MORE ABOUT ADULT OUTCOMES IN AUTISM SPECTRUM DISORDER

Catherine Lord, Ph.D
In collaboration with Andrew Pickles, Ph.D. from Kings College, London and James McCauley, Ph.D. from UCLA
Conflicts of interest and funding

- I receive royalties from Western Psychological Services for the ADI-R, ADOS and SCQ. Proceeds from projects and clinics in which I am involved are donated to HAVE DREAMS in a wrap-around program in Chicago.

- I receive funding from NIMH, NICHD, DoD, HRSA, Autism Speaks and the Simons Foundation.
ASD as a Neurobiological Disorder of Learning and Processing
That changes with development and affects development in turn with opportunities to intervene and improve
Core Symptom Domains
PLUS Associated Medical Features

- Social – Communication Impairment & Restricted Interests
  - Autism Spectrum Disorders
  - ADHD
  - Social Anxiety
  - OCD
  - Aggression

- Sleep Disturbance
- Motor problems: Apraxia
- Language Disorders
- Intellectual Disabilities

- Gastrointestinal Dysfunction
- Epilepsy-EEG abnormalities
- Immune Dysfunction

- Intellectual Disabilities
- ADHD
- OCD
- Social Anxiety
- Aggression

Autism Spectrum Disorders

Language Disorders

Motor problems: Apraxia

Social – Communication Impairment

Sleep Disturbance

Gastrointestinal Dysfunction

Epilepsy-EEG abnormalities

Immune Dysfunction
Can we diagnose autism in 2 year olds?

- Multiple measures
- Two different cohorts: range of income, rural/urban, education levels; white and African American
- Parent reports and direct observations
- 192 consecutive referrals for ASD; 21 DD controls (no evid ASD); about 50 “new” recruits
Watching “separate groups” become less distinguishable

- In our longitudinal study: face to face at 2, 3, 4, 5, 9, 19, 26, 30 (long interview at 14)
- Some kids moved out of the spectrum – out of 192, one at 5, one more at 9, 8 at 19, 5 at 26
- Some moved into the spectrum, 2 at 3, 2 at 9, 2 at 19, 1 at 26
- Many of the outcomes of our “control” participants are not that different than the ASD participants with similar IQs
Age 2 by age 19 NVIQ Categories

NVIQ Category at age 19
- Severe/Profound
- Moderate
- Mild
- Borderline
- Average

NVIQ Category at Age 2
- Average (n=17)
- Borderline (n=26)
- Mild (n=20)
- Moderate (n=16)
- Severe/Profound (n=5)
Trajectories of Vineland Communication Ages

- Class1 31%
- Class2 14%
- Class3 8%
- Class4 12%
- Class5 8%
- Class6 21%
- Class7 6%

age at data-point
Quality of peer interactions during childhood (age 9) and early adolescence (age 14) predict autism outcomes

*Jones et al., 2017*
Variability in achievement levels at age 9 and 18 for low vs. high IQ groups

* Red boxes indicate the proportions of children in the grade level
Percent of Each of Four Groups, n=101

<table>
<thead>
<tr>
<th>Group</th>
<th>Percent</th>
<th>Percent of participants with IQ &gt;70, n=46</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD-LCA</td>
<td>56.8</td>
<td>56.2</td>
</tr>
<tr>
<td>ASD- MCA</td>
<td>24.3</td>
<td>16.7</td>
</tr>
<tr>
<td>ASD- VPO</td>
<td>7.2</td>
<td>16.7</td>
</tr>
<tr>
<td>No- ASD</td>
<td>11.7</td>
<td>27.1</td>
</tr>
</tbody>
</table>
Major Milestones

- Expressive Language
  Ages: 2-4
- Repetitive Behaviors
  Ages: 2-3
- Hyperactivity
  Age: 3
- Adaptive Skills
  Ages: 4-9
- Social Skills/ Peer Connectedness
  Ages: 9-14
- Academic Achievement
  Ages: 9-19
- Current Outcomes
  Ages: 19-26
Class 1: Best outcome
Class 2: High IQ Autism
Class 3: Low IQ Autism w/o behavioural prob
Class 4: Low IQ Autism with behavioural prob

CSS 25%
VIQ-rev 90%
NVIQ-rev 89%
HYP 38%
IRRIT 25%
CBCL 10%
BDI 17%
PANAS-P-rev 22%
PANAS-N 3%
WBQ-rev 23%
Meds 31%
work 62%
Living 51%
friends 66%
Daily_liv-rev 79%

Class1 22%
Class2 26%
Class3 25%
Class4 27%
Incremental Prediction of adult Outcome classes:

Class 1 Best outcome
Class 2 High IQ Autism
Class 3 Low IQ Autism w/o behavioural prob
Class 4 Low IQ Autism with behavioural prob

reference class prevalence

No Clinical Info
Age 2 CSS & IQs
Age 5 CSS & IQs
Age 2 CSS
Age 3 CSS & IQs
Age 5 CSS & IQs
reference line for class prevalence
Figure S1 4-class adult outcome latent profile omitting adult verbal and non-verbal IQ
Figure S2 Prediction of adult outcome classes for profile omitting adult verbal and non-verbal IQ.
Key messages so far

- Subjective and objective measures of adult outcome are not the same
- We struggle with how to measure subjective outcome
- ASD outcomes are not that different than those of children referred at 2 or at 10 for possible autism
- Can’t deny or underestimate the effects of intellectual disability, which are not that apparent at age 2, but become clearer by 3
- We can’t underestimate the importance of trajectories of language, adaptive and social development
- We can measure milestones such as peer connectivity, academic progress, decreases in repetitive behavior but we don’t really no directions of causality
- Remember role of parents and probably nonspecific aspects of the environment
Patterns of Development

Late Bloomers
- Minimal Language
- Fewer DLS
- Peer Connectedness

Early Language
- Overactive
- Good DLS

Language
- First words
- Late Bloomers
- Minimal Language

Activity
- Overactive
- Not Overactive

DLS
- Daily Living Skills

Peer Connectedness
- Peer Connectedness
- Less Peer Connectedness
Milestones

Under 3
- Early Strengths
  - Nonverbal IQ
  - Motor Skills
  - Joint Attention

Between 2 and 3
- Milestone
  - Acquisition of structural expressive language

Positive Predictor
- Parent involvement in treatment

Negative Predictor
- General delays
- Hyperactivity
- Sensory Needs
- Insistence on sameness

Milestone
- Increased self reliance
- Academic skills

School age to Adolescence
- Opportunities
  - Typical peers
  - Part time work

Adult Outcomes
- Dignity and Independence
- Happiness and well being
- Community participation
- Freedom from other challenges

Opportunities
- Increased self reliance
- Academic skills
- Milestone
- Acquisition of social skill
- More complex language
Thanks to you

And the families and all the people who worked on this research, Andrew and Jamie

Catherine Lord