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

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A.J. Drexel Autism Institute

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 every year.

(Shattuck, Roux, et al 2012)
What is a life course perspective?
Building gauges

• Using existing indicators data, capitalizing on money already spent

• Creating information products that are accessible, understandable and impactful

• Identifying gaps between available vs. needed data
Autism CARES and Transition

“...a report concerning young adults with autism spectrum disorder and the challenges related to the transition from existing school-based services to those services available during adulthood.”
National Autism Indicators Report series:

Anne M. Roux, MPH, MA
Jessica E. Rast, MPH
Paul T. Shattuck, PhD
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%
- **Up to $25K**: 23%
- **$25K to $50K**: 30%
- **$50K to $75K**: 21%
- **More than $75K**: 26%

**Race/ethnicity**

**Household income**

Percent of youth with autism

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

- **Read and understand common signs**
  - Not able to: 11%
  - A lot of trouble: 10%
  - A little trouble: 19%
  - No trouble: 60%

- **Tell time on a clock with hands**
  - Not able to: 26%
  - A lot of trouble: 15%
  - A little trouble: 14%
  - No trouble: 45%

- **Count change**
  - Not able to: 20%
  - A lot of trouble: 26%
  - A little trouble: 21%
  - No trouble: 33%

- **Look up a number in a phonebook and use the phone**
  - Not able to: 36%
  - A lot of trouble: 19%
  - A little trouble: 18%
  - No trouble: 28%
What happened to transition-age youth with autism between high school and their early 20s?
The services cliff

Source: NLTS2
One-third ever attended post-secondary education.

- Ever attended 2-year college: 70%
- Vocational, business, or technical school: 33%
- Ever attended 4-year college: 32%
- Attended 2-year and 4-year college: 16%
Half ever held a job.

Employment
Had a job for pay
58%

40%
Did not work during high school

90%
Worked during high school
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.

Source: NLTS2
Young adults with autism fared worse relative to those with other disabilities.
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
Rates of independent living

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

Percent ever lived independently

Source: NLTS2
Rates of employment

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

Percent ever worked after high school
National Autism Indicators Report:
Vocational Rehabilitation
2016

A comprehensive report from A.J. Drexel Autism Institute’s Life Course Outcomes Research Program describing how people with autism use Vocational Rehabilitation services and their outcomes. Freely available for download.

drexel.lu/autismindicators16
Annual case closures for individuals with autism have increased steadily.

- 2009: 7,428
- 2010: 9,020
- 2011: 10,664
- 2012: 12,900
- 2013: 15,567
- 2014: 17,753

Source: Rehabilitation Services Administration (RSA-911), FFY 2009-2014
**Characteristics**

Most were unemployed, living at home, with financial support from family and friends.

<table>
<thead>
<tr>
<th>Employment</th>
<th>Currently employed (11%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Where they lived</td>
<td>Private residence (96%), Community homes (3%), Other settings (1%)</td>
</tr>
<tr>
<td>Insurance</td>
<td>Private (38%), Public (33%), Uninsured (25%), Both (5%)</td>
</tr>
<tr>
<td>Benefits</td>
<td>SSI (29%), SSDI (9%), Other public support (5%)</td>
</tr>
</tbody>
</table>
Two-thirds of eligible VR applicants with autism received services through VR.

Source: Rehabilitation Services Administration (RSA-911), FFY 2014
Exiting VR with employment

Over half of VR service users with autism exited VR with a job.

Source: Rehabilitation Services Administration (RSA-911), FFY 2014
Of those with autism who left VR with a job:

80% worked part-time.

$160 was the median weekly income for part-time workers.

$380 was the median weekly income for full-time workers.

69% were employed without supports.

31% were employed with supports.
VR service users with autism worked in supported employment less often than those with ID but more often than those with other disabilities. *

- Autism: 29%
- Intellectual disability: 38%
- All other disabilities: 7%
Where you live matters.
State comparisons

How many eligible applicants with autism received VR services?

North Dakota: 39%
Pennsylvania: 88%
Average: 68%
State comparisons

How many with autism exited VR with employment?

New Mexico: 29%
Alabama: 79%
Average: 60%
Outputs/Costs

• ~ $12B/yr on special education
• ~ $1.5B on research 2008-2012
• ~ 4,000 publications in 2015

• ~ $110B/yr aggregated national “costs”
Outputs/Costs

A cost can only become an investment if outcomes are measured.
If we want to “move the needle” then we must build gauges and continuously measure indicators.

Will we spend? Or invest in people?
Ecological, Systems Perspectives

Where is most of our thinking focused?
Measuring the Social Dynamics of Autism Intervention (SoDI)

CONNECT PEOPLE:
Parents, Caregivers, School Staff, Community Providers, Neighbors, Family

COORDINATE CONTEXTS:
Schools, community organizations and homes and how these contexts shape interventions

SHARE KNOWLEDGE:
Goals, Interventions, Resources and Training networks

Life Course Outcomes Research Program
We won’t move the needle on adult outcomes unless we use systems and population data.

*How can we study social systems and develop organization- and community-level interventions that influence individual outcomes?*
2012
ASD Research Funding by IACC Strategic Plan Question – All Funders
Total Funding: $331,949,933
Number of Projects: 1,312

Q2. Biology 30% ($100,254,414)
Q3. Risk Factors 17% ($56,487,025)
Q4. Treatments and Interventions 19% ($64,149,900)
Q5. Services 7% ($22,827,101)
Q6. Lifespan Issues 1% ($3,859,177)
Q7. Infrastructure and Surveillance 14% ($47,516,197)
Q1. Screening and Diagnosis 11% ($36,856,119)
If we want to build gauges to see if we’re moving the needle on outcomes, we have to move the needle on funding priorities.

“If you always do what you’ve always done, you will always get what you’ve always got.”
Information & Acknowledgments

A.J. Drexel Autism Institute’s Life Course Outcomes Research Program
www.drexel.edu/AutismOutcomes

National Autism Indicators Report 2015
drexel.edu/autismindicators

National Autism Indicators Report: Vocational Rehabilitation
drexel.edu/autismindicators16