

The Developing Phenotype: Measuring ASD Features Beyond Childhood

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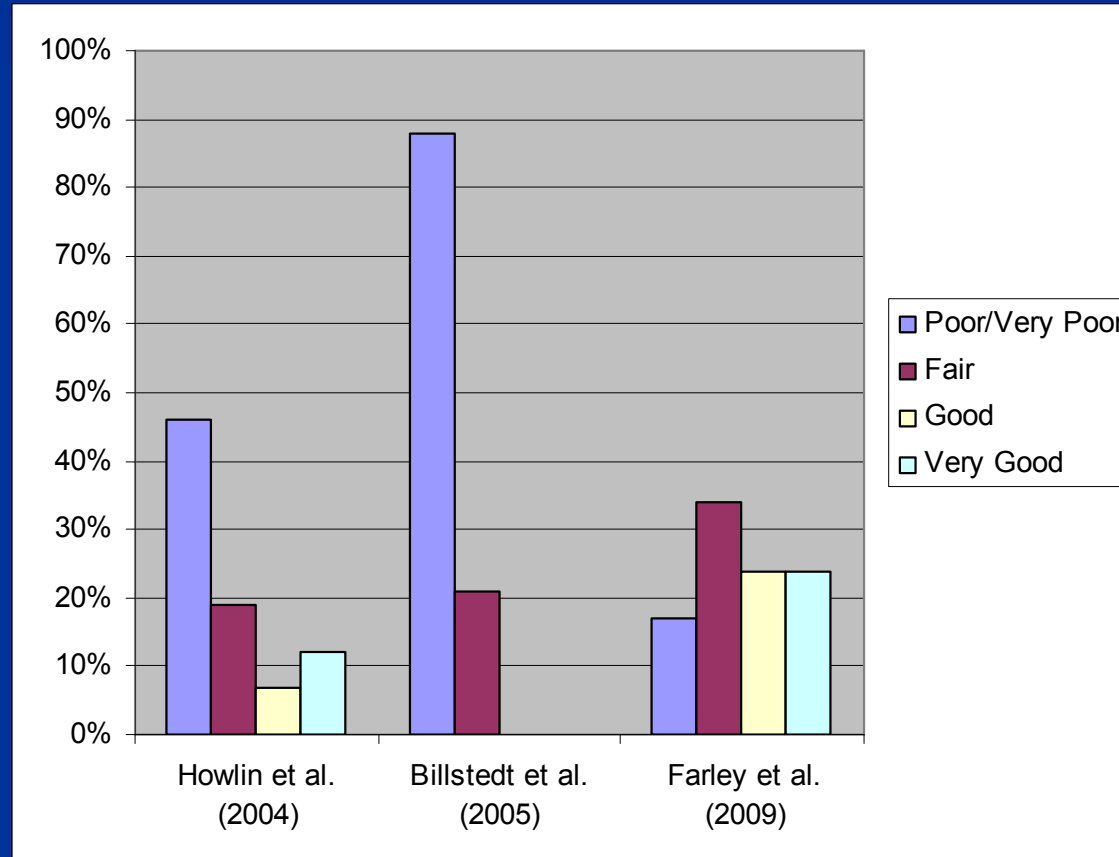
Conflict of Interest: None

Children with ASD grow up

- Need for more adult-focused research
 - What happens to adults with a history of ASD? Who will do the best? What will promote successful transitions? How can we enhance quality of life for individuals and their families?
- Answering questions about adults relies on identifying appropriate measures
 - Which outcomes are *meaningful*? How should they be measured?

Outcome in terms of adult “success”

- Composite measures of typical adult milestones (employment, residence, friendships)



Who is most successful?

- Better outcomes associated with higher IQ, better language
 - “Best” outcomes may not be attainable for everyone given cognitive limitations
 - Substantial variability even among those with higher IQ (e.g., Szatmari et al., 2003; Howlin et al., 2004)
- Role of comorbid psychiatric and medical conditions, family and contextual factors

What about ASD symptoms?

- Social-occupational vs. symptomatic outcome
(Szatmari et al., 1987)
 - Different predictors?
- How should ASD-related impairments be conceptualized in adulthood?
- What is the relationship between ASD symptoms and other measures of outcome?

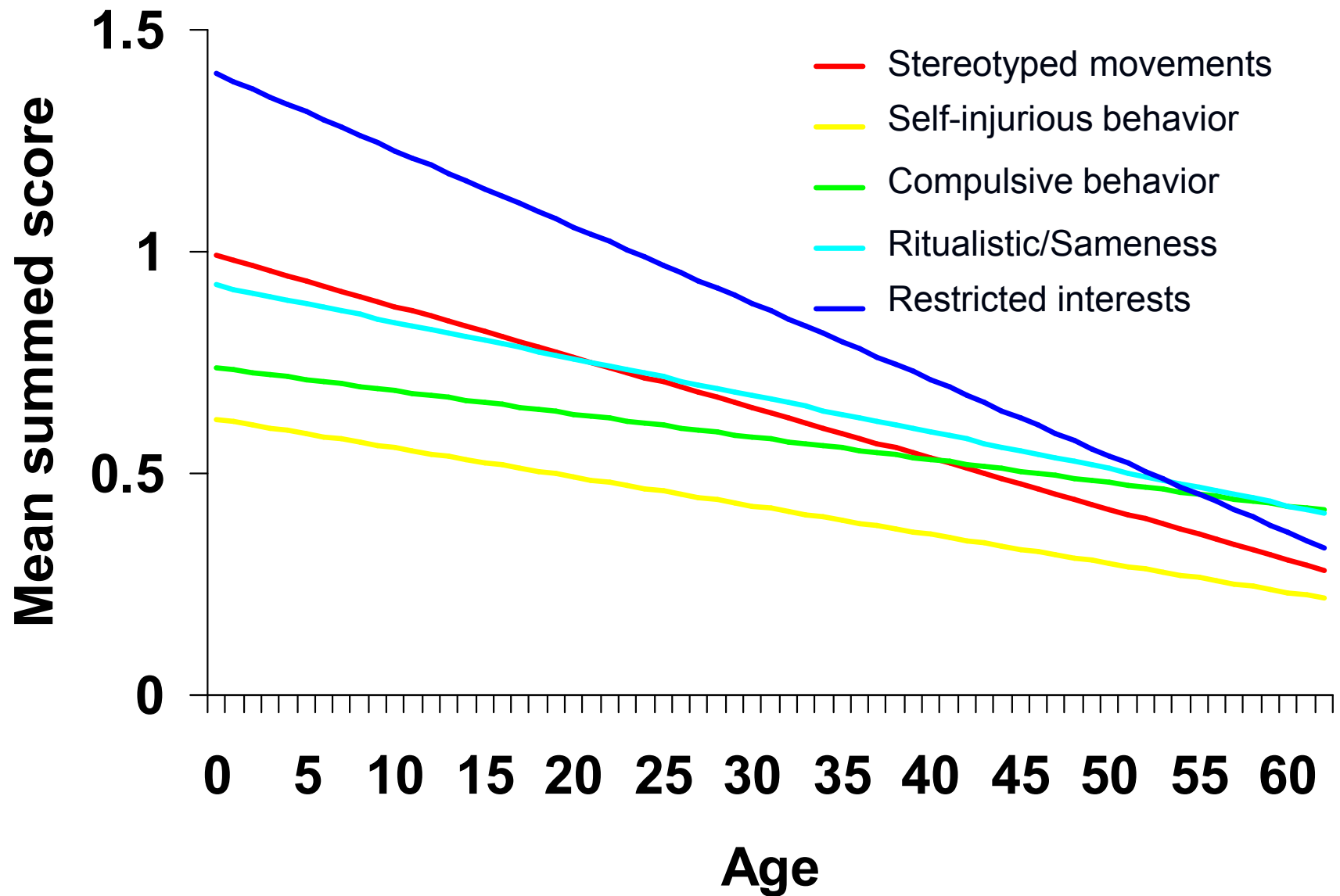
ASD and outcome

- Longitudinal investigations concerned primarily with diagnostic stability
 - Billstedt et al. (2005): 107 out of 108
 - Farley et al. (2009): 40 out of 41
- Theoretical importance
 - ASD as a life-long disorder
- Practical Implications
 - Securing adult services for the individual
 - Economic and policy planning

What do adults with *ASD* look like?

- Persistent symptoms in the context of overall improvement (e.g., Szatmari et al., 1989; Seltzer et al., 2003, Shattuck et al., 2007)
 - Variability across domains and behaviors
 - Stable impairments: nonverbal communication (e.g., facial expressions), social response, social initiations, friendships
 - Lower prevalence of restricted and repetitive behaviors

Restricted and Repetitive Behaviors



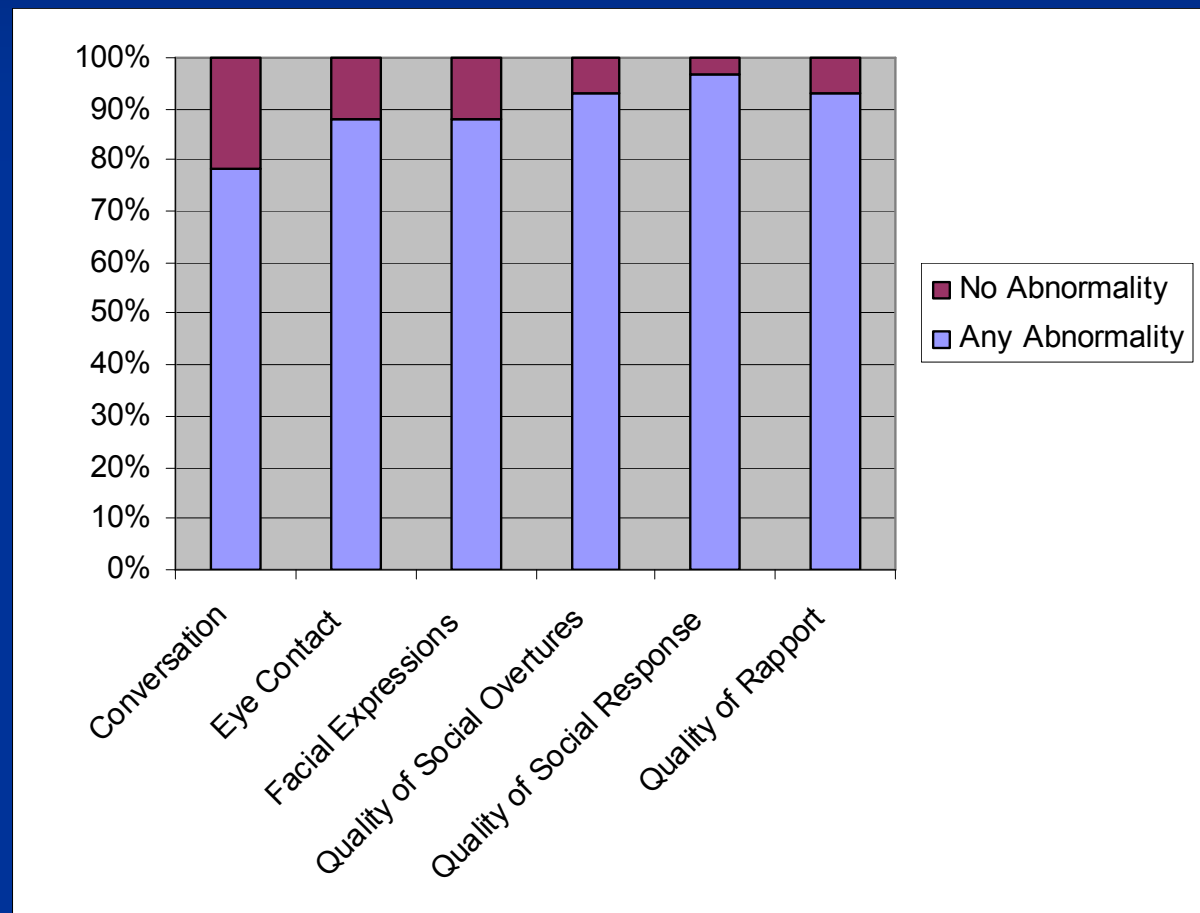
Measurement considerations

- Diagnostic instruments focused mainly on children
- Ongoing adaptation and validation of adult assessment tools to ensure diagnostic validity
 - Adapted ADOS
 - Self-report vs. parent-report
- What do diagnostic instruments tell us (or not tell us) about ASD symptom outcome?

Longitudinal Studies 2 to 22

- 59 adults with current best-estimate of ASD
 - Initially diagnosed at 2 years
- Mean age of 18.83 years
- 93% male
- 59% adapted ADOS

ADOS Item Scores



Social strengths and difficulties

- Separate from issue of diagnostic validity, do diagnostic instruments provide all of the necessary information for understanding ASD-related outcomes?
- Quinny and Steven
 - History of ASD from age 2
 - Different cognitive/language profiles
 - Different symptoms

Beyond diagnostic stability

- ASD vs. no ASD is only a first step
- Which ASD symptoms are most relevant in conceptualizing adults?
 - Different language levels
- Capturing a fuller range of adult symptom manifestations
 - Necessary to address questions of ASD outcomes

What should we be measuring?

- Need for more detailed characterizations
- Revisit important questions from the childhood literature
 - Operationalize broad diagnostic concepts
 - Adult comparison studies
 - Do the same symptoms differentiate?
- Expand on traditional child symptom concepts
 - Be open to other symptoms (as with toddlers)

Emerging opportunities

- Follow-ups of well characterized samples
 - Assessments focused on current presentation
- Different instruments for different purposes
 - Diagnosis
 - Behavioral dimensions
- Modifying assessment batteries
 - Incorporating information from outside of the clinic (community, employment settings)

Moving Forward

- Identify specific aspects of the ASD phenotype that play a critical role in adulthood
 - As longitudinal and concurrent predictors of other adult outcomes
 - Success? Depression? Well-being?
- Which features are most disruptive? Protective?
- Inform assessment and intervention services for children and adults

Questions?

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