Dilemmas of Omission in Services
Research about Adults with an AS

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Ethical and Social Implications of...

• Understudied stage of life

• Understudied populations

• Underreporting of study details

• Under-explored questions
Understudied stage of life

Majority of lifespan

Years
Post-High School “Services Cliff”
In- vs. Post-HS Service Receipt

- **Case Manager**: 64%
- **Mental Health**: 35%
- **Medical**: 24%
- **Speech**: 9%
- **None**: 39%
No Engagement Post-HS, ASD

Preliminary Estimates

<table>
<thead>
<tr>
<th>Verbal Ability</th>
<th>Income &lt; $25K</th>
<th>Income &gt; $75K</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nonverbal</td>
<td>76%</td>
<td>43%</td>
</tr>
<tr>
<td>Verbal</td>
<td>36%</td>
<td>12%</td>
</tr>
</tbody>
</table>
Understudied Populations

• 2-way link between poverty and intellectual disability (ID)
  – Contributes to ID risk
  – ID as risk factor for poverty

• Race emerging as correlate of reduced service access in our research with national data
Underreporting of Study Details

• Forthcoming lit. review
  – 23 studies from 2000-2010
  – Mean N: 14
  – Mostly convenience samples
  – Inconsistent reporting of
    • Sampling, recruitment, criteria
    • ASD heterogeneity
    • Income, race, ethnicity
Under-explored Questions

• Efficiency
  – Global economic recession and declining resources VS.
  – Growing population in need of help

• Community and Social Context
  – WHO ICF & developmental models emphasize person X environment
  – Not purely an individual level problem to fix
Research Opportunities

- Reframe adulthood as intrinsically worth studying
- Raise the bar re. external validity
- Adhere to editorial standards
- Study:
  - Efficiency
  - Community factors
  - Measurement based care