

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

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