An Introduction to Autism Spectrum Disorders (ASD)

Professor Cory Shulman
Director of the Autism Center
Hebrew University in Jerusalem
Cory.Shulman@mail.huji.ac.il

Today:
- Understanding Autism
- Diagnosis/Assessment
- Epidemiology
- Principles of Intervention
- Impact of the Family
- Directions for Future Research

This presentation may leave you with more questions than answers!
What are we talking about?

ASD

PDD

Aspergers

Autism

PDD-NOS

Autistic Disorder

ASD in 2019:
How did we get here?

Psychiatrist at Johns Hopkins

Hans Asperger, 1944

Case studies of 11 children: 8 boys and 3 girls

- Clinic/residential school
- Series of cases, all male
- Marked social difficulties
- Circumscribed interests

BUT

- Cognitive, language development intact

"a lack of empathy, little ability to form friendships, one-sided conversations, intense absorption in a special interest, and clumsy movements"
Hans Asperger
Viewed autism as a continuum:
Giftedness $\leftrightarrow$ Disability
“little professors” “awkward scientists”

Looking for answers:
Rimland (1964)
Wing & Gould (1978)

American Psychological Association 1980
- Broad definition of autism in DSM-III
- Established notion of pervasiveness
developmental not form of schizophrenia
- Broader definition of autism in DSM-IV
- Categories of autism diagnoses:
  - Autism
  - Rett Syndrome
  - Childhood Disintegrative Disorder
  - Asperger Syndrome
  - Pervasive Developmental Disorder

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**DSM 5 (May 2013)**

A. Deficits in social communication & interaction

B. Restricted, repetitive behaviors, interests, activities

C. Symptoms present in early childhood

D. Symptoms limit and impair everyday functioning

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If you know one person with autism

You know that person

- Limited capacity
- Average
- Above avg.

(Georgiades et al., 2013; Mancuso et al., 2008; Campbell et al., 2014; Sherer & Schreibman, 2005)
Diagnostic & Statistical Manual-5th Ed (DSM-5)

One diagnosis: Autism Spectrum Disorder

Two Core Domains

A. Deficits in social communication and social interaction
   1. Social-emotional reciprocity
   2. Nonverbal communication
   3. Developing, maintaining, and understanding relationships

B. Presence of restricted and repetitive patterns of behavior (RRBs)
   1. Stereotyped or repetitive motor movements
   2. Insistence on sameness, routines, and rituals
   3. Highly restricted, fixated patterns of interest
   4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment

ASD may present differently in different groups

- Age
- Developmental and Language Level
- Sex
- Ethnic Groups

ASD Specifiers and Modifiers

<table>
<thead>
<tr>
<th>Specifiers</th>
<th>Modifiers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Associated with medical/genetic diagnoses</td>
<td>With or without intellectual impairment (e.g., ASD with intellectual disabilities)</td>
</tr>
<tr>
<td>Associated with neuropsychiatric/mental bx disorder (e.g., ASD with Rett Syndrome)</td>
<td>With or without structural language impairment with level of language (e.g., ASD with loss of words)</td>
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ASD Specifiers

- Mean to indicate another important factor

ASD Modifiers

- With or without
- Intellectual level
- Communication level
- Behavioral level

Diversity in Autism Spectrum Disorders

- Intellectual level
- Communication level
- Behavioral level

- With Catatonia

Level of Severity

(i.e., level of support required)
Diagnosis and Assessment

Diagnosing ASD
- Both presence of abnormal behaviors and the absence of normal behaviors required to make a diagnosis of ASD
- Age, developmental level (e.g., IQ, mental age), expressive language level, sex, culture, and context (e.g., different settings or social circumstances) can significantly affect how behaviors manifest

Bottom line…
- Diagnostic assessment (of ASD or anything else) is not easy and should not be taken lightly
- These are real people and real families, so the stakes are high

Co-morbidities with ASD
Medical Conditions in Autism

- Higher rates of all medical conditions studied including:
  - Eczema
  - Allergies
  - Asthma
  - Ear and respiratory infections
  - Gastrointestinal problems
  - Severe headaches and Migraines
  - Seizures (Kohane et al., 2012)

- 81% of parents of youth with ASD state their health concerns for their child had not be adequately investigated by professional (Treating Autism Survey, 2018)

Psychiatric Comorbidities

- Attention Deficit Hyperactivity (Executive Dysfunction, Hyperactivity, Impulsivity, Inattention)
- Mood Disorders (Mood Dysregulation, Anxiety, Depression, Mania)
- Anxiety Disorders (Social Interactions, Empathy, Obsessive-Compulsive, Social Phobia, DisinhibitedSocial, Hostile Intent/Schizotypal)
- Obsessive Compulsive Disorder (Restricted Interests, Rigid behavior, Stereotypic behavior, Compulsions)
- Asperger's

Comorbid Psychiatric Diagnoses Given by Community Providers Per Parent Survey (Rosenberg et al., 2011)
Epidemiology

The epidemiology of ASD

- The Center for Disease Control (CDC) in the USA funds large surveys to detect prevalence of ASD in the USA across different groups.
- What is required is ascertainment of cases through effective screening and universal definitions.
- Large sample size and definition of samples.
- Danger of under-estimating prevalence of ASD.
- Strong registry allows for the possibility of detecting incidence of ASD.

Recent Trends in Epidemiology (cont.)

- Rates of comorbid disorders like ADHD, depression, and anxiety are very high.
- Longitudinal studies suggest that the majority of children with ASD continue to exhibit ASD-related difficulties into adulthood.
- Though a very small number may lose their diagnoses.

Is this an epidemic?

<table>
<thead>
<tr>
<th>Year</th>
<th>Total</th>
<th>With ASD</th>
<th>Prevalence</th>
</tr>
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<tbody>
<tr>
<td>1975</td>
<td>1/5000</td>
<td>1/5000</td>
<td>1/5000</td>
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<tr>
<td>1985</td>
<td>1/2500</td>
<td>1/2500</td>
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<td>1995</td>
<td>1/500</td>
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<td>2004</td>
<td>1/125</td>
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<td>2006</td>
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<td>2008</td>
<td>1/88</td>
<td>1/88</td>
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<tr>
<td>2010</td>
<td>1/68</td>
<td>1/68</td>
<td>1/68</td>
</tr>
</tbody>
</table>

- 1975: 1/5000
- 1985: 1/2500
- 1995: 1/500
- 2000: 1/150
- 2004: 1/125
- 2006: 1/110
- 2008: 1/88
- 2010: 1/68
Early identification and intervention not only has the potential to maximize developmental and educational gains for the child, but also improves family functioning and wellbeing → reaps long-term benefits for society.

The importance of public education about the early characteristics of autism, and the value of early identification and intervention cannot be underestimated.

NDBIs integrate principals of developmental and behavioral science.
NDBIs utilize "naturalistic" approaches delivered in everyday interactive social contexts (e.g., play and daily routines) which infants and toddlers find themselves in.
The materials used in therapy are those preferred and selected by the child rather than the adult.
Intervention methods strongly informed by developmental theory.
Teaching incorporated within affectively rich social interactions and routine based.
Follow into the child’s attentional focus.

Let's do it
Early Start Denver Model
Sally Rogers & Geraldine Dawson

Goal: to provide structured, hands-on strategies
Suitable for children aged from 12 months.
Specific curriculum and teaching practices
Equips therapists/parents with the necessary skills to engage, communicate with, and teach their very young children with or at risk for ASD

ESDM Goals

- To bring child back into the social loop by teaching the building blocks of social life
  - Imitation
  - Emotions
  - Communication
  - Sharing experiences
  - Social and Symbolic Play
  - Language

Fill in gaps and accelerate developmental rate

Treatment of Autism Spectrum Disorders

- Multi-Modal Approach
  - Behavioral
  - Educational
  - Pharmacological
- Target Appropriate Developmental Stage
  - Early Assessment and Intervention
  - Ongoing Therapy

Structured Teaching

How structure can help

- Promote independence & meaning through structure.
- Transform curriculum/learning tasks into concrete, visual sequences that compensate for poor communication skills
- Use a stronger modality
- Structure is not faded or removed but is modified and adjusted
**Structured Teaching**

How structure can help

- It is not based on punishment
- It is not based on reinforcement
- Strengthens competence
- Increases motivation

**Routines**

- Schedule
- Define Physical Space
- Demonstrate Tasks
- Modify / Build on Routines

**Choices**

- Extremes vs. Mutually Desirable
- Sabotage to Promote Interaction
- Sequences to Promote Independence
- Visual Timers
- Down Time Reinforcement Choices

**“Best” Methodology Principles**

- Establish routine or schedule
- Modify environment and accommodate special needs
- Control overwhelming stimuli
- Give individual person space and freedom
- Allow movement
- Introduce calming stimuli
Impact of Autism on Family
- Increased stress for each family member
- Primary focus becomes helping the individual with autism
- May put additional stress on:
  - Marriage
  - Other children
  - Work
  - Personal relationships
  - Finances

Autism Research and Care: Future Challenges
- Relating biology and behavior to understand underlying mechanisms in autism
- Understanding co-occurring conditions
- Identifying subgroups
- Finding underrepresented and misdiagnosed individuals
- Streamlining and personalizing intervention
- Receiving support from policy makers and service providers
“After all, the really social people did not invent the first stone spear. It was probably invented by an Aspie who chipped away at rocks while the other people socialized around the campfire. Without autism traits we might still be living in caves.”

Temple Grandin

“I have Asperger’s Syndrome, a ‘milder’ form of Autism, (yeah right!). That means that I have difficulties with social interaction, communication and imagination. Of course you could say that that is a matter of opinion because after all interaction and communication are a two way thing - maybe I have it right and others have the difficulties!!”

(Luke Jackson, aged 14)

"Autism is mainly one’s interpretation of one’s own view which can be very different from the rest of community or another autistic person so we need to have different approaches and methods based on each individual."

(Temple Grandin, 2017)
Questions and additional thoughts

Please be in touch:
Cory Shulman
The Hebrew University

cory.shulman@mail.huji.ac.il
autismcenter@mail.huji.ac.il
www.autismcenter.huji.ac.il