ASD in 3D: Autism Spectrum Disorders across the Lifespan

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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

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

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

ASD has a Natural History
Topics

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

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

Impaired Socialization

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- “Withdrawn”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

Age: 22 months. Nonverbal. CARS=44.
Difficulty with eye contact

Q: “How does the boy feel?”
A: “I don’t know. I can’t see his mouth.”

Idiosyncratic Language

- Echolalia
- Delayed Echolalia
- Pronoun Reversal
- Odd inflection

Repetitious Behaviors

- Rigid Routines
- Stereotypies
- Lining up / spinning objects

Unusual sensory responses

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

Kanner, 1938 → 1943

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

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

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

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

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

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

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

Quantifying severity of ASD, and changes over time

<table>
<thead>
<tr>
<th>Clinical Domain - Social, Language, Repetitious Behavior, Sensory</th>
<th>Decreasing Atypicality / Increasing Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe / Youngest</td>
<td>Moderate / Older</td>
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</table>

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** |
| - No eye contact | - Intermediate eye contact | - Good eye contact |
| - No physical affection | - Seeks affection "on his own terms" | - Shows interest in others, but often does not know how to join in |
| - Cannot be engaged in imitative tasks | - May invade personal space of others (not true affection) | - Has difficulty if perceives that rules have been broken |
| - Intermittent eye contact | - Engageable in imitative tasks, although with difficulty | - Difficulty with "Theory of Mind" tasks |

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

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

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

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)
2. Language

“My child talks, but he doesn’t communicate.”

Mother of a 3 year old with autism

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

Language Deficits in ASD

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

Language Deficits in ASD

Quantifying severity of ASD - 2

<table>
<thead>
<tr>
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</tr>
</thead>
</table>
| 2. Language
  - Pragmatics
  - Prosody |
|                  | Nonverbal                              |                   |                 |             |
|                  | - No response to voice; may “act deaf”   |                   |                 |             |
|                  | - Use of gestures as a means of          |                   |                 |             |
|                  |   communication for absence of spoken    |                   |                 |             |
|                  |   language                              |                   |                 |             |
|                  | - May use “hand-over-hand” to guide      |                   |                 |             |
|                  |   caregiver to desired objects          |                   |                 |             |
|                  | - Echolalia, Delayed echolalia, verbal  |                   |                 |             |
|                  |   Perseveration                          |                   |                 |             |
|                  |   (stilted, sing-song, robotic, volume)  |                   |                 |             |
|                  | - May use stock phrases in attempt to    |                   |                 |             |
|                  |   communicate                           |                   |                 |             |
|                  | - Makes use of visual communication    |                   |                 |             |
|                  |   modalities (symbol cards, sign       |                   |                 |             |
|                  |   language)                             |                   |                 |             |
|                  | - Speaks fluently, but literal; lacks   |                   |                 |             |
|                  |   understanding of verbal nuance        |                   |                 |             |
|                  | - Difficulty with Pragmatic (framing,   |                   |                 |             |
|                  |   turn-taking, topic maintenance;       |                   |                 |             |
|                  |   conversational repair;                |                   |                 |             |
|                  |   echolalia)                            |                   |                 |             |
|                  | - "At" rather than "with" others; Theory|                   |                 |             |
|                  |   of Mind Language tasks                 |                   |                 |             |
|                  | - Makes use of visual communication     |                   |                 |             |
|                  |   modalities (symbol cards, sign        |                   |                 |             |
|                  |   language)                             |                   |                 |             |

3. Repetitious Behavior

“My child has over-attention deficit disorder.”

Father of a 10 year old with autism and perseverative behavior

“Draw a picture of your family: Mommy, Daddy, Riley, You.”
### Quantifying severity of ASD - 3

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</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Severe / Youngest</td>
</tr>
<tr>
<td>3. Repetitious Behaviors</td>
<td></td>
</tr>
<tr>
<td>Cognitive</td>
<td>Extreme distress if routines are changed or when required to transition from one task to another</td>
</tr>
<tr>
<td></td>
<td>Fascination with odd objects (tags, wheels, fans, etc.)</td>
</tr>
<tr>
<td></td>
<td>Extreme distress if routines are changed or when required to transition from one task to another</td>
</tr>
<tr>
<td></td>
<td>Motoric</td>
</tr>
<tr>
<td></td>
<td>Frequent, intense stereotypical movements (flapping, spinning, toe-walking, finger twiddling)</td>
</tr>
</tbody>
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9 y.o. with ASD and normal intelligence (lives in Philadelphia, not NYC)   MRN 06-0211
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.”
"The man is swimming, and the car is about to fall on him."

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?

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

"The girl is screaming."
“That girl is trying to steal the other girl’s book.”

“The man is trying to fix the truck.”

“The man is playing with his dog. The truck can’t go because all the people are in the way.”

“He’s cleaning the truck. The driver is distressed because it’s taking so long.”

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 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

<table>
<thead>
<tr>
<th>Clinical Domain</th>
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<th>Mild / Older</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Sensorimotor</td>
<td>• Intense aversion or attraction to specific classes of stimuli • Clumsiness</td>
<td>• Auditory: Hyperacusis, covers ears, acts deaf • Visual: self-stimulation (lights/patterns), looks at objects from odd angles • Tactile: rubbing, licking, mouthing, deep pressure, aversive to light touch • Olfactory: Sniffing • Extreme food selectivity • # Pain threshold • Fear: Heightened / blunted</td>
<td>Same, but diminishing intensity</td>
<td>Same, but diminishing intensity</td>
</tr>
</tbody>
</table>


Abnormal responses to sensory stimuli

Mirror Neurons: The Missing Link?

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


“The Spectrum”: ASD in One Dimension

Severe Moderate Mild

ATYPICALITY

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


Topics

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

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"

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)

Non-verbal Problem-Solving

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

Problem-Solving

1" Cubes
- Takes one: 6 m
- Transfers: 7 m
- Bangs two: 9 m
- Takes three: 10-12 m
- Copies
  - Builds:
    - 14 m
    - 18 m
    - 24-27 m
    - 30-36 m

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
- Draws:
  - 30-36 m
  - 3 1/2 yr
  - 4 yr
  - 5 yr
  - 6 yr
- 24-27 m
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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Combining atypicality and IQ scales...

- **ATYPICALITY**
  - Severe
  - Moderate
  - Mild

- IQ
  - 120
  - 110
  - 100
  - 90
  - 80
  - 70
  - 60
  - 50
  - 40
  - 30
  - 20
  - 10

---

ASD & IQ: 2 Dimensions

- Any degree of atypicality can be accompanied by any level of intelligence
ASD in 2 Dimensions: Autism

IQ Genes

Severe to moderate atypicality = Autism

ATYPICALITY

Profound ID

ASD in 2 Dimensions: Asperger Syndrome

IQ Genes

IQ > 70
• Hyperverbal
• Odd topics
• Pragmatics

Asperger Syndrome

ATYPICALITY

Profound ID

ASD in 2 Dimensions: PDD-Not Otherwise Specified

IQ Genes

Not Autism; Not AS either + PDD-NOS

PDD-NOS

ATYPICALITY

Profound ID

At the “Borderland” of ASD

• Nonverbal Learning Disability (NLD)
  – Language pragmatics
  – Social skills
  – Disregard for personal space
• Semantic-Pragmatic Language Disorder (SPLD)
  – Language pragmatics only

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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


ASD, IQ, & Age: 3 Dimensions

Topics

- Core features of ASD
- Co-Morbidity
- Prognosis
- Transition to Adulthood / Long-term issues
Atypicality, IQ, & Age: ASD in 3 Dimensions

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

Transition to Adulthood

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

Adult outcome

- “Losing the diagnosis” does not mean “cured”
- Persistence of
  - Cognitive patterns
  - Behavioral patterns
  - Emotional patterns
- Symptoms ⇒ Quirks ⇒ Traits
- Non-ASD neuropsychiatric disorders
ASD in 3D: A Lifespan perspective
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Presentation in Childhood

ASD (Autism, PDD-NOS, AS)

“Broad Autistic Phenotype”

• Social Impairment
• Communication Impairment
• Restricted, repetitive behaviors & interests

• Anxiety Disorders
• Obsessive-Compulsive Disorder
• Depression, Bipolar Disorder
• Alcoholism

Extended Family

Non-ASD Psych D/O

“Broad Autistic Phenotype”

Adult outcomes for children who “lose the diagnosis”

• Social Impairment
• Communication Impairment
• Restricted, repetitive behaviors & interests

• Anxiety Disorders
• Obsessive-Compulsive Disorder
• Depression, Bipolar Disorder
• Alcoholism

Non-ASD Psych D/O

Extended Family

NLD, SPLD

NLD: Non-Verbal LD, SPLD: Semantic-Pragmatic Lang. Disorder

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”


Summary

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

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Thank You!