Autism and DSM5: Implications for Identification and Intervention
Workshop 027
James Coplan, MD
Neurodevelopmental Pediatrics of the Main Line, PC
Rosemont, PA
610-520-2130
www.DrCoplan.com
info@drcoplan.com

WS027: Autism and the DSM-5: Implications for Identification and Intervention
Thursday, February 20, 2014 12:30 PM–3:30 PM
Description:
ASD is a condition defined on the basis of outwardly visible behavior. This workshop will use lecture, case vignettes, and citations to the published literature to help participants explore the evolving definition of ASD in the DSM and the impact of those changes on the apparent prevalence of ASD (the so-called autism explosion). It also will present alternative ways of conceptualizing ASD that transcend the limitations of the DSM.

Clinical Features and Natural History of ASD [12:30 – 2:00 a.m.]
• Leo Kanner’s lasting contributions
• Degrees of Atypicality (ASD in one dimension)
• Non-verbal IQ (ASD in 2 dimensions)
• Atypicality, Age, and IQ: ASD in 3D
• Progression of therapies tied to Natural History
Break [2:00 – 2:15]
Etiology, Epidemiology, and Quackery [2:15-3:30]
• The autism “explosion”: Where did it come from, what does it mean?
• Impact of DSM5

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

www.drcoplan.com
info@drcoplan.com
Outline

Clinical Features and Natural History of ASD [12:30 – 2:00 a.m.]
- Leo Kanner’s lasting contributions
- Degrees of Atypicality (ASD in one dimension)
- Non-verbal IQ (ASD in 2 dimensions)
- Atypicality, Age, and IQ: ASD in 3D
- Progression of therapies tied to Natural History

Break [2:00 – 2:15]

Etiology, Epidemiology, and Quackery [2:15-3:30]
- The autism “explosion”: Where did it come from, what does it mean?
- Impact of DSM5

---

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

---

Impaired Socialization

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- “Withdrawn”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

---

Impaired Socialization

“In his own little world”

Age: 22 months. Nonverbal. CARS=44.
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

“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

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, 1938 → 1943

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

Leo Kanner, 1943

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

Kanner, 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

Natural History: “The temporal course a disease from onset to resolution”

Center for Disease Control & Prevention

ASD has a Natural History

www.drcoplan.com

www.drcoplan.com

www.drcoplan.com

info@drcoplan.com
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 reminiscence, 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.

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 dual failures. The question arises whether or to what extent this fact has contributed to the condition of the children. The children’s aloofness from the beginning of life makes it difficult to attribute the whole picture exclusively to the type of the early parental relations with our patients.

Kanner’s contributions

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

Outline

Clinical Features and Natural History of ASD [12:30 – 2:00 a.m.]
  - Leo Kanner’s lasting contributions
  - Degrees of Atypicality (ASD in one dimension)
  - Non-verbal IQ (ASD in 2 dimensions)
  - Atypicality, Age, and IQ: ASD in 3D
  - Progression of therapies tied to Natural History
Break [2:00 – 2:15]

Etiology, Epidemiology, and Quackery [2:15-3:30]
  - The autism “explosion”: Where did it come from, what does it mean?
  - Impact of DSM5

“Line up alphabetically by height”
Quantifying severity of ASD, and changes over time

Social Interaction

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

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
Theory of Mind

How does the boy feel?
Why?

www.drcoplan.com

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.”

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.

Q: How would Muff feel, if you gave her a bath?
A: Clean!

www.drcoplan.com

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?

www.drcoplan.com

www.drcoplan.com
info@drcoplan.com
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, Turn taking
- Conversational repair
- Impaired Pragmatics:
  - Echolalia, delayed echolalia (“scripting”)
  - Lack of framing
  - 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
- Difficulty “reading” prosodic cues of others
  [Difficulty with nonverbal cues (body language)]

Quantifying severity of ASD - 2

<table>
<thead>
<tr>
<th>Clinical Domain</th>
<th>Decreasing Atypicality / Increasing Age</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>2. Language</strong></td>
<td></td>
</tr>
<tr>
<td>- Pragmatics</td>
<td></td>
</tr>
<tr>
<td>- Prosody</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Decreasing Atypicality / Increasing Age</td>
</tr>
<tr>
<td></td>
<td>Severe / Youngest</td>
</tr>
<tr>
<td></td>
<td>Operate 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)</td>
</tr>
<tr>
<td></td>
<td>Echolalia, Delayed echolalia; Odd Inflection (stilted, sing-song, volume)</td>
</tr>
<tr>
<td></td>
<td>May use stock phrases in an attempt to communicate; Makes use of visual communication modalities (symbol cards; sign language)</td>
</tr>
<tr>
<td></td>
<td>May use “hand-over-hand” to guide caregiver to desired objects</td>
</tr>
</tbody>
</table>

Quantifying severity of ASD - 2

<table>
<thead>
<tr>
<th>Clinical Domain</th>
<th>Decreasing Atypicality / Increasing Age</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>2. Language</strong></td>
<td></td>
</tr>
<tr>
<td>- Pragmatics</td>
<td></td>
</tr>
<tr>
<td>- Prosody</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Decreasing Atypicality / Increasing Age</td>
</tr>
<tr>
<td></td>
<td>Severe / Youngest</td>
</tr>
<tr>
<td></td>
<td>Operate 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)</td>
</tr>
<tr>
<td></td>
<td>Echolalia, Delayed echolalia; Odd Inflection (stilted, sing-song, volume)</td>
</tr>
<tr>
<td></td>
<td>May use stock phrases in an attempt to communicate; Makes use of visual communication modalities (symbol cards; sign language)</td>
</tr>
<tr>
<td></td>
<td>May use “hand-over-hand” to guide caregiver to desired objects</td>
</tr>
</tbody>
</table>

www.drcoplan.com
Quantifying severity of ASD - 2

<table>
<thead>
<tr>
<th>Clinical Domain</th>
<th>Decreasing Atypicality / Increasing Age</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Severe / Youngest</td>
</tr>
<tr>
<td>2. Language</td>
<td></td>
</tr>
<tr>
<td>Pragmatics</td>
<td></td>
</tr>
<tr>
<td>Prosody</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Inverval or response to voice; may “act deaf”</td>
</tr>
<tr>
<td></td>
<td>Also use of gestures to compensate for absence of spoken language</td>
</tr>
<tr>
<td></td>
<td>May use “hand-over-hand” to guide caregiver to desired objects</td>
</tr>
<tr>
<td></td>
<td>Echolalia, Delayed echolalia</td>
</tr>
<tr>
<td></td>
<td>Verbal Perseveration; Odd inflection (stilted, sing-song, flat)</td>
</tr>
<tr>
<td></td>
<td>May use stock phrases in an attempt to communicate</td>
</tr>
<tr>
<td></td>
<td>Makes use of visual communication modalities (symbol cards, sign language)</td>
</tr>
<tr>
<td></td>
<td>* speaks fluently; but literal; lacks understanding of verbal nuance</td>
</tr>
<tr>
<td></td>
<td>Pragmatic (telling; formulating; topic maintenance; conversational repair; talk “at” rather than “with” others) and Theory of Mind language basis (talking; humor; verbal make-believe)</td>
</tr>
</tbody>
</table>

**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)
- It was a most unusual story, because you don’t often find cows in the woods. (Asperger Syndrome)

**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

<table>
<thead>
<tr>
<th>Clinical Domain</th>
<th>Decreasing Atypicality / Increasing Age</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Severe / Youngest</td>
</tr>
<tr>
<td>3. Repetitious Behaviors</td>
<td></td>
</tr>
<tr>
<td>Cognitive Rigidity</td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Extreme distress if routines are changed or when required to transition from one task to another</em></td>
</tr>
<tr>
<td></td>
<td><em>Preference for routines; may become obsessive</em></td>
</tr>
<tr>
<td></td>
<td><em>Same, but with diminishing level of distress; able to accept verbal preparation for change in routine</em></td>
</tr>
<tr>
<td></td>
<td><em>Complex repetitive play (lining up objects, remembering numbers, letters, etc)</em></td>
</tr>
<tr>
<td></td>
<td><em>May demonstrate conscious awareness of preference for routines; may appear more socially interactive</em></td>
</tr>
<tr>
<td></td>
<td><em>May demonstrate resistance to change, but may become less rigid</em></td>
</tr>
<tr>
<td></td>
<td><em>May demonstrate decreased stereotypic behavior</em></td>
</tr>
<tr>
<td>Motoric</td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Frequent, intense stereotypical movements (sitting, spinning, toe-walking, finger twiddling)</em></td>
</tr>
<tr>
<td></td>
<td><em>Motor stereotypes occasional; may re-emerge when excited</em></td>
</tr>
</tbody>
</table>

**Quantifying severity of ASD - 3**

<table>
<thead>
<tr>
<th>Clinical Domain</th>
<th>Decreasing Atypicality / Increasing Age</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Severe / Youngest</td>
</tr>
<tr>
<td>3. Repetitious Behaviors</td>
<td>Cognitive</td>
</tr>
<tr>
<td>Motoric</td>
<td>#frequent, intense stereotypical movements (tapping, spinning, toe-walking, finger-tiddling)</td>
</tr>
</tbody>
</table>

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

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

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

"My parents and my brother"

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

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?
“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?

What's happening in this picture?
“Two strangers got into the house and are handing out newspapers.”
What’s happening in this picture?

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

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.”
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
Repetitious behavior in ASD

- A direct expression of the underlying biology
  - Cognitive Rigidity
  - Stereotypies
- Stress relief
- A coping mechanism, to offset deficits in Theory of Mind & Central Coherence
  - “Better the devil you know…”
Sensory & Motor Processing

Quantifying severity of ASD - 4

<table>
<thead>
<tr>
<th>Clinical Domain</th>
<th>Decreasing Atypicality / Increasing Age</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Severe / Youngest</td>
</tr>
<tr>
<td>4. Sensorimotor</td>
<td></td>
</tr>
<tr>
<td>- Intense aversion or attraction to specific classes of stimuli</td>
<td>- Auditory: Hyperacusis, covers ears, acts deaf</td>
</tr>
<tr>
<td>- Clumsiness</td>
<td>- Visual: Self-stimulation (lights/patterns); looks at objects from odd angles</td>
</tr>
<tr>
<td></td>
<td>- Tactile: Rubbing, licking, sucking, deep pressures; averse to light touch</td>
</tr>
<tr>
<td></td>
<td>- Olfactory: Sniffing</td>
</tr>
<tr>
<td></td>
<td>- Extreme food selectivity</td>
</tr>
<tr>
<td></td>
<td>- Fears: Heightened / blunted</td>
</tr>
</tbody>
</table>

Same, but diminishing intensity

Auditory: Hyperacusis, covers ears, acts deaf
Visual: Self-stimulation (lights/patterns); looks at objects from odd angles
Tactile: Rubbing, licking, sucking, deep pressures; averse to light touch
Olfactory: Sniffing
Extensive food selectivity
Fears: Heightened / blunted

Abnormal responses to sensory stimuli

Mirror Neurons: The Missing Link?

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


Figure 2.8: Stimulus tools of Andrew Meltzoff and a young mimic.

ATYPICALITY

Severe Moderate Mild

"The Spectrum": ASD in One Dimension

- Atypical features can range from severe to mild

Coplan, J. Making Sense of Autistic Spectrum Disorders; Figure 5.1

“Over time, the ice melts”

- Atypical behaviors improve over time

Outline

Clinical Features and Natural History of ASD [12:30 – 2:00 a.m.]
- Leo Kanner’s lasting contributions
- Degrees of Atypicality (ASD in one dimension)
- Non-verbal IQ (ASD in 2 dimensions)
- Atypicality, Age, and IQ: ASD in 3D
- Progression of therapies tied to Natural History

Break [2:00 – 2:15]

Etiology, Epidemiology, and Quackery [2:15-3:30]
- The autism “explosion”: Where did it come from, what does it mean?
- Impact of DSM5

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
- 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
  - 14 m
  - 18 m
  - 24-27 m

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

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

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)
Cognitive Profile in ASD

**Weaker**
- Fluid Verbal Intelligence
- WISC: Comprehension
- Reading comprehension (>2G)
- Oral pragmatics
- Often
- Executive Function
  - Working Memory Index
  - Processing Speed Index
- Obsessive Mentation and/or Anxiety can mimic ADD

**Stronger**
- Crystallized Verbal Intelligence
- WISC: Information, Vocabulary
- Reading comprehension <2G
- Pseudoword decoding

**Non Verbal Intelligence**
- WISC: Block Design, Matrices

BASC: Anxiety, Attention, Atypicality, Withdrawal (look for differences between raters)

<table>
<thead>
<tr>
<th>ATYPICALITY</th>
<th>IQ</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe</td>
<td>+2 SD</td>
</tr>
<tr>
<td>Moderate</td>
<td>+1 SD</td>
</tr>
<tr>
<td>Mild</td>
<td>0 SD</td>
</tr>
<tr>
<td>Low Average</td>
<td>-1 SD</td>
</tr>
<tr>
<td>Borderline</td>
<td>-2 SD</td>
</tr>
<tr>
<td>ID - Mild</td>
<td>-3 SD</td>
</tr>
<tr>
<td>ID - Moderate</td>
<td>-4 SD</td>
</tr>
<tr>
<td>ID - Severe</td>
<td>-5 SD</td>
</tr>
</tbody>
</table>

Combine atypicality and IQ scales......

ASD & IQ: 2 Dimensions

Any degree of atypicality can co-exist with any level of IQ

Coplan, J. Making Sense of Autistic Spectrum Disorders; Figure 5.3

ASD in 2 Dimensions: Autism

Coplan, J. Making Sense of Autistic Spectrum Disorders; Figure 5.4

ASD in 2 Dimensions: Autism

Coplan, J. Making Sense of Autistic Spectrum Disorders; Figure 5.4
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. Tsai

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

At the “Borderland” of ASD

- Nonverbal Learning Disability (NLD)
  - Language pragmatics
  - Social skills
  - Disregard for personal space
  - Coordination / Sensory processing
  - Verbal IQ > Performance IQ
- Semantic-Pragmatic Language Disorder (SPLD)
  - Language pragmatics only
  - DSM5: “Social (Pragmatic) Communication D/O”
- (Broad Autistic Phenotype: Traits, not disorder)
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)

---


---

Outline

Clinical Features and Natural History of ASD [12:30 – 2:00 a.m.]
• Leo Kanner’s lasting contributions
• Degrees of Atypicality (ASD in one dimension)
• Non-verbal IQ (ASD in 2 dimensions)
• Atypicality, Age, and IQ; ASD in 3D
• Progression of therapies tied to Natural History

Break [2:00 – 2:15]

Etiology, Epidemiology, and Quackery [2:15-3:30]
• The autism “explosion”: Where did it come from, what does it mean?
• Impact of DSM5
The warmer the water, the faster the ice melts
Outline
Clinical Features and Natural History of ASD [12:30 – 2:00 a.m.]
- Leo Kanner’s lasting contributions
- Degrees of Atypicality (ASD in one dimension)
- Non-verbal IQ (ASD in 2 dimensions)
- Atypicality, Age, and IQ: ASD in 3D
- Progression of therapies tied to Natural History

Break [2:00 – 2:15]

Etiology, Epidemiology, and Quackery [2:15-3:30]
- The autism “explosion”: Where did it come from, what does it mean?
- Impact of DSM5

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

Progression of Interventions Follows the Natural History

“Bottom Up” versus “Top Down” - 1

“Bottom Up” versus “Top Down” - 2

“Bottom Up” versus “Top Down” - 3
**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**

**Bottom-up therapies**
- Shape behavior

**Top-down therapies**
- Teach concepts

**Degree of Atypicality**

<table>
<thead>
<tr>
<th>Severe</th>
<th>Moderate</th>
<th>Mild</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social</td>
<td>No or rare eye contact, No social reciprocity (imitation, initiation)</td>
<td>Occasional eye contact &amp; social reciprocity</td>
</tr>
<tr>
<td>Language</td>
<td>Nonverbal, nonfunctional (Echolalia, delayed echolalia)</td>
<td>Labeling, requesting; E-commuting, reciprocating</td>
</tr>
</tbody>
</table>

**Social / Behavioral Therapies for ASD**

**ABA-Discrete Trial Training**
- 1:1
- Physical prompts
- External rewards (praise, access)
- Prompting, Imitation

**ABA-NET; PRT, DIR**
- Play-based
- External rewards (praise, access)
- Prompting, imitation

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

**Social / Behavioral Therapies for ASD**

**Social Stories**

**Social Skills Groups**

**www.drcoplan.com**
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?
Incidence = Rate

- The number of new cases of a disorder, over a specified period of time, in a defined population
- New cases of Influenza / 100,000 persons / wk
- Incidence of ASD =
  - Birth rate of newborns who will have ASD +
  - Attack rate of autistic regression among children
- The Incidence of ASD is Unknown

Prevalence = Proportion

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

Scientific Illiteracy

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

Administrative Prevalence (“Explosion”)

Changing the Course of Autism

A Scientific Approach for Parents and Physicians

Bryan Jetson, M.D. and Jane Johnson

Evidence-based medicine shows that:
- Autism is a neurocognitive disorder
- Autism is not a medical disease, nor a psychological disorder
- Autism is the body’s response to the world
- Autism is treatable, children are improving

Scientific Illiteracy

FALSE TRUE

FALSE
What difference does it make?

- 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

**Administrative Prevalence of ASD**

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

Relationship between *diagnostic criteria* and apparent 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......

**DSM III**

<table>
<thead>
<tr>
<th>Yr</th>
<th>Event Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>6 mandatory criteria: Onset &lt; 30 mo. Pervasive lack of responsiveness to other people Gross impairment in communication skills Peculiar speech patterns if speech is present Bizarre responses to various aspects of the environment Absence of delusions</td>
</tr>
</tbody>
</table>

**DSM Criteria and the ASD Explosion**

**DSM III-R**

<table>
<thead>
<tr>
<th>Year</th>
<th>Event Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Introduces “Menu” for Dx of Autistic D/O: At least 8 of 16 items across 3 domains: Social, Verbal, and Restricted Activities &amp; Interests*</td>
</tr>
<tr>
<td></td>
<td>PDD-NOS encompasses children who never met full criteria for Autism, as well as children who once met such criteria but improved over time.</td>
</tr>
</tbody>
</table>

* “Polythetic approach”
### DSM Criteria and the ASD Explosion

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

- **1994: DSM-IV**
  - Menu Dx of Autism
  - Asperger Syndrome

### DSM IV

<table>
<thead>
<tr>
<th>Year</th>
<th>Event Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1994</td>
<td>6 of 12 milder criteria, such as:</td>
</tr>
<tr>
<td></td>
<td>- Lack of spontaneous seeking to share achievements with other people</td>
</tr>
<tr>
<td></td>
<td>- Difficulty sustaining a conversation</td>
</tr>
<tr>
<td></td>
<td>- Lack of varied social imitative play</td>
</tr>
<tr>
<td></td>
<td>- Persistent preoccupation with parts of objects</td>
</tr>
</tbody>
</table>

* "Polythetic" approach

### Shifting epidemiology of ASD

- **1950’s** 2-4/10,000
- **2000’s** 100/10,000

### Autism Spectrum Disorder

**Two Clinical Domains (vs. 3 in DSMIV, and 4 in Kanner)**

A. **Deficits in Social Communication and Interaction**
   - Combines Social & Language domains

B. **Restricted, Repetitive, Behaviors, Interests, and Activities**
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):…

* Doesn’t say “all” of the following; intent unclear

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)…

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.

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.

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

• “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”
• Implications:
  1. No such thing as “Compensated” ASD:
     • If you’re not impaired, you can’t have ASD
     • What if you were significantly impaired in the past?
  2. Excludes “Broad Autism Phenotype,” and all other forms of “sub-threshold” atypicality
### ASD vs. Social (Pragmatic) Communication D/O

<table>
<thead>
<tr>
<th>Symptom Domain</th>
<th>Autism Spectrum D/O</th>
<th>Social (Pragmatic) Communication D/O</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social and Language</td>
<td>“Deficits in social-emotional reciprocity in nonverbal communication, and maintaining understanding relationships”</td>
<td>“Deficits in social communication resulting in functional limitations in effective communication, social participation, development of social relationships, academic achievement, or occupational performance”</td>
</tr>
<tr>
<td>Restricted, repetitive patterns of behavior, interests, or activities</td>
<td>“Disinhibited or repetitive motor movements, use of objects, or speech; insistence on sameness, inflexible adherence to routines, or restricted patterns of verbal or nonverbal behavior; highly restricted, fixated interests that are abnormal in intensity or focus; hyper- or hypo-reactivity to sensory input (at least 2 out of 4)”</td>
<td>NO</td>
</tr>
</tbody>
</table>

### DSM5: ASD vs. Social 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”

Implication: Cannot use ADOS, CARS, etc. to exclude Dx of ASD. Must also elicit detailed early developmental history.

### Autism in DSM-5: progress and challenges

- DSM-IV: 3 categories (Language, Social, Repetitive Behavior) and a menu of qualifying items within each category gave >2,000 combinations of items that would yield an autism diagnosis
- Combining Social and Language into one category, and requiring 3 out of 3 criteria to be met for Repetitive Behavior results in many fewer potential combinations
- “Despite the name change to Autism Spectrum Disorder, the concept actually proposed is apparently more restricted than the DSM-IV approach”

- “The impact is probably greatest among the most cognitively able cases and those with less classic autism presentations”
- Up to 10% may lose Dx of ASD

### 2013: DSM5

- THE GOOD
- THE BAD
- THE UGLY
**The Good**
- Emphasis on early developmental history as an integral component of diagnosis

**The Bad**
- Combines Social & Language
  - Simplistic view of language
    - Pragmatics
    - Prosody
  - Eliminates Asperger Syndrome (ditto)

**The Ugly**
- Creates Social Pragmatic Language Disorder, and locates it outside of the circle of ASD
- ~10% of children with ASD will lose the diagnosis
  - Risk is greatest among highest-functioning children
  - Risk increases with age (as early developmental hx recedes into the past, and examiners place inordinate reliance on measures of current function
- Excludes adults with well-compensated ASD. (If you aren’t impaired, you can’t have ASD)

“One hundred and twenty-eight publications were identified through an extensive search of major electronic databases and journals. Based on >90 clinical variables…. 94 publications concluded that there were statistically significant or near significant level of quantitative and/or qualitative differences between Asperger’s Disorder and Autistic Disorder / High Functioning Autism. Although DSM-5 ASD will eliminate Asperger’s disorder…. 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.”

Up to 10% of children with ASD may lose their Dx: Risk is greatest for children with “High Functioning Autism”

“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 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.)

Known causes of \( \uparrow \) prevalence of children with a Dx of ASD

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

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?

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
<th>Comment</th>
</tr>
</thead>
</table>
| 1986 | PL 99-457: Early Intervention Amendments to PL 94-142 | 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

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
<th>Comment</th>
</tr>
</thead>
</table>
| 1990 | Congress Amends PL 94-142 again (PL101-476) | - Renamed *Individuals with Disabilities Education Act* (IDEA)  
- 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

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>1991</td>
<td>US Department of Education, Office of Special Education Programs (OSEP) requires reporting of autism by the States, starting in 1992.</td>
<td>- Coincides with implementation of Part B (3 to 5 yr olds) &amp; Part H (birth to 3) of PL 99-457</td>
</tr>
</tbody>
</table>

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

Known causes of ↑ prevalence of children with a Dx of ASD

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


Diagnostic Substitution

Known causes of increased prevalence of children with a Dx of ASD

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

Ascertainment Methods for ASD

- Old: Count already-identified cases
  - School data
  - Medical clinics
- New: Search for unrecognized cases
  - Population Screening (EI, ACA, etc.)
- Ascertainment Bias?

Population Screening

- Subjects
  - Missouri Twin Study
  - 788 twin pairs, age 7-15
  - No identified developmental disorder
- Methods
  - Social Responsiveness Scale (SRS); mother = informant (97%)

Prevalence of Autistic Traits in “Normal” Children

- Boys: 1.4% 1 in 71
- Girls: 0.3% 1 in 333

Differences in Prevalence, or Ascertainment Bias?

- Variations in administrative prevalence
  - By race
  - By geographic region
  - By socioeconomic status

The Affordable Care Act and Autism-Related Conditions


- New health insurance plans or insurance policies must cover preventive services without cost-sharing, including autism screening for children at 18 and 24 months
11.3 cases / 1000 children = 1 in 88

**CDC Prevalence Estimates for ASD, 2008**

- Autism and Developmental Disabilities Monitoring Network (ADDM)
  - 14 Sites (Universities, State Depts of health; not demographically representative of the US as a whole)
- Data sources:
  - Healthcare organizations (general & specialty)
  - Schools (some sites)
- N = 337,093 children, age 8
- 3,820 met surveillance case criteria for ASD
  - 79% had a pre-existing Dx of ASD in their records
  - 21% had no ASD Dx in their records

http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm?s_cid=ss6103a1_w

**Socioeconomic Inequality in the Prevalence of Autism Spectrum Disorder: Evidence from a U.S. Cross-Sectional Study**
Durkin MS, Maenner MJ, Meaney FJ, et al.

Prevalence of ASD increased with increasing SES** in a dose-response manner, with prevalence ratios relative to medium SES of 0.70 for low SES, and of 1.25 for high SES, (P<0.001).

*Based on an analysis of the same dataset as MMWR 2012
** SES = Socioeconomic Status (income, education)
“Hot Spots”
- Increased risk of having a child with Autism, compared to state-wide average

Adjusted autism risk = 4x State-wide average
1993 - 2001
- Area is within cluster for at most 2 years
- Area is within cluster for 3 to 4 years
- Area is within cluster for 5 to 7 years

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 Increase in number of children with autism diagnosis?

Where have all the adults gone?
“Since 1% of adults don’t have ASD, doesn’t that prove we’re in an epidemic?”

“Missing” adults: NHS Survey
Autism Spectrum Disorders in adults living in households throughout England
Report from the Adult Psychiatric Morbidity Survey 2007

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

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)

Prevalence x Age: Not statistically significant

Outcome for children with High Functioning Autism:
~ 15% “Lose the Dx” of ASD, but may “grow into” a Mental Health D/O

NHS Survey 2007
Prevalence of ASD (ADOS 10+), by age

<table>
<thead>
<tr>
<th>All adults</th>
<th>2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age group</td>
<td>2007</td>
</tr>
<tr>
<td>16-44</td>
<td>1.1</td>
</tr>
<tr>
<td>45-74</td>
<td>0.9</td>
</tr>
<tr>
<td>75+</td>
<td>0.8</td>
</tr>
</tbody>
</table>

Prevalence x Age: Not statistically significant

“Missing adults”

- Reality:
  - The prevalence of ASD among today’s senior citizens is as great or greater than the prevalence among today’s children
  - Must include:
    - Adults in supervised settings
    - Adults who have “outgrown ASD,” but would have met criteria as children

NHS Survey 2007

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

Outcome for children with High Functioning Autism:
~ 15% “Lose the Dx” of ASD, but may “grow into” a Mental Health D/O

Adult Outcomes
- Social Impairment
- Communication Impairment
- Restricted, repetitive behaviors & interests
- Anxiety Disorders
- Obsessive-Compulsive Disorder
- Depression, Bipolar Disorder
- Alcoholism

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

Non-ASD Psych D/O

Broad Autism Phenotype

© Coplan, 2010
Summary

- ASD has a natural history
- Any level of atypicality can coexist with any level of intelligence
- IQ is the major co-factor driving prognosis
- 3D “map” of ASD + IQ + Time:
  - Track child’s progress over time
  - Select best therapy at any given point in time
  - Anticipate future needs (prognosis)
- Therapies follow a bottom-up to top-down progression, in parallel with the natural hx of ASD itself

“Losing the diagnosis”

- Just because someone outgrows childhood criteria for ASD does not mean that they are cured
  - Persistence of cognitive deficits
  - Persistence or emergence of Mental Health disorders

Summary

- Administrative prevalence of ASD has increased, but no evidence of true increase in prevalence
- Beware of any arguments that rest on the claim that we are in an epidemic
  - Allegations as to cause
  - Promises of cure

Problems with DSM

- Non-theoretical approach (symptoms not tied to neuropsychological constructs)
- Does not recognize language or sensory processing as developmental domains
- Remains tied to the goal of clinical homogeneity within diagnostic categories (“ASD” actually more restrictive than DSM-IV)

Summary

- Impact of DSM5 on educational practices is unknown
  - “Makes no difference to us” ?
  - 10% of children may lose Dx
  - Risk is greatest among highest functioning children
Thank You!