

***Treatments for Persons with ASD Across the
Lifespan: One Size Does Not Fit All***

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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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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
www.drcoplan.com

Impaired Socialization

- **“Aloof”**
- **“Withdrawn”**
- **Limited eye contact**
- **Indifferent to others**

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Idiosyncratic Language

- **Echolalia**
- **Delayed Echolalia**
- **Pronoun Reversal**
- **Odd inflection**

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Repetitious Behaviors

- **Rigid Routines**
- **Stereotypies**
- **Lining up / spinning objects**

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Unusual sensory responses

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

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
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

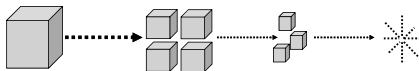
www.drcoplan.com

Kanner's contributions

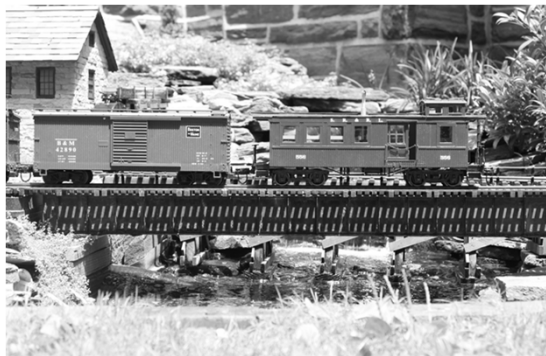
- **Clinical Description**
 - Social, Language, Repetitious behavior,
& Sensory aversions / attractions
- **Attribution: An “inborn error of
affective contact”**
- **Described the *Natural History* of
improvement over time**

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Over time, the ice melts



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Quantifying severity of ASD, and changes over time

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

© 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

Quantifying severity of ASD - 1

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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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



*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 unusual story, because you don't often find cows in the woods. (Asperger Syndrome)

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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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Repetitious Behavior

**“My child has over-attention
deficit disorder.”**

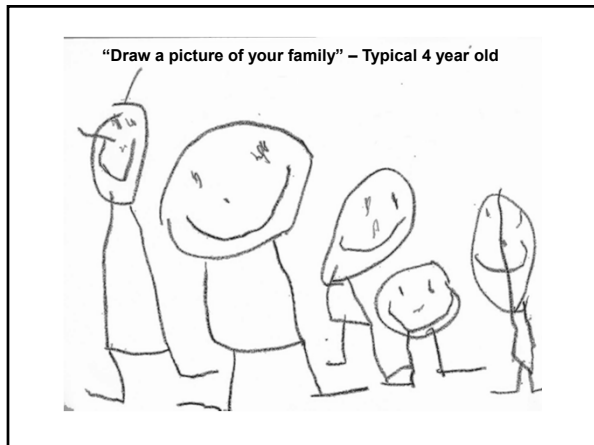
*Father of a 10 year old with autism and
perseverative behavior*

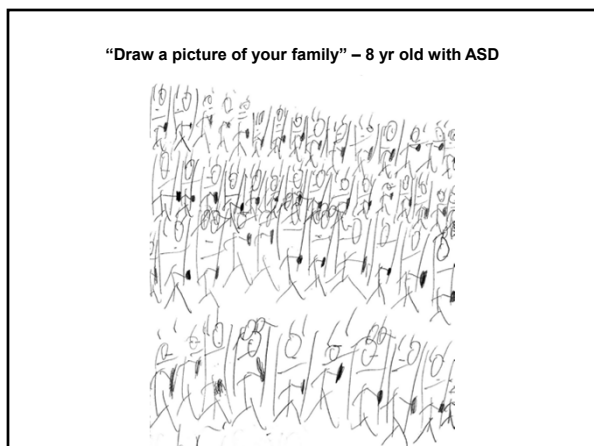
Quantifying severity of ASD - 3

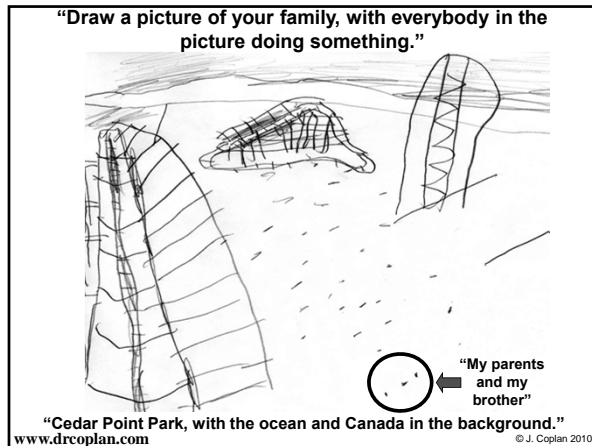
Clinical Domain ↓	Decreasing Atypicality / Increasing Age ⇒		
	Severe / Youngest	Moderate / Older	Mild / Older
3. Repetitious Behaviors <i>Cognitive</i>	•Extreme distress if routines are changed or when required to transition from one task to another •Fascination with odd objects (tags, wheels, fans, 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
<i>Motoric</i>	•Frequent, intense stereotypical movements (flapping, spinning, toe-walking, finger twiddling)	• Motor stereotypies occasional; may re-emerge when excited	• Motor stereotypies rare or absent

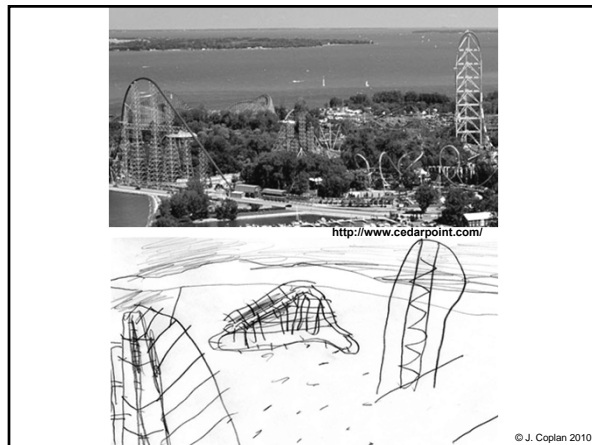
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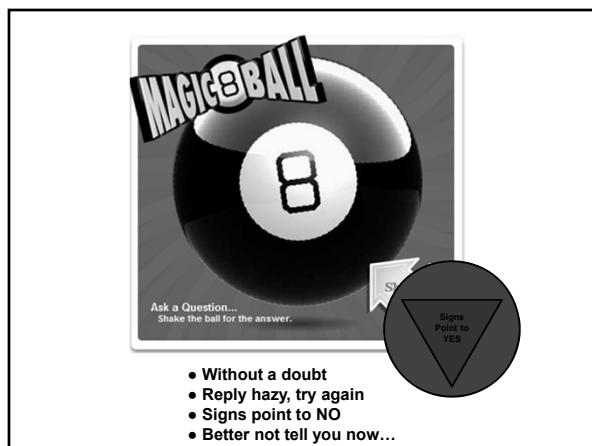


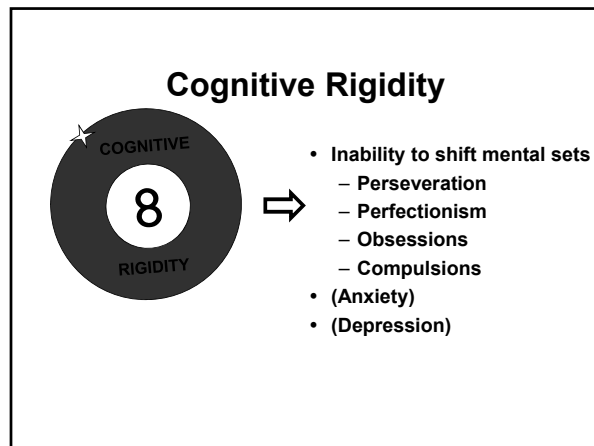


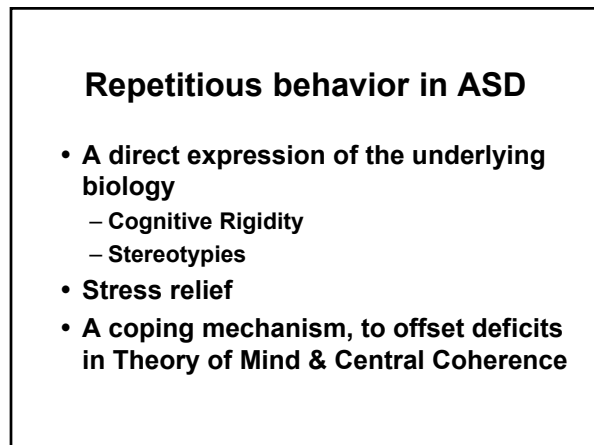


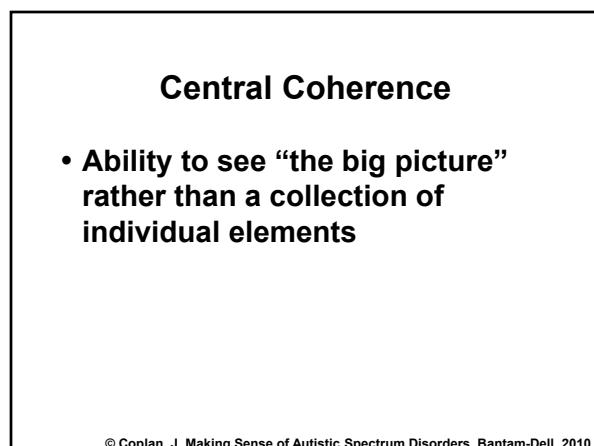












**Tasks requiring Central Coherence
(in addition to Theory of Mind)**

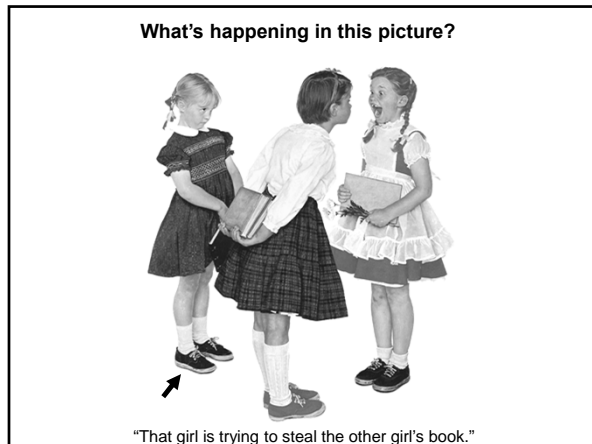
What's happening in this picture?

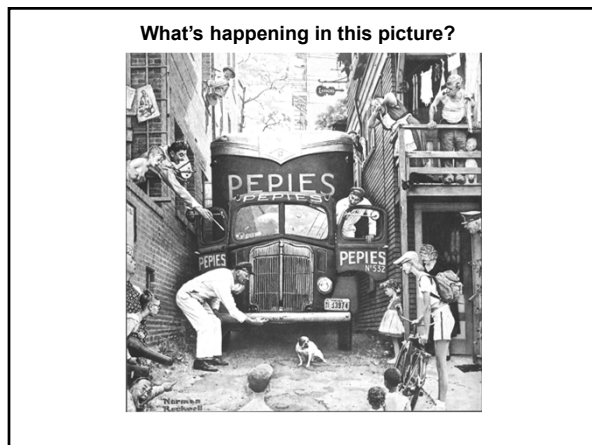


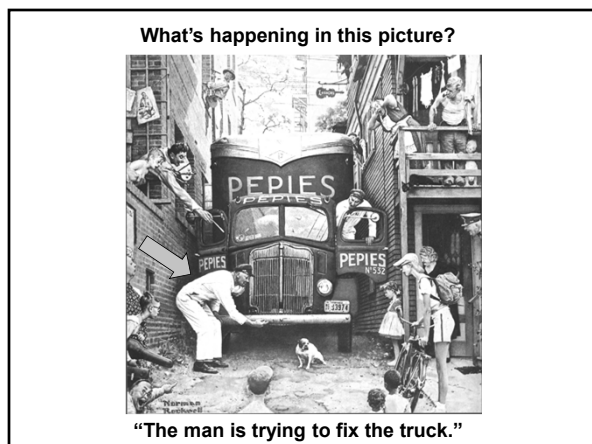
What's happening in this picture?



"The girl is screaming."





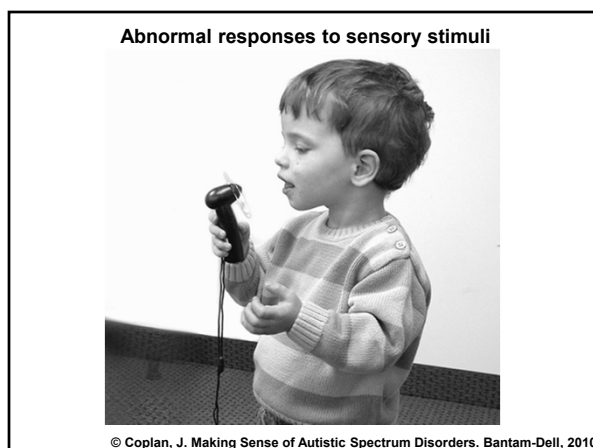


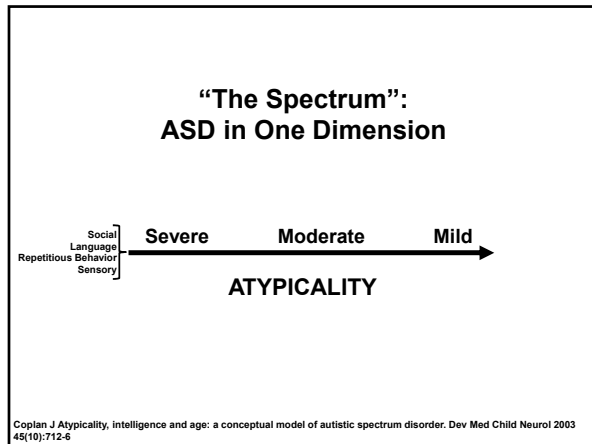


Quantifying severity of ASD - 4

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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Conclusions & Questions

- **ASD can range from severe to mild**
- **ASD has a *Natural History* for improvement over time**
- **What factors determine outcome?**
 - Intrinsic (biological variables)
 - Extrinsic (therapy)

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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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Intelligence in ASD

- No mention of intelligence in the DSM definition of Autism or PDD-NOS
- Intelligence stated to be normal in Asperger Syndrome
 - By implication, therefore, it is possible to measure intelligence in the presence of atypicality
- Some children with ASD are clearly brighter than others (although this is not synonymous with “normal intelligence”)

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Measuring intelligence in ASD

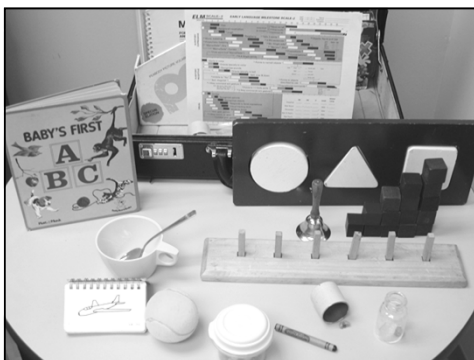
- How to operationalize the measurement of intelligence in ASD?
 - Omit ASD-specific areas of dysfunction or inflator scores:
 - Language
 - Social judgment
 - Savant skills
 - What's left?
 - Non-verbal Problem-Solving
 - Adaptive skills (somewhat)
 - Play skills (somewhat)

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Non-verbal Problem-Solving

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

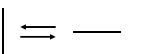
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





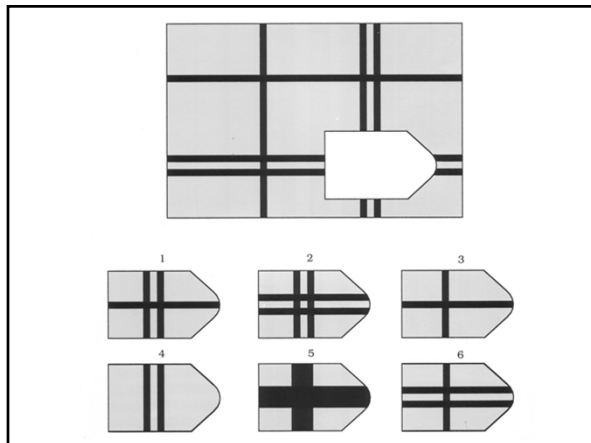
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Problem-Solving

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

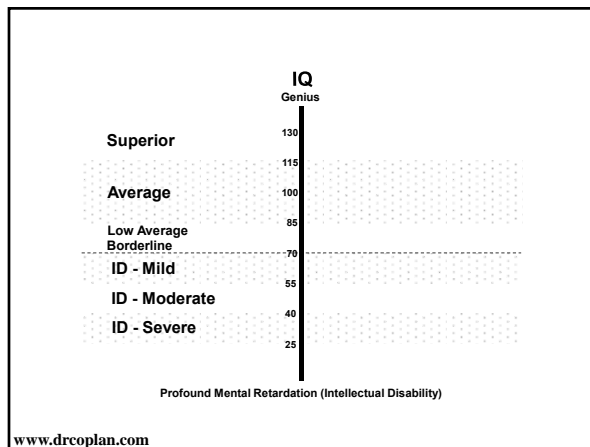
- **Self-feeding**
 - Finger-feeding
 - Cup
 - Spoon (tool use)
- **Self-dressing**
 - Unbuttoning, buttoning
 - Zippers, Snaps
 - Tie shoes
- **Toilet-training**

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Play

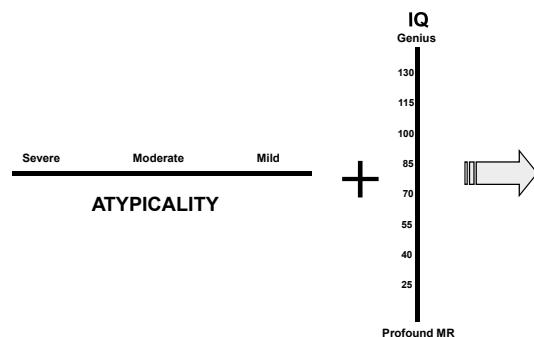
- Midline hand play (3 mo)
- Banging & Mouthing (7 - 9 mo)
- Casting (12 mo)
- Tools (crayon) ~ 14 mo
- Cause & Effect (14 to 16 mo & up)
- Imitative Play (24 mo)
- Imaginative Play (36 mo)
- Rule-based Play (48 mo)

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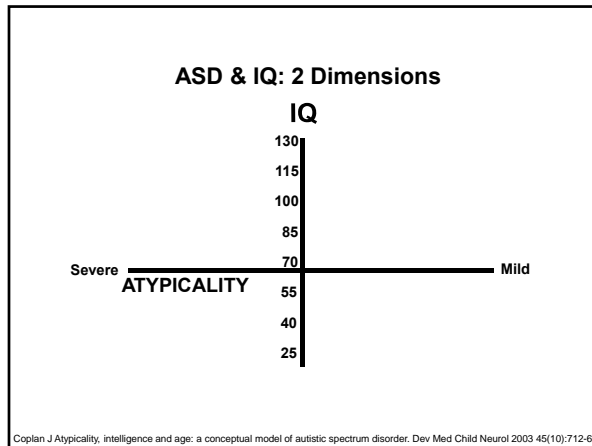


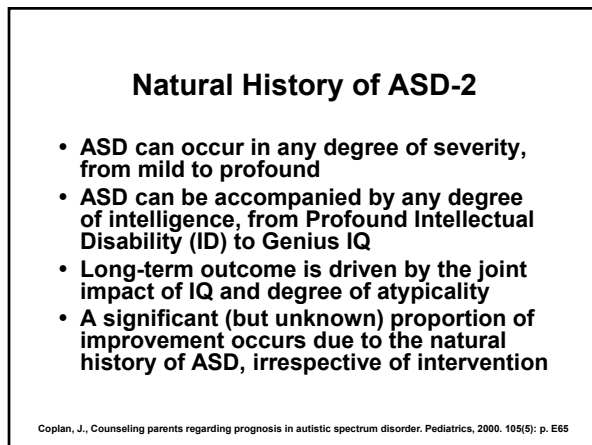
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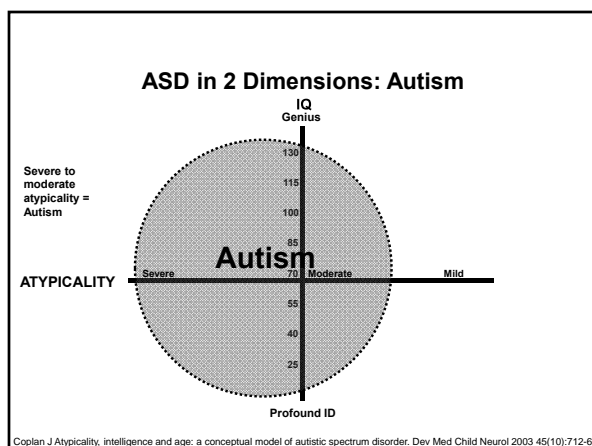
Combine atypicality and IQ scales.....

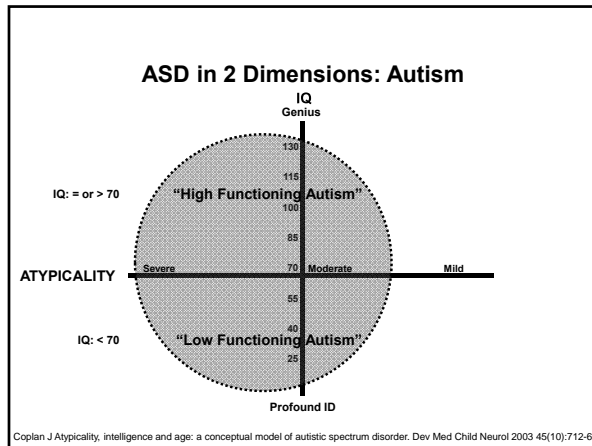


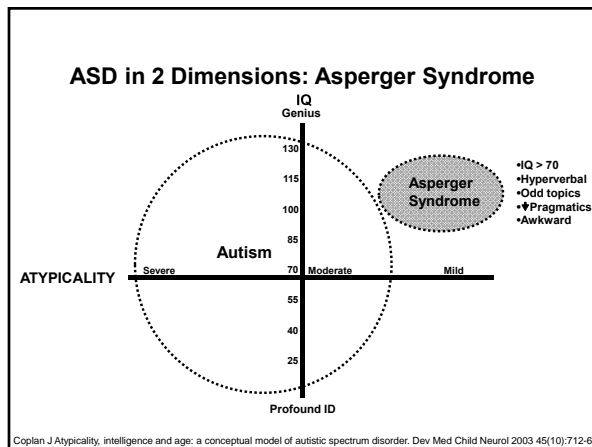
Coplan J Atypicality, intelligence and age: a conceptual model of autistic spectrum disorder. Dev Med Child Neurol 2003 45(10):712-6



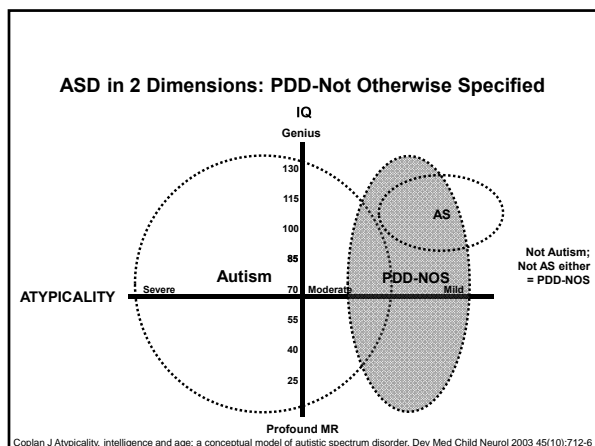








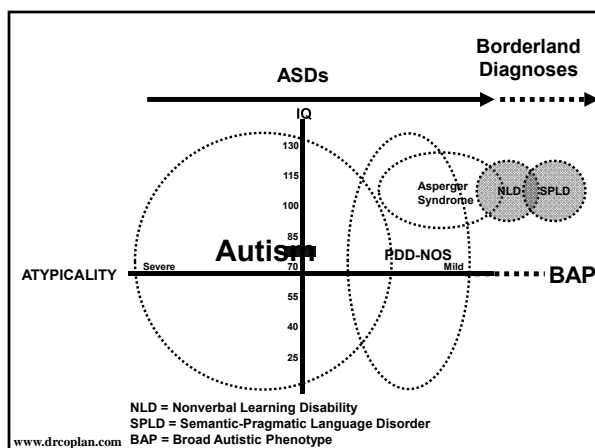




At the “Borderland” of ASD

- **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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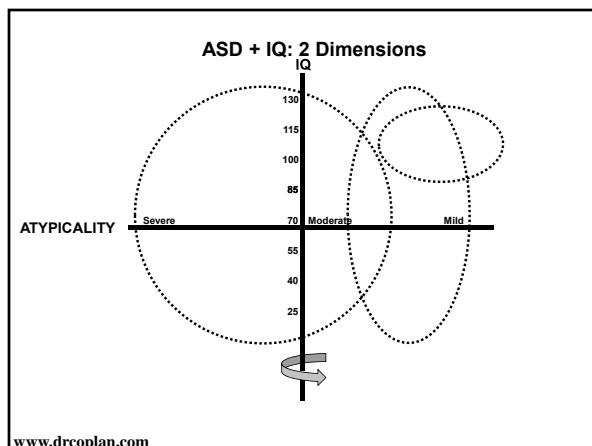


Influence of IQ on Prognosis

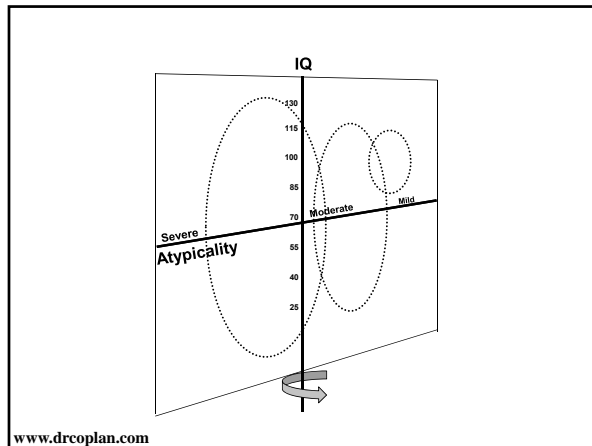
- “In terms of scholastic progress, social competence, and work opportunities, the child’s IQ level is as influential as the presence of autism.”*
- 1973-2005: > 10 studies; >1000 subjects

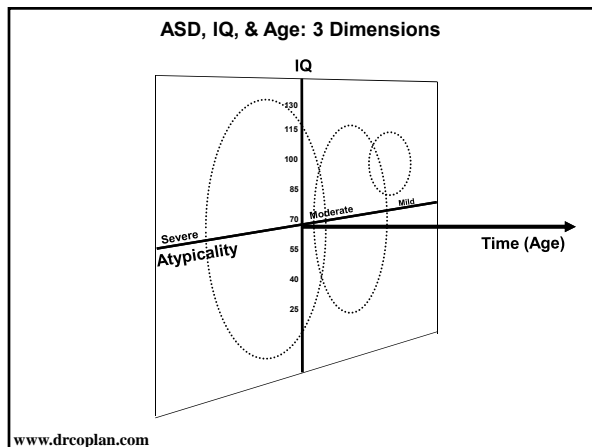
* Bartak, L. and M. Rutter, Differences between mentally retarded and normally intelligent autistic children. Journal of Autism & Childhood Schizophrenia, 1976. 6(2): p. 109-20

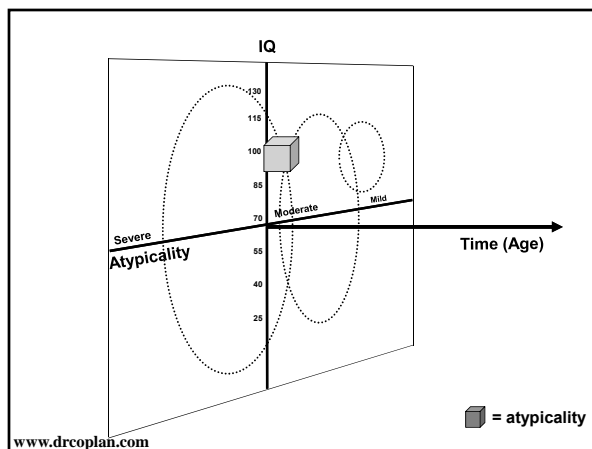
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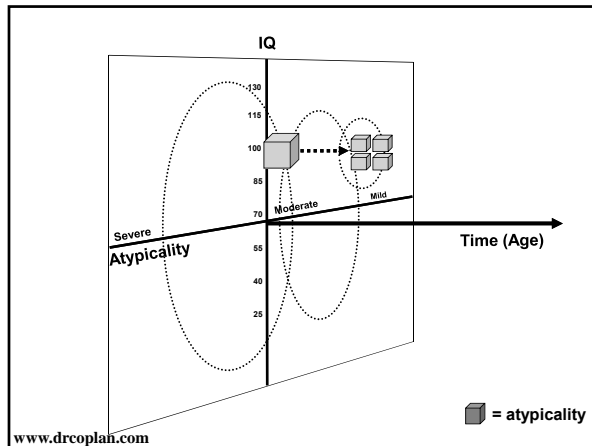


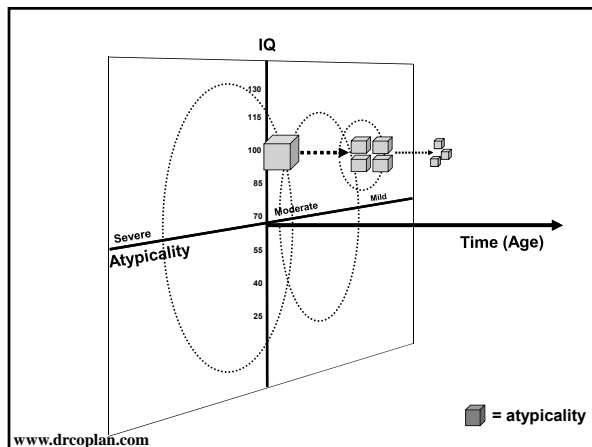
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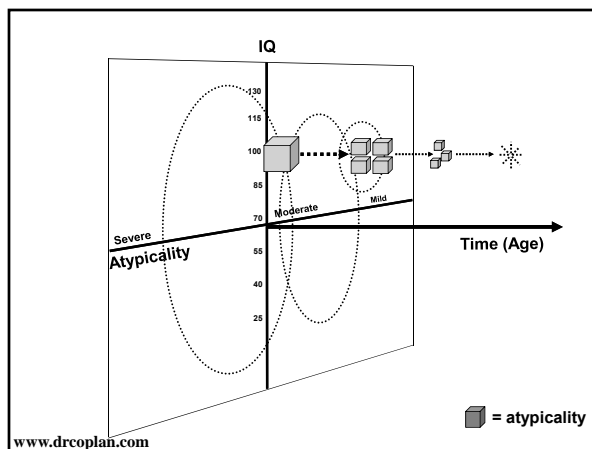


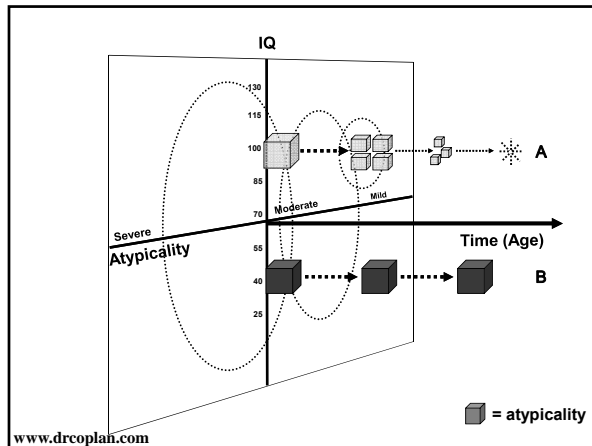


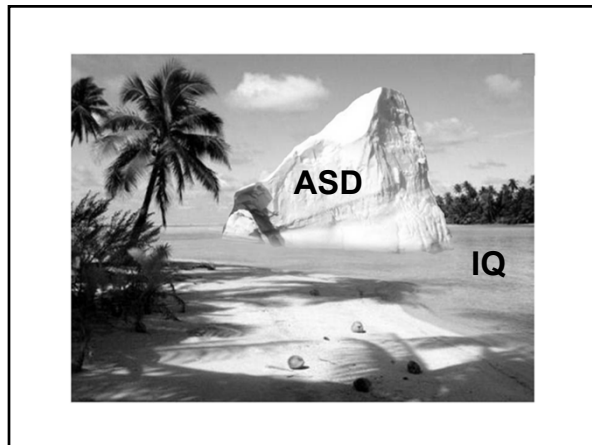


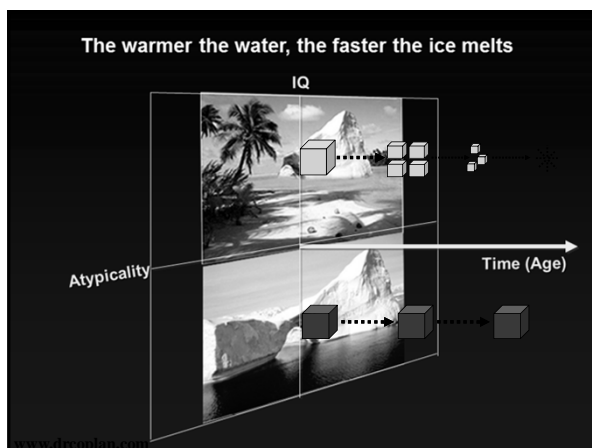








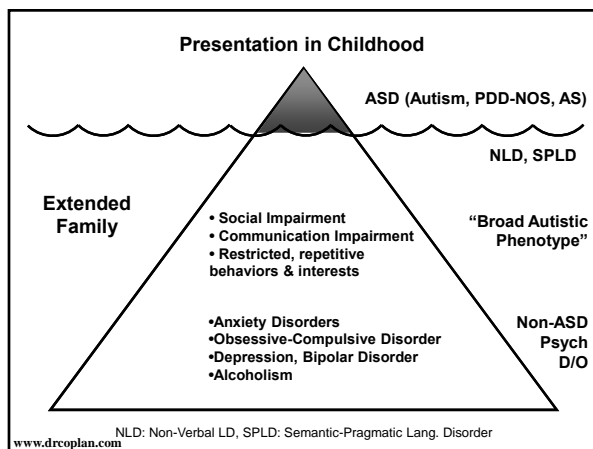


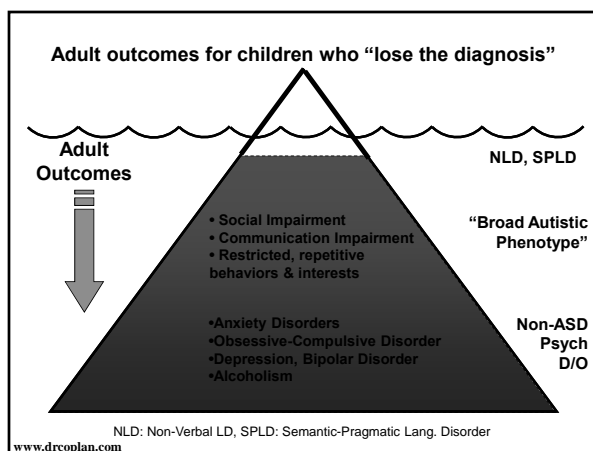


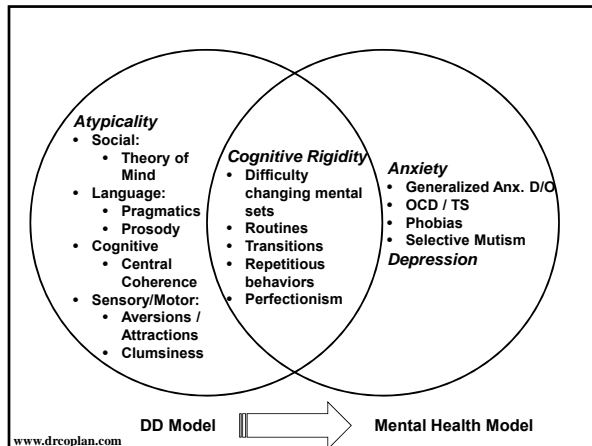
Adult outcome

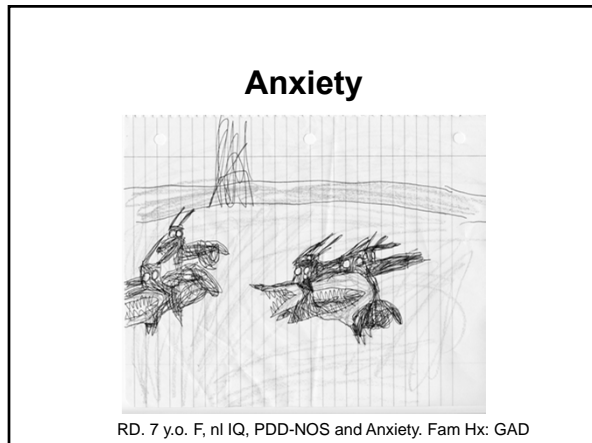
- “Losing the diagnosis” does not mean “cured”
- Persistence of
 - Cognitive patterns
 - Behavioral patterns
 - Emotional patterns
- Symptoms ⇒ Quirks ⇒ Traits
- Non-ASD neuropsychiatric disorders

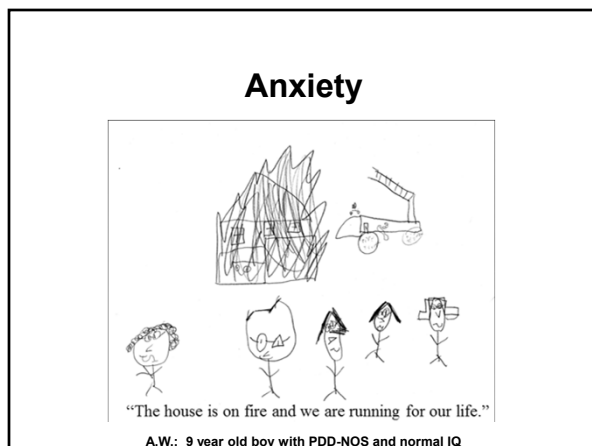
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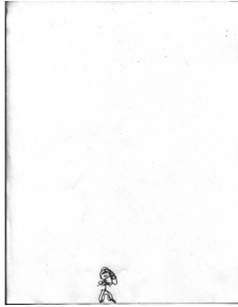






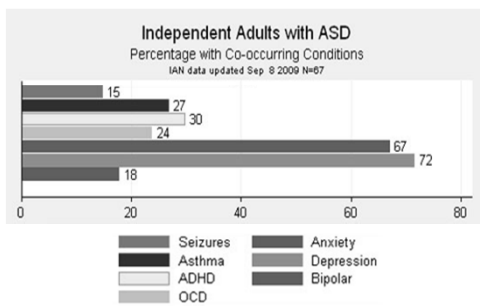


Depression



KO; 10 yr old female, PDD-NOS, normal IQ

Interactive Autism Network On-Line Survey



http://www.iانcommunity.org/ian_research_reports/adults_on_the_autism_spectrum_september_2009



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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 to '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!"

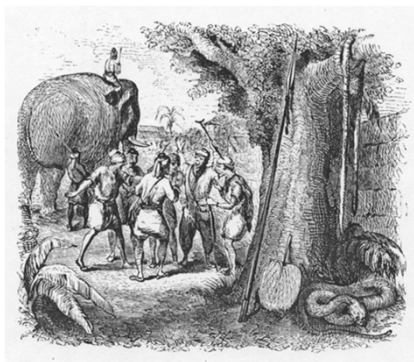
The Fourth reached out his eager hand,
And felt about the knee;
"What most this wondrous beast is like
is mighty plain," quoth he;
""T is clear enough the Elephant
Is very like a tree!"

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)

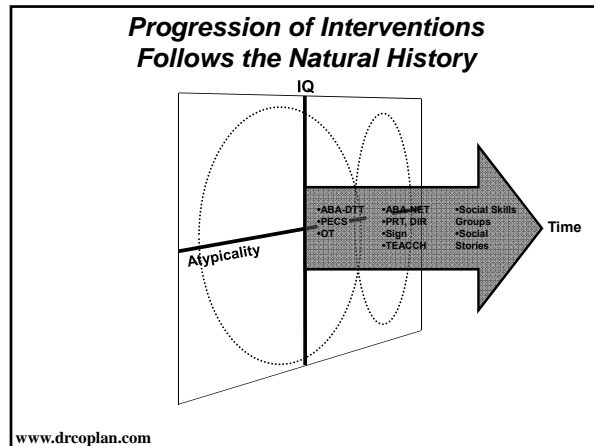
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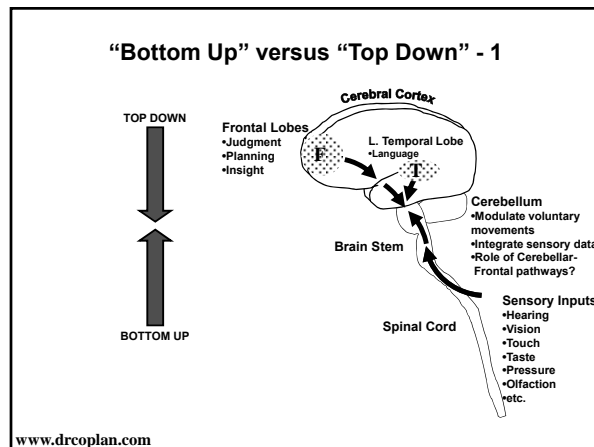


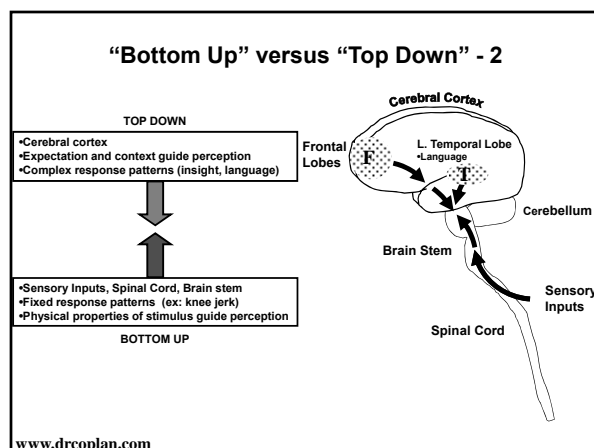
Therapies for ASD: A Modest Proposal

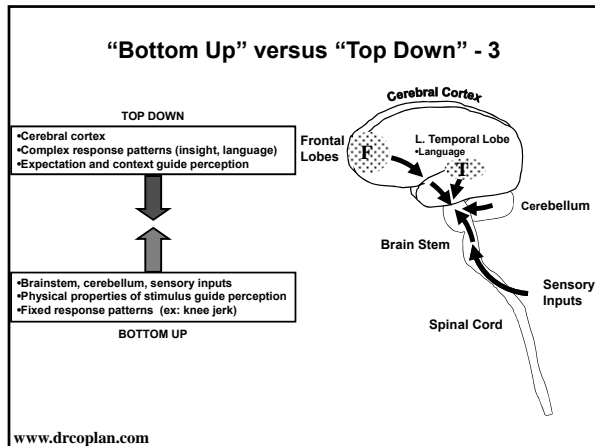
- Therapies for ASD should be matched to the natural history of ASD itself
 - *As the person's symptoms evolve, so should the forms of therapy*
 - *It's not a matter of right vs wrong; It's a matter of what & when*

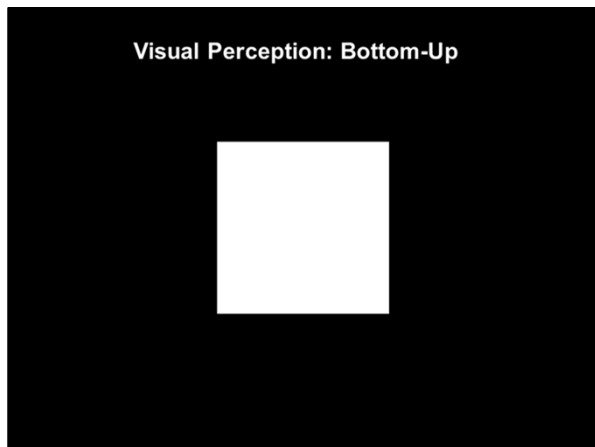
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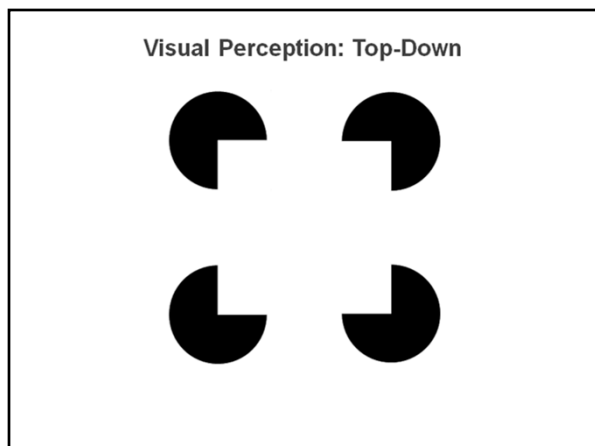


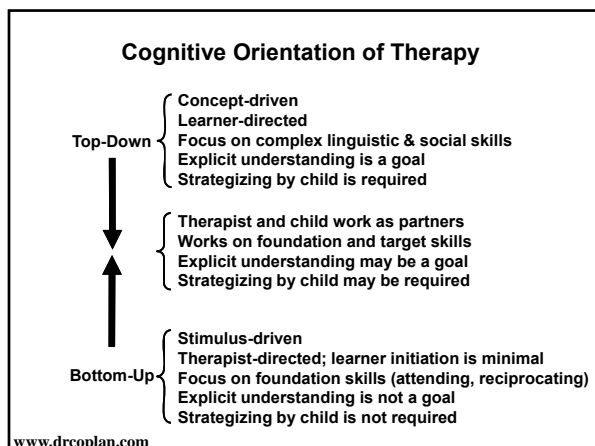


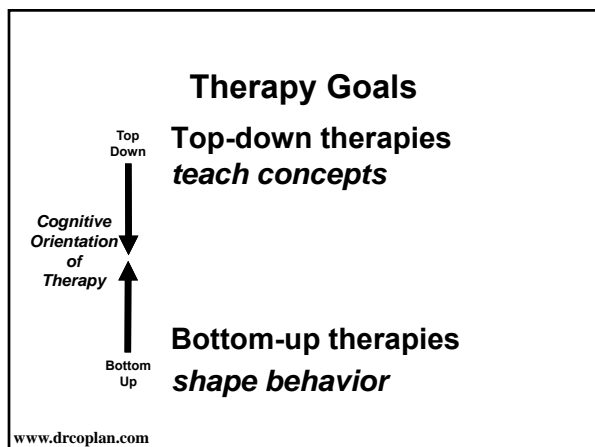


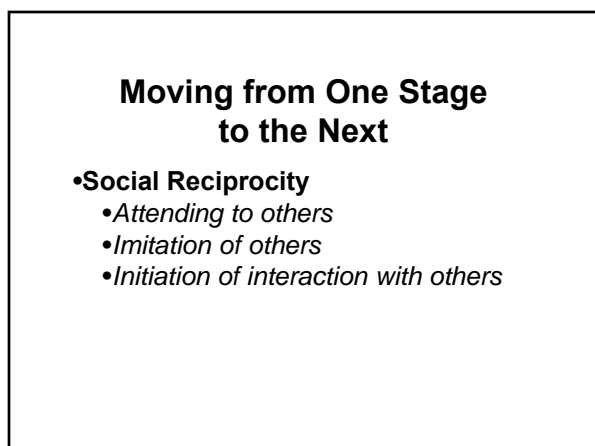






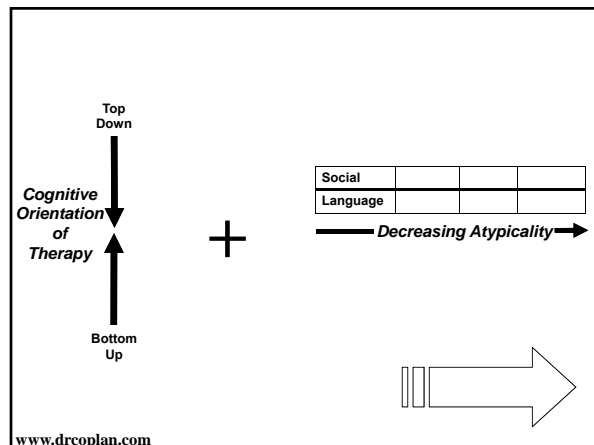


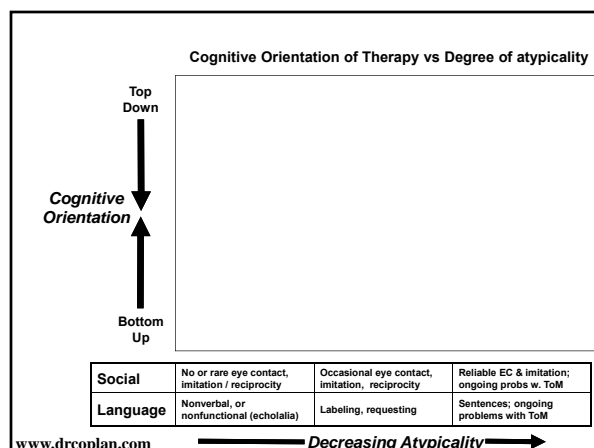


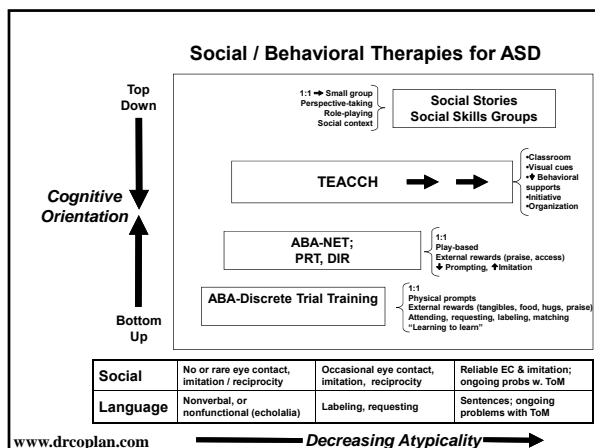


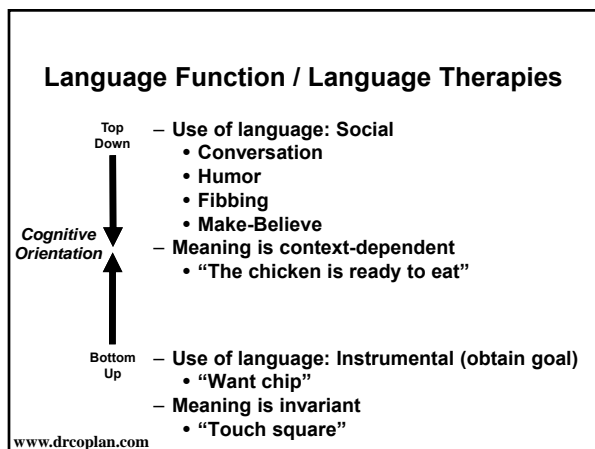
Degree of Atypicality			
	Severe	Moderate	Mild
Social	No or rare eye contact, No social reciprocity (imitation; initiation)	Occasional eye contact & social reciprocity	Reliable EC & reciprocity; Ongoing problems with Theory of Mind (personal space, rules, etc.)
Language	Nonverbal, or nonfunctional (Echolalia,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

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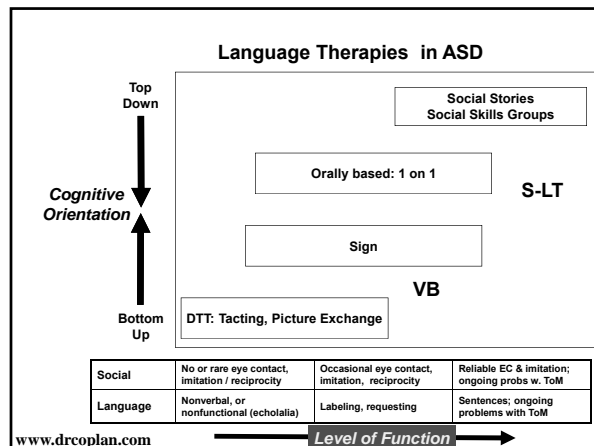


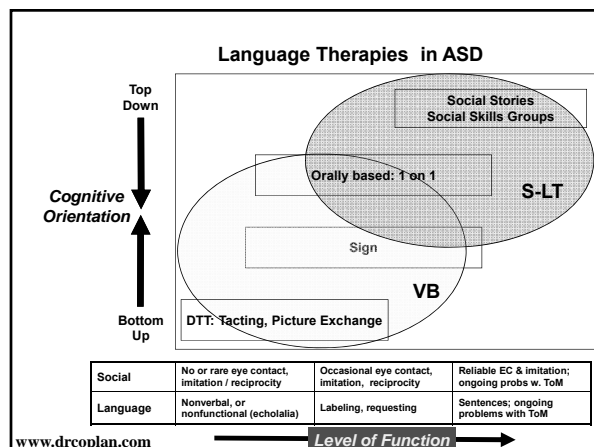












Verbal Behavior (VB)

“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

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Verbal Behavior (VB)

**“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)

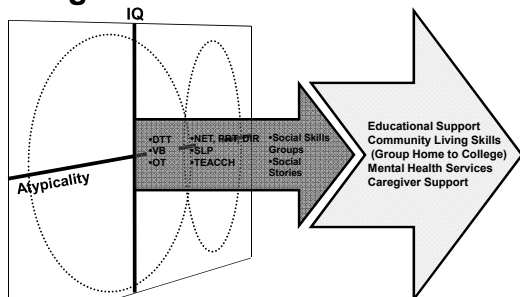
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Sensory-Based therapies for ASD

- **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)

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Progression of Interventions



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Summary

- The *Natural History* of ASD 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”
- Progression of Therapies parallels natural history of ASD itself:
 - Shift from Bottom-Up to Top-Down
 - Shift from Developmental Disability model to Mental Health model
- Need for adult services

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Thank you!