Key Findings from the National Autism Indicators Report: Transition into Young Adulthood

This fact sheet summarizes key findings from the National Autism Indicators Report which can be found here: drex.lu/autismindicators. The Autism Indicators report tracks statistics about issues facing individuals on the autism spectrum. These statistics set the stage to discover whether quality of life for those with autism and their families is improving over time.

The Life Course Outcomes Research Program is building a base of knowledge about the things other than clinical interventions that promote positive outcomes for people on the autism spectrum and their families and communities.

The Services Cliff Among Young Adults on the Autism Spectrum

Not receiving services in adulthood is not necessarily a bad thing. Some people may no longer need help. But because autism is a lifelong disorder, it is reasonable to expect that many youth still need some or many services during adulthood. In particular, those who do not transition into either work or postsecondary education in the years after high school likely have a strong need for services.

Increasing continuity in service delivery from high school into young adulthood may improve adult outcomes for some. Still, we can’t precisely say what percentage of youth will need intensive levels of daily support versus relatively light amounts of support. Inability to clearly describe how many youth will need which types and amounts of support makes it difficult to plan ahead.

In this report, we examine services and supports – meaning special education services, therapeutic services, health-related services, personal counseling, access/mobility services, personal assistance and case management. We used data from the National Longitudinal Transition Study-2 (NLTS2) collected in 2009 when young adults were 21 to 25 years old.

Services consistently decreased following high school.

Over half of youth received these services during high school: speech-language therapy, personal assistant services, social work, case management, transportation and occupational therapy. Less than one-third received these same services during their early 20s—with the exception of case management which was more frequent. In fact, every type of service decreased in frequency between adolescence and adulthood.

Autism does not end when children reach adulthood. Most will need some type of services or supports.

- 26% of young adults received no services during their early 20s.
Accessing adult services may require great effort.
The amount of effort needed to access services also changed as youth entered adulthood. While half of families reported needing some or a great deal of effort to find and access services when the youth was 17 years old, after high school this number jumped to more than 70%.

Nearly 28% of young adult who were disconnected (never had a job or continued school) received no services during their early 20s.

Some never received services to support employment.
The amounts and types of services people need may change as they age. They also change with life circumstances and according to youths’ goals. Vocational and life skills services are particularly important for people who need help to become employed, continue their education, or live more independently. Despite low rates of employment, postsecondary education and independent living, few young adults with autism received the vocational or life skills services that might have improved these outcomes. Over half of young adults never received these services during their early 20s.

Over half of young adults with autism received no vocational or life skills services during their early 20s.

% received service after high school

<table>
<thead>
<tr>
<th>Service Type</th>
<th>Percent Received</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vocational services or job training</td>
<td>37%</td>
</tr>
<tr>
<td>Life skills or occupational therapy</td>
<td>32%</td>
</tr>
<tr>
<td>No vocational or life skills services</td>
<td>53%</td>
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</tbody>
</table>

Source: National Longitudinal Transition Study-2

Services Factors
We explored factors that may be related to the receipt of services:

Service Needs
Approximately 58% of young adults and their parents said they needed services other than what they were receiving. The most common service needs were vocational or job training (37%) and life skills services (32%).

Case Management
Two thirds (67%) of youth received case management services during high school. Less than half (42%) received case management during their early 20s - even though case management was the most frequent service received during adulthood.

Life Skills Training
In the first several years after leaving high school, one-third (33%) of young adults with autism ever received occupational or life skills therapy, which is helpful for building skills to increase independent living.

Decrease in Services
As youth entered adulthood, dramatic increases occurred in the number of people who received no services at all. We don’t know why services tend to decrease in frequency. Maybe fewer people need them, or maybe fewer people are able to access them.

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