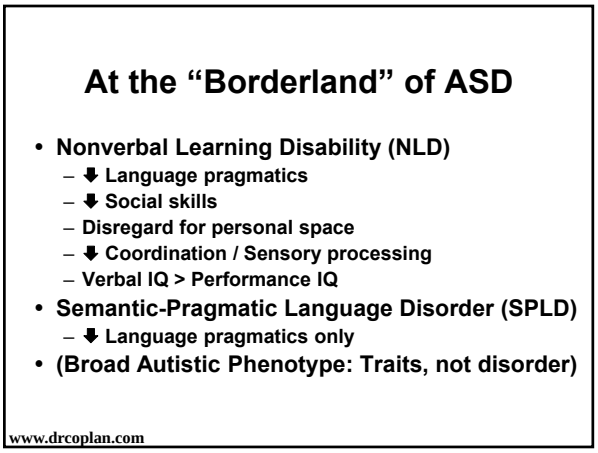
At the "Borderland" of ASD
• Nonverbal Learning Disability (NLD)
– ⬇ Language pragmatics
– ⬇ Social skills
– Disregard for personal space
– ⬇ Coordination / Sensory processing
– Verbal IQ > Performance IQ
• Semantic-Pragmatic Language Disorder (SPLD)
– ⬇ Language pragmatics only
• (Broad Autistic Phenotype: Traits, not disorder)
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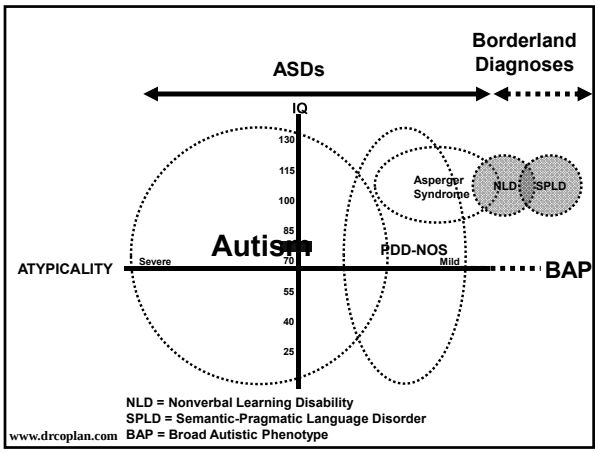

Topics

- Core features of ASD
- Co-Morbidity
- ➢ Prognosis
- Transition to Adulthood / Long-term issues

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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

* 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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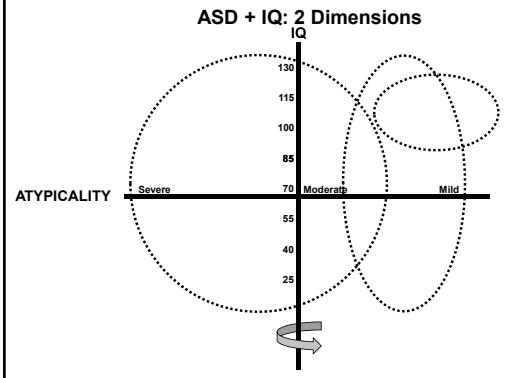
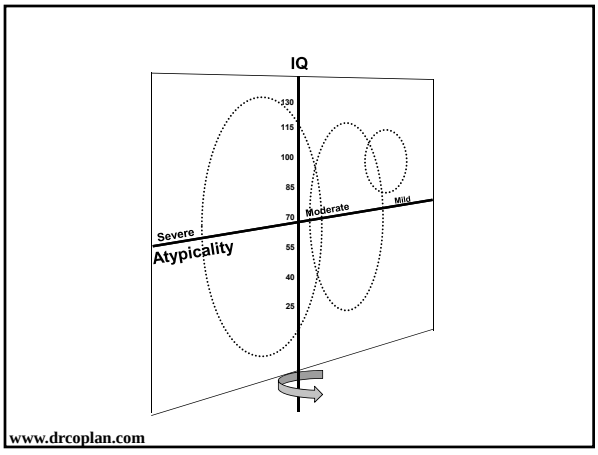
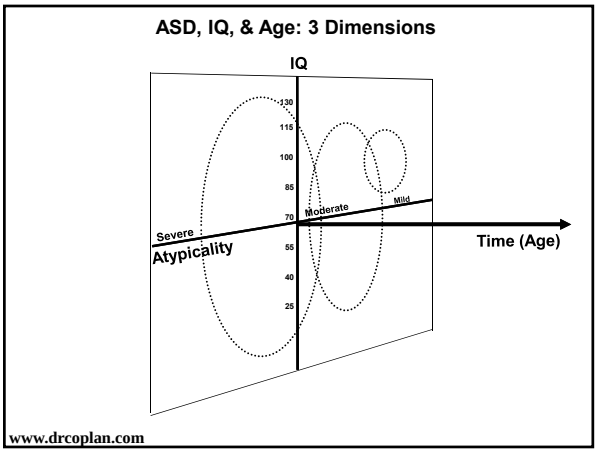
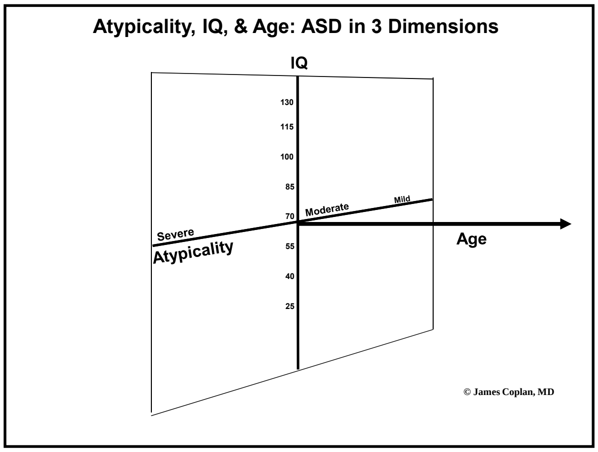
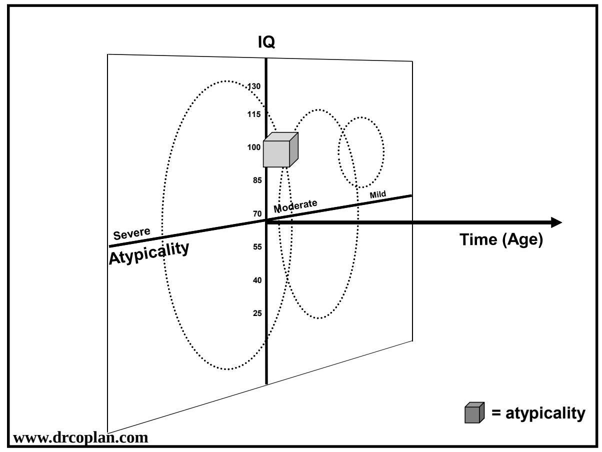
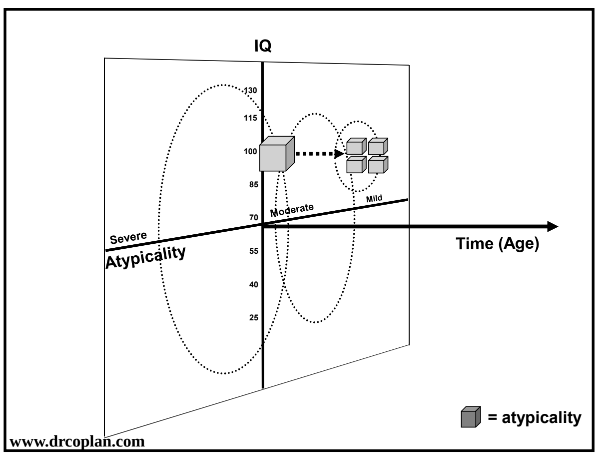


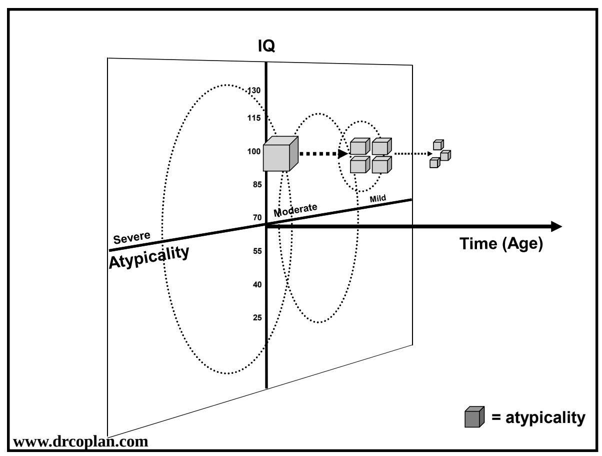


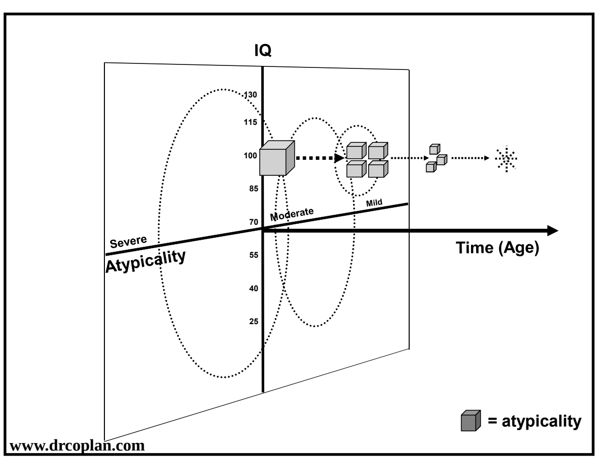


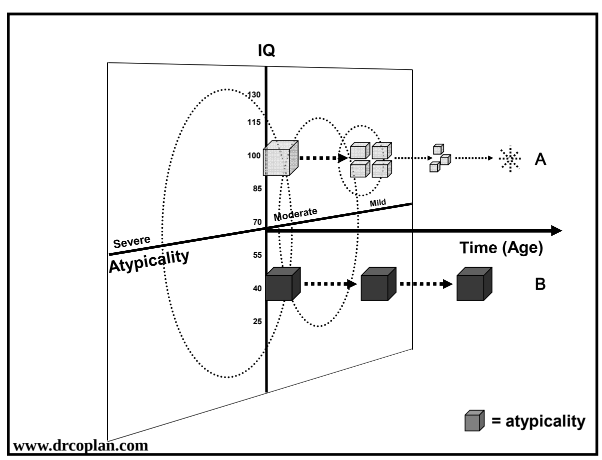

Atypicality, IQ, & Age: ASD in 3 Dimensions
IQ
130
115
100
85
70
55
40
25
Severe
Moderate
Mild
Atypicality
Age
© James Coplan, MD


IQ
130
115
100
85
70
55
40
25
Severe
Atypicality
Time (Age)
= atypicality
www.drcoplan.com


IQ
130
115
100
85
70
55
40
25
Severe
Atypicality
Time (Age)
= atypicality
www.drcoplan.com


IQ
130
115
100
85
70
55
40
25
Severe
Atypicality
Time (Age)
= atypicality
www.drcoplan.com


IQ
130
115
100
85
70
55
40
25
Severe
Atypicality
Time (Age)
= atypicality
www.drcoplan.com


IQ
130
115
100
85
70
55
40
25
A
B
Severe
Atypicality
Time (Age)
= atypicality
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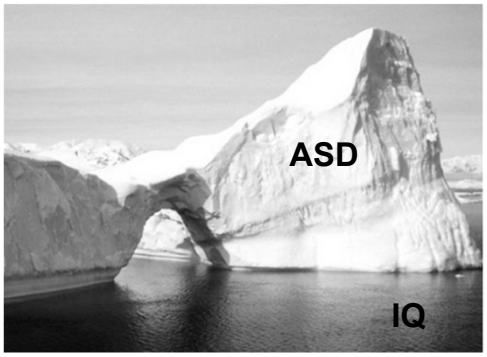
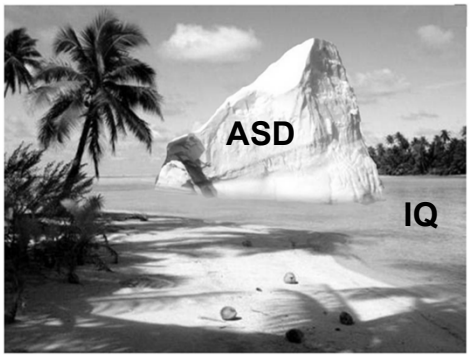
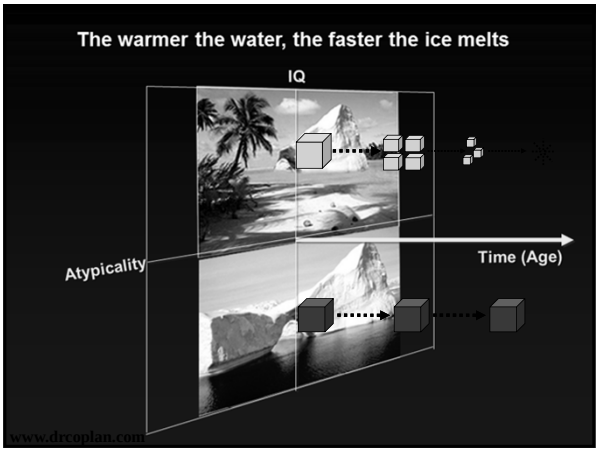




The warmer the water, the faster the ice melts



Transition to Adulthood

Our son turned 13 last year. We are noticing that…the world interacts very differently to an autistic child vs. an autistic man.

MRN 04-0011

Transition to Adulthood

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

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

DC: MRN 13-0854

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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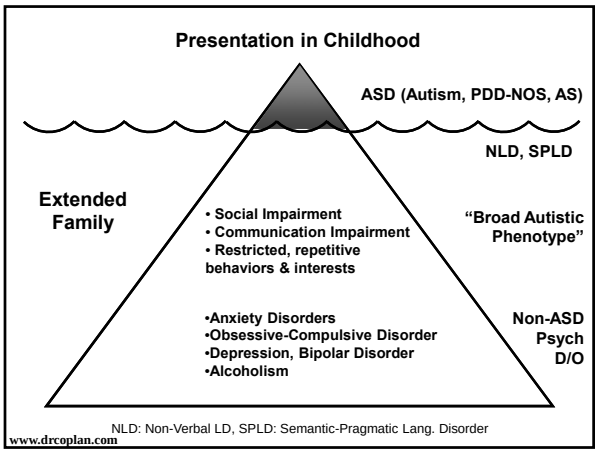

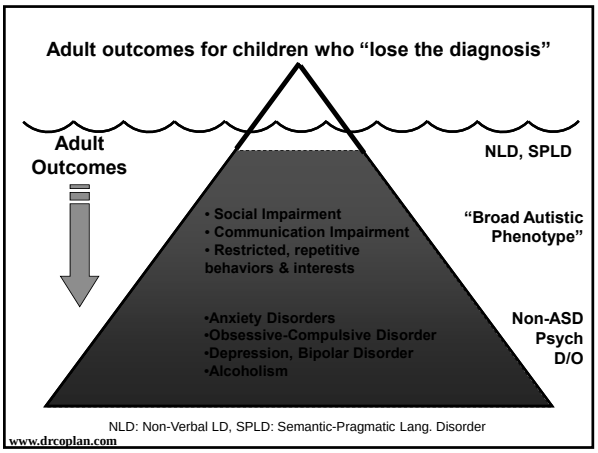

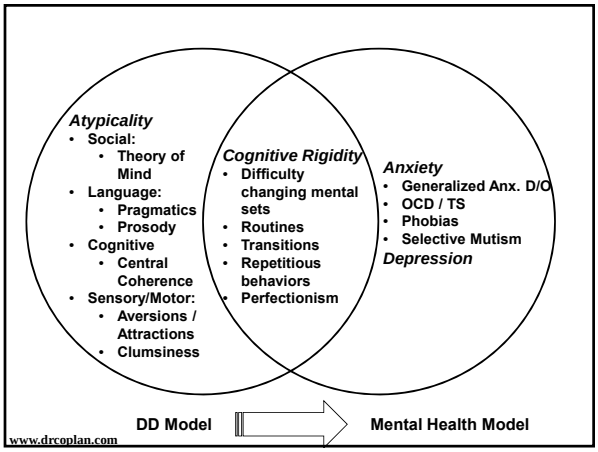

Summary

- **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**
- **"The warmer the water, the faster the ice melts"**

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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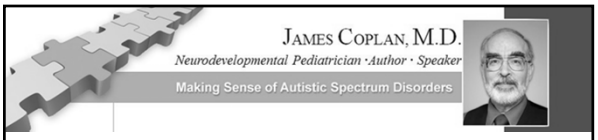

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Thank You!

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