Factors Associated with Outcomes and Quality of Life in Adults with Autism Spectrum Disorder

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Overview of Today’s Talk

- New findings on outcomes and quality of life from the Adolescents and Adults with Autism (AAA) study
Autism Spectrum Disorder

- Characterized by:
  - Difficulties with social communication
  - Difficulties with restricted interests and/or repetitive behaviors

- Important facts:
  - Affects 1 in 68 kids
  - Great heterogeneity
  - Lifelong condition
Diagnostic Boom

- 1990: beginning of the surge in diagnosis of autism
- Children diagnosed at age 4-6 in 1990 are now young adults
- The future: surge in number of adults with autism over the next 10 years


waismancenter, universityofwisconsin-madison
Research to Date:

- Focus on adult outcomes
  - Education
  - Employment
  - Independent living
- Small but emerging literature on treatment

But what about quality of life?
Fully characterizing the complex nature of adult life for all individuals, including individuals with ASD, necessarily goes beyond normative markers such as living independently and being self-supporting to include other aspects of quality of life that add more subtle gradation to one’s life experience.
Normative Outcomes and Objective Quality of Life

- Normative Outcomes
  - Social engagement
  - Competitive employment
  - Independent or semi-independent living

- Objective Quality of Life
  - Good physical health
  - Good mental health
  - Good quality of neighborhood
  - Frequent contact with siblings and extended family
Adolescents and Adults with Autism (AAA) Study

- Large sample (n=406)
- Recruited from the community (MA and WI)
- Wide age range -- 10 to 52 years of age at Time 1 (1998)
  - 62% adolescents age 10-21
  - 38% adults age 22-52
We used data from
Quality of Life Study Aims

(1) Characterize the diversity in quality of life during adulthood

(2) Obtain self-reports and parent reports of quality of life

(3) Identify factors that are associated with favorable quality of life and adult outcomes
Methods

- Data from 180 adults with autism
  - Ages 21.9 to 58.7
  - 91.7% male
  - 60.6% also had an intellectual disability
- We classified adults with ASD into groups based on normative outcomes and objective quality of life
- Looked at predictors of membership to “good” outcome groups
Findings

- Normative outcomes (2.8% achieved all three):
  - 20.0% were competitively employed
  - 21.1% lived independently or semi-independently
  - 27.8% socialized with friends of neighbors at least monthly

- Objective quality of life (13.9% achieved all four):
  - 80.0% had good or very good physical health
  - 80.0% lived in a good or very good neighborhood
  - 47.8% did not have a co-occurring mental health condition
  - 42.7% spent time with siblings or neighbors at least weekly

- Overall, two people (1.1%) met all seven markers of normative outcomes and objective quality of life

- Most people had high subjective quality of life
Findings

- Three groups:
  - Greater Dependence (44.4%)
  - Good Physical and Mental Health (37.22%)
  - Greater Independence (18.33%)
Greater Dependence Group

- Do not work in a competitive job
- Live with family or in agency settings
- Sees friends less than once a month
- Have poorer daily living skills
- Similar subjective QoL to the Greater Independence group
Case Study: Jacob

- Diagnosed with intellectual disability at age 2 and autism at age 6
- Responds to questions with one-word answers
- Very interested in watches
- Enjoys participating in church and a recreation program for adults with disabilities
- Participates in an adult day program and sheltered workshop and lives with his parents
Good Physical and Mental Health Group

- Physically healthy
- Few comorbid mental health conditions
- Live in good neighborhoods
- Greater maternal warmth
- Continued co-residence with parents
- Good subjective quality of life
Case Study: Alex

- Diagnosed with autism at age 5; has average IQ
- Parents are well-educated
- Received high-quality special education services
- Very involved in school and was the manager for the school basketball team in high school
- Studies graphic design at local community college
- Works at bead store of family friend on weekends
- Parents plan to purchase an apartment close to a four-year college when she matriculates
Greater Independence Group

- Employed in competitive jobs
- Live independently
- Similar subjective and objective quality of life to Greater Dependence group
Case Study: Rich

- Diagnosed with Asperger’s disorder at age 7
- Comorbid anxiety and depression
- IQ of 130
- Received PhD in Medieval Studies but moved back home when he could not find a job
- Now works at bank doing data entry and lives on his own in a studio apartment
- Travels to gaming conventions in his free time and is trying to find a girlfriend who shares his interest in Dungeons and Dragons
## Predictors of Group Membership

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<thead>
<tr>
<th>Variable</th>
<th>Greater Dependence vs. Good Physical &amp; Mental Health</th>
<th>Greater Dependence vs. Greater Independence</th>
<th>Good Physical &amp; Mental Health vs. Greater Independence</th>
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<tbody>
<tr>
<td>Intellectual disability</td>
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<tr>
<td>Age</td>
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<td>Daily living skills</td>
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<td>Autism symptoms (social)</td>
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<td>Autism symptoms (behaviors)</td>
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<td>Executive function</td>
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<td>Maternal criticism</td>
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<tr>
<td>Maternal warmth</td>
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**Daily living skills:**  Good Physical and Mental Health > Greater Dependence  
Greater Independence > Greater Dependence

**Maternal warmth:**  Good Physical and Mental Health > Greater Independence
Summary

- Normative outcomes and objective quality of life are relatively poor for adults with ASD, although most people have high subjective QoL.

- Having “good outcomes” does not necessarily lead to better objective quality of life.

- Better daily living skills and higher maternal warmth are strong predictors of better outcomes and quality of life.
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