National-level outcomes of transition-age youth on the autism spectrum

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A public health approach to autism

**Primary**
Reduce/eliminate avoidable causes

**Modifiable Risk Factors**
Craig Newschaffer, Ph.D.

**Secondary**
Identify symptoms early and intervene

**Early Detection & Intervention**
Diana Robins, Ph.D.

**Tertiary**
Minimize disability and promote quality of life

**Life Course Outcomes**
Paul Shattuck, Ph.D.
50-70,000 children with autism turn 18 and enter the adult service system every year.

What is a life course perspective?
Data Sources

• National Longitudinal Transition Survey 2 (NLTS-2)

• Survey of Pathways to Diagnosis and Services
Outcome domains
What were the characteristics of youth at the time of transition?
Autism Demographics

**Male** - 85%

**White** - 65%

**Black** - 23%

**Other race(s)** - 12%

**Hispanic** - 11%

**Race/ethnicity**

**Household income**

- Up to $25K - 23%
- $25K to $50K - 30%
- $50K to $75K - 21%
- More than $75K - 26%

Percent of youth with autism

Source: NLTS2
Ability to perform activities of daily living varied.

<table>
<thead>
<tr>
<th>Activity</th>
<th>Not able to</th>
<th>A lot of trouble</th>
<th>A little trouble</th>
<th>No trouble</th>
</tr>
</thead>
<tbody>
<tr>
<td>Read and understand common signs</td>
<td>11%</td>
<td>10%</td>
<td>19%</td>
<td>60%</td>
</tr>
<tr>
<td>Tell time on a clock with hands</td>
<td>26%</td>
<td>15%</td>
<td>14%</td>
<td>45%</td>
</tr>
<tr>
<td>Count change</td>
<td>20%</td>
<td>26%</td>
<td>21%</td>
<td>33%</td>
</tr>
<tr>
<td>Look up a number in a phonebook and use the phone</td>
<td>36%</td>
<td>19%</td>
<td>18%</td>
<td>28%</td>
</tr>
</tbody>
</table>

Source: NLTS2
Over half had great difficulty conversing.

<table>
<thead>
<tr>
<th>Ability</th>
<th>Not able to</th>
<th>A lot of trouble</th>
<th>A little trouble</th>
<th>No trouble</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ability to understand</td>
<td>20%</td>
<td>60%</td>
<td>20%</td>
<td></td>
</tr>
<tr>
<td>Ability to communicate</td>
<td>22%</td>
<td>43%</td>
<td>35%</td>
<td></td>
</tr>
<tr>
<td>Ability to converse</td>
<td>16%</td>
<td>35%</td>
<td>36%</td>
<td>13%</td>
</tr>
</tbody>
</table>

Source: NLTS2
What supports did youth with autism receive as they entered adulthood?
Inconsistent receipt of transition planning

58% of youth with autism had a transition plan by the required age according to their teachers.
The services cliff

Source: NLTS2
What happened to transition-age youth with autism between high school and their early 20s?
One-third ever attended post-secondary education.
Half ever held a job.

- Employment
  - Had a job for pay
    - 58%
  - Did not work during high school
    - 40%
  - Worked during high school
    - 90%
One-quarter were socially isolated.

- Not invited to social activities with friends: 48%
- Never saw friends: 39%
- Never talked with friends on phone: 48%

Percent with no participation in past year
One-third had no community participation.

- No volunteer or community service: 65%
- Never took lessons or classes outside of school: 69%
- No participation in community activities outside of school: 54%

Percent with no participation in past year
Postsecondary Connection

Employment
College
Voc/tech school
Four in 10 were completely disconnected from both work and continued education opportunities.
One in four disconnected young adults had **no access to services** since high school.
Disconnection levels are high in those with lower level skills and lower income.

Source: NLTS2

Insights from the NLTS2

Young adults with autism fared worse relative to those with other disabilities.
Rates of employment

- Learning disability: 95%
- Speech/language impairment: 91%
- Emotional disturbance: 91%
- Intellectual disability: 74%
- Autism: 58%

Percent ever worked after high school

Source: NLTS2
Rates of independent living

- Learning disability: 77%
- Emotional disturbance: 66%
- Speech/Language impairment: 62%
- Intellectual disability: 34%
- Autism: 19%

Percent ever lived independently
Rates of social isolation

- Autism: 24%
- Intellectual disability: 8%
- Speech/Language impairment: 3%
- Emotional disturbance: 2%
- Learning disability: 2%

Percent socially isolated in past year

Source: NLTS2
Rates of disconnection

- Autism: 37%
- Intellectual disability: 34%
- Speech/Language impairment: 8%
- Emotional disturbance: 7%
- Learning disability: 7%

Percent never worked or went to school
Results

- Congressional autism caucus briefing
- Consultation with the U.S. Government Accountability Office
- NPR On Point interview
- NPR Diane Rheme show
- 7 additional media interviews
- 4 invitations for national conference presentations
- Drexel top news events of 2015
BETTER RESEARCH MEANS BETTER OUTCOMES

How can we improve the lives of people on the autism spectrum? This is the big question we at the Life Course Outcomes team are working to answer. Our award winning research informs policy and services at the community and national levels in ways to improve quality of life.

We cover a wide range of topics, all related to producing better life outcomes for people on the autism spectrum.

- TRANSITION TO ADULTHOOD
- ACCESS TO SERVICES
- EDUCATION
- EMPLOYMENT

Life Course Outcomes
Research Program
Looking ahead

Paramount needs:

- Population health research
- Funding for secondary data analysis
- Purposeful planning of data collection
- Longitudinal study
National Autism Indicators Report:
Vocational Rehabilitation
2016
VR and Autism
Preliminary numbers

• Nearly 18,000 applicants with autism exited vocational rehabilitation in 2014.

\[
\begin{align*}
\text{2009} & : 7,428 \\
\text{2010} & : 9,020 \\
\text{2011} & : 10,664 \\
\text{2012} & : 12,900 \\
\text{2013} & : 15,567 \\
\text{2014} & : 17,753
\end{align*}
\]
VR and Autism
Preliminary numbers

• Approximately 1/3 of those who applied did not receive services.
• 60% of VR participants with autism exited with employment
• Age is an important factor in employment outcomes for this group.
What we would like to know

- Size of the population who needs VR help
- Reasons families do not apply for VR help
- Reasons for not receiving services
- Why some states have better outcomes
- What works or does not works about VR
- Job placement satisfaction and match
- Movement in/out of VR over time
- Changes in need for public benefits
Information & Acknowledgments

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Life Course Outcomes Research Program
www.drexel.edu/AutismOutcomes

National Autism Indicators Report
drexe.lu/autismindicators

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