

# Diagnosis of Autism Spectrum Disorders in Adults: Ethical Issues

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# General issues

- ▶ Shared with other developmental disabilities and psychiatric disorders
- ▶ Uniqueness
  - Tremendous heterogeneity
    - Needs, challenges and abilities
    - Trajectories
    - Family resources and involvement
  - Strengths and difficulties associated with ASD
  - Access to services as children; falling between the cracks as adults
- ▶ Absence or very limited research

# A “success” story for ASD research



To access this video, please contact Catherine Lord at [cal2028@med.cornell.edu](mailto:cal2028@med.cornell.edu)

# Being an adult participant in research as part of an ASD sample

## Informed consent

Current IRB process acts against rationality

Issues with language level,  
guardianship and amount of  
information (not specific to ASD)

Transparency of the purpose of the research  
(e.g., neuroimaging)

## Coercion vs. fair reimbursement

## Privacy

Getting a valid history and context

# Having a diagnosis or not



- ▶ For ASD
  - Autism, PDD–NOS, Asperger Syndrome
  - Various specific genetic conditions
    - (Fragile X, Rett, 16p 11.2 deletions)
  - Intellectual disability
  - Psychiatric disorder

# Appropriate behavioral measures

- ▶ Direct observation
  - Limitations of the Autism Diagnostic Observation Schedule ( ADOS: module 4)
  - Adapted ADOS (for nonverbal, minimally verbal or not quite fluent adolescents and adults)
  - TTAP (vocational measure)
- ▶ Self-report
- ▶ Caregiver reports
  - ADI-R – algorithm and current
  - Adult SRS
  - Vineland Adaptive Behavior Scales
  - Other adaptive measures and psychiatric measures

# Accuracy of diagnostic measures


- ▶ Difficulties in specificity
  - Add in ADOS data
- ▶ Difficulties in sensitivity
  - Psychiatric measures
  - ADOS

# Unique considerations with individuals seeking first ASD diagnoses as adults

- ▶ Specificity of self-referrals is very low
  - People seek diagnoses because of personal crises
    - Job related
    - Financial
    - Relationships (marriages, parents, step-parents, siblings)
    - Problems with the law
- ▶ Do we want to be very careful about not missing diagnoses



# Self-advocacy

- ▶ New directions to address ethical issues
    - Inclusion of individuals with ASD on research advisory boards
    - Representativeness of individuals and how recruit
  - ▶ Standard ways to decide consent and whether to share information and how and when to include families
  - ▶ Shared databases
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# What is Autism?

Diagnoses

Where are we now?

Where are we going? (calibration, DSM V, trajectories)



# Autism is more than the sum of its parts

- ▶ So many people are trying so hard to change trajectories
- ▶ Autism is not all that is problematic for many families and individuals (comorbidities including language delay, intellectual disabilities and other psychological disorders)
- ▶ There are many things we can do to help





Heading in the right direction and working together