Living Life: Health, School, Workforce, and Independent Living

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World Autism Awareness Day Interagency Roundtable
5600 Fishers Lane, Rockville, MD 20857
Background

• One in 59 children has ASD diagnosis in U.S.
• ASD is under-identified or identified late in low-income and minority population.
• Access to early intervention services, appropriate psychoeducational or Applied Behavior Analysis (ABA) services continue to be difficult for children with ASD.
• Transition-age youth with ASD continue to experience poorer outcomes in health, employment, education, and overall well-being.
Individual Characteristics

• Children with ASD are:
  • 4 times more likely to be males;
  • 1.2 times more likely to be Non-Hispanic Whites;
  • 1.5 times more likely to be poor (i.e., < 100% FPL); and
  • 2 times more likely to be obese, compared to children without disabilities.

• 72% of children with ASD had four or more co-occurring medical conditions; compared to 30% children with other disabilities.
Family Characteristics

• One quarter of children with ASD belong to single-parent families compared to only 16% of children without disabilities.

• 35% of parents of children with ASD received welfare benefits compared to 19% of parents of children without disabilities.

• Parents/caregivers are 3 times more likely to experience hardships, 2.5 times more likely to have poor health, and 15 times more likely to be unemployed/stopped working compared to parents/caregivers of children without disabilities.

• 15% of children with ASD experience three or more adverse family events compared to 5% of children without disabilities.
Percentage Distribution of Challenges in Managing Child's Healthcare Needs

- **ASD**
  - Problems Paying Medical Bills: 33.8%
  - Stopped Working: 18.7%
  - Cut Down Hours: 18.5%
  - Avoided Job Change: 16%

- **Other Disabilities**
  - Problems Paying Medical Bills: 22.4%
  - Stopped Working: 3.1%
  - Cut Down Hours: 8.7%
  - Avoided Job Change: 10.5%

- **No Disabilities**
  - Problems Paying Medical Bills: 14.9%
  - Stopped Working: 0.9%
  - Cut Down Hours: 0.2%
  - Avoided Job Change: 3.8%
Percentage Distribution of School Engagement

<table>
<thead>
<tr>
<th></th>
<th>Sports</th>
<th>After School</th>
<th>Lessons</th>
<th>Service/Volunteer</th>
<th>Work</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASD</td>
<td>26</td>
<td>38</td>
<td>36</td>
<td>37</td>
<td>17</td>
</tr>
<tr>
<td>Other Disabilities</td>
<td>51</td>
<td>48</td>
<td>45</td>
<td>50</td>
<td>35</td>
</tr>
<tr>
<td>No Disabilities</td>
<td>63</td>
<td>41</td>
<td>50</td>
<td>56</td>
<td>38</td>
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</tbody>
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Access to Healthcare

• Though children with ASD are 3 times more likely to have health insurance, they are 2 times as likely to indicate poorer quality of coverage.

• About half of children with ASD indicated lack of availability of suitable services nearby their home, nearly 70% indicated problem with getting appointment to seek clinical services, and 34% indicated problems with transportation.

• Children with ASD are 4 times more likely to report unmet healthcare needs compared to their peers without disabilities.*

• Social determinants predict unmet healthcare needs more than functional limitations or the co-occurring conditions. (Karpur, Lello, Frazier, Dixon, & Shih, 2018).
Access to Healthcare (continued)

• Children with ASD continue to have lower quality of life – more often predicted by support needs and cooccurring conditions (Arias et al., 2018).

• Children with ASD, especially from Black and Hispanic families, continue to experience persistent lower quality of services.

• Transition to adulthood continues to pose challenges – where many lose access to public health insurance (Shea et al., 2019).

• As Individuals with ASD grow older, they loose access to needed services that address core functional limitations – a “service cliff” (Turcotte, Mathew, Shea, Brusilovskiy, & Nonnemacher, 2016; Shattuck et al., 2012).
Life-long Learning and Work

• Among individuals with disabilities, young people with ASD are least likely to be engaged in work or community-based opportunities to learn and/or attend post-secondary education (Chen, Sung, & Pi, 2015).

• Individuals belonging to lower socio-economic status and minorities were least like to be engaged in work and community-based activities.

• Less than one in five youth with ASD receive services from Vocational Rehabilitation to support their life-long learning needs (Rast, Roux, & Shattuck, 2019).
Framework for Response
Opportunities

• Strengthening access to healthcare through reforms, expanding Medicaid, and access to private insurance.

• Strengthening independent living center programs.

• WIOA provides an unparallel opportunity to improve access to services to prepare young adults with ASD for careers after high-school.

• HCBS Waiver programs offer opportunities for states to structure services for individuals with ASD to improve access to transportation, housing, and other community-based services to address the “service cliff.”

• Financial and benefits management programs have ability to support families as they support their child with ASD.
Reference


Thank You

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