Introduction

Public policy increasingly acknowledges the importance of addressing the employment-related challenges facing young adults on the autism spectrum (for example, CARES Act [2020]). However, there has been limited rigorous research on interventions that can improve employment outcomes for young adults on the autism spectrum (Shenk et al. 2022) and, more broadly, on barriers to and catalysts for improving work outcomes and career development for this population. Several existing data sets include employment-related information for young adults on the autism spectrum that researchers can use to shed light on the topic, although these data sets are limited in their ability to provide a detailed, longitudinal assessment of this population and employment outcomes.

This issue brief presents an inventory of 11 such data sets, including both administrative and survey data sources (Table 1). We considered data sources that included (1) young adults ages 16 to 28, (2) information to identify individuals on the autism spectrum, and (3) employment-related measures (either employment outcomes or services related to employment).

Key conclusions of the data inventory

- Identification of autism varies across data sources. Although most survey data include self- or proxy-reports of autism, several data sources use some form of medical identification in administrative records to identify autism.
- Surveys focused on specific populations may not accurately represent the larger group of young adults on the autism spectrum. For example, youth receiving special education or disability benefits from the Social Security Administration are unlikely to accurately represent the larger group of youth on the autism spectrum.
- Small sample sizes of individuals on the autism spectrum limit analysis options. For example, youth receiving special education or disability benefits from the Social Security Administration are unlikely to accurately represent the larger group of youth on the autism spectrum.
- Employment information is often limited. Most data sources contain limited employment information, focusing, for example, on employment status, earnings, and hours worked.
- Data sets often include other information relevant to employment. Data on health, residential status, and demographics might be relevant to describe and account for characteristics that can influence the labor market experiences of young adults on the autism spectrum.
- Most data sets are not readily available. A few data sources have a public-use version that is readily available for analysis but with data limitations (for example, autism may be grouped with other types of disability). All data sets identified have a restricted-use version typically available at no cost.

Glossary for acronyms

DAF = Disability Analysis File
PROMISE = Promoting Readiness of Minors in Supplemental Security Income
PRS = polygenic risk scores
PUF = public-use file
RUF = restricted-use file

This brief was prepared for the U.S. Department of Labor (DOL), Office of Disability Employment Policy (ODEP) by Mathematica, under contract number 1605DC-18-A-0020. The views expressed are those of the authors and should not be attributed to DOL, nor does mention of trade names, commercial products, or organizations imply endorsement of the same by the U.S. Government.
Table 1. Key features of data sets with autism and employment information for youth ages 16 to 28

<table>
<thead>
<tr>
<th>Name and source</th>
<th>Type and access options</th>
<th>Sample period, unit, and population</th>
<th>Estimated number of observations</th>
<th>Autism identification</th>
<th>Employment-related measures</th>
<th>Additional content</th>
<th>Data considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case Service Report—Rehabilitation Services Administration (RSA-911)</td>
<td>Type: Administrative data</td>
<td>Period: 1978–2021; Unit: Individual</td>
<td>Data source: About 362,000 individuals in 2019 (who applied to the VR program)</td>
<td>Self-report and medical evidence in support of the disability (the assessment process and types of evidence used could vary across state agencies)</td>
<td>Earnings, hours worked, type of job, employment-related services, training and supports</td>
<td>Medical conditions, VR service use; types of VR case closure, public supports, health insurance, some demographic and socioeconomic characteristics</td>
<td>• Large sample size of youth with autism • Recent data (2020) and annual files available • Restricted data contain individual identifier (such as SSN) that can potentially be used to link to other data sets • The classification of individuals on the autism spectrum is entered by an agency staff member based on self-report and some medical evidence. Although the classification is likely accurate, it is possible that people with autism and another disabling condition are classified under their other condition. (Roux et al. 2016) • Annual files for program years before 2017 only contained closed cases; files from program year 2017 and later include all active cases</td>
</tr>
<tr>
<td>Source of Data on Employment Outcomes for Young Adults on the Autism Spectrum 2</td>
<td>Access: RUFs</td>
<td>Population: All individuals who received pre-employment transition services, applied for VR services, received VR services, or recently had their VR cases closed</td>
<td>Period: 1996–2019; Unit: Individual</td>
<td>Intended population: Among applicants eligible to receive VR services, 3.2% were on the autism spectrum in 2019 (Roux et al. 2016). About 85% of these are 16 to 26 years old (Migliore et al. 2014). This percentage suggests a sample of about 11,000 young adults on the autism spectrum in 2019</td>
<td>Medical documentation</td>
<td>DAF: Ticket-to-Work information DAF-PUF: suspension or termination of benefits for work, value of benefits forgone for work</td>
<td>Non-earned income, program participation and benefits, Medicare and Medicaid eligibility</td>
</tr>
<tr>
<td>Disability Analysis File (DAF)</td>
<td>Type: Administrative data</td>
<td>Period: 1996–2019; Unit: Individual</td>
<td>Data source: Approximately 30 million individuals in the 2019 DAF and 2 million in the 2019 DAF-PUF</td>
<td>Medical documentation</td>
<td>DAF: Ticket-to-Work information DAF-PUF: suspension or termination of benefits for work, value of benefits forgone for work</td>
<td>Non-earned income, program participation and benefits, Medicare and Medicaid eligibility</td>
<td>Non-earned income, program participation and benefits, Medicare and Medicaid eligibility</td>
</tr>
<tr>
<td>Disability Analysis File (DAF)</td>
<td>Access: PUFs and RUFs</td>
<td>Intended population: Approximately 184,000 individuals in the 2019 DAF-PUF have a primary diagnosis of autistic disorders, developmental disorders, or childhood and adolescent disorders not elsewhere classified</td>
<td>Medical documentation</td>
<td>DAF: Ticket-to-Work information DAF-PUF: suspension or termination of benefits for work, value of benefits forgone for work</td>
<td>Non-earned income, program participation and benefits, Medicare and Medicaid eligibility</td>
<td>Non-earned income, program participation and benefits, Medicare and Medicaid eligibility</td>
<td>Non-earned income, program participation and benefits, Medicare and Medicaid eligibility</td>
</tr>
<tr>
<td>Disability Analysis File (DAF)</td>
<td>Period: 1996–2019; Unit: Individual</td>
<td>Intended population: Approximately 184,000 individuals in the 2019 DAF-PUF have a primary diagnosis of autistic disorders, developmental disorders, or childhood and adolescent disorders not elsewhere classified</td>
<td>Medical documentation</td>
<td>DAF: Ticket-to-Work information DAF-PUF: suspension or termination of benefits for work, value of benefits forgone for work</td>
<td>Non-earned income, program participation and benefits, Medicare and Medicaid eligibility</td>
<td>Non-earned income, program participation and benefits, Medicare and Medicaid eligibility</td>
<td>Non-earned income, program participation and benefits, Medicare and Medicaid eligibility</td>
</tr>
<tr>
<td>Disability Analysis File (DAF)</td>
<td>Period: 1996–2019; Unit: Individual</td>
<td>Period: 1996–2019; Unit: Individual</td>
<td>Intended population: Approximately 184,000 individuals in the 2019 DAF-PUF have a primary diagnosis of autistic disorders, developmental disorders, or childhood and adolescent disorders not elsewhere classified</td>
<td>Medical documentation</td>
<td>DAF: Ticket-to-Work information DAF-PUF: suspension or termination of benefits for work, value of benefits forgone for work</td>
<td>Non-earned income, program participation and benefits, Medicare and Medicaid eligibility</td>
<td>Non-earned income, program participation and benefits, Medicare and Medicaid eligibility</td>
</tr>
<tr>
<td>Disability Analysis File (DAF)</td>
<td>Period: 1996–2019; Unit: Individual</td>
<td>Period: 1996–2019; Unit: Individual</td>
<td>Intended population: Approximately 184,000 individuals in the 2019 DAF-PUF have a primary diagnosis of autistic disorders, developmental disorders, or childhood and adolescent disorders not elsewhere classified</td>
<td>Medical documentation</td>
<td>DAF: Ticket-to-Work information DAF-PUF: suspension or termination of benefits for work, value of benefits forgone for work</td>
<td>Non-earned income, program participation and benefits, Medicare and Medicaid eligibility</td>
<td>Non-earned income, program participation and benefits, Medicare and Medicaid eligibility</td>
</tr>
<tr>
<td>Disability Analysis File (DAF)</td>
<td>Period: 1996–2019; Unit: Individual</td>
<td>Period: 1996–2019; Unit: Individual</td>
<td>Intended population: Approximately 184,000 individuals in the 2019 DAF-PUF have a primary diagnosis of autistic disorders, developmental disorders, or childhood and adolescent disorders not elsewhere classified</td>
<td>Medical documentation</td>
<td>DAF: Ticket-to-Work information DAF-PUF: suspension or termination of benefits for work, value of benefits forgone for work</td>
<td>Non-earned income, program participation and benefits, Medicare and Medicaid eligibility</td>
<td>Non-earned income, program participation and benefits, Medicare and Medicaid eligibility</td>
</tr>
</tbody>
</table>
## Sources of Data on Employment Outcomes for Young Adults on the Autism Spectrum

<table>
<thead>
<tr>
<th>Name and source</th>
<th>Type and access options</th>
<th>Sample period, unit, and population</th>
<th>Estimated number of observations</th>
<th>Autism identification</th>
<th>Employment-related measures</th>
<th>Additional content</th>
<th>Data considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Beneficiary Survey (NBS) (<a href="http://ssa.gov/disabilityresearch/nbs.html">http://ssa.gov/disabilityresearch/nbs.html</a>)</td>
<td><strong>Type:</strong> Survey data Access: RUFs</td>
<td><strong>Period:</strong> 2004, 2005, 2006, 2010, 2015, 2017, 2019  <strong>Unit:</strong> Individual  <strong>Population:</strong> Adult SSDI beneficiaries and SSI recipients</td>
<td><strong>Data source:</strong> 9,092 in 2019  <strong>Intended population:</strong> Approximately 63 adults aged 18–25 with intellectual disabilities in 2019  <strong>Self- or proxy-reported survey responses</strong></td>
<td><strong>Earnings, hours worked, occupation, industry, experience at the job, employment-related services, training and supports</strong></td>
<td><strong>Medical conditions, health status, health insurance, income, program participation and benefits, service use</strong></td>
<td>• Detailed employment information (occupation, industry, experience at the job)  • Recent data (2019)  • 2019 round incorporates longitudinal component interviewing individuals from the 2017 sample  • Individuals who receive SSI or SSDI might not be representative of other individuals on the autism spectrum  • Although a PUF exists, individuals on the autism spectrum are identifiable only in RUF  • Small sample of individuals on the autism spectrum (247 individuals with any intellectual disability) (Callahan et al. 2021)</td>
<td></td>
</tr>
<tr>
<td>National Core Indicators (NCI) Adult In-Person Survey (<a href="https://www.nationalcoreindicators.org/">https://www.nationalcoreindicators.org/</a>)</td>
<td><strong>Type:</strong> Survey data Access: RUF; payment required to access RUFs</td>
<td><strong>Period:</strong> 2008–2021  <strong>Unit:</strong> Individual  <strong>Population:</strong> Adults ages 18 and older who receive publicly-funded Developmental Disability services</td>
<td><strong>Data source:</strong> 25,671 individuals in 2017–2018  <strong>Intended population:</strong> 4,742 on the autism spectrum; of those, 20% ages 18–22 and 48% ages 23–34. This percentage suggests a sample of about 3,225 adults aged 18–34 on the autism spectrum in 2017–2018  <strong>State records</strong></td>
<td><strong>Earnings, hours worked, job industry, type of job (for example, community job, job with and without publicly funded supports)</strong></td>
<td><strong>Medical conditions, health status, service use, community participation, self-determination, training</strong></td>
<td>• Large sample size of individuals on the autism spectrum  • Detailed employment information  • Recent data (2021)  • Publicly available chart generator of summary statistics  • Include data for most states (except Iowa, Montana, North Dakota, and West Virginia) but not all states have data in all years  • Individuals who receive publicly-funded Developmental Disability services might not be representative of other individuals on the autism spectrum  • Not nationally representative  • Details of data collection can differ across states  • Service eligibility criteria vary from state to state, such that state-level samples are not directly comparable</td>
<td></td>
</tr>
<tr>
<td>National demonstration data set: Promoting Readiness of Minors in Supplemental Security Income (PROMISE) (<a href="http://ssa.gov/disabilityresearch/promise.htm">http://ssa.gov/disabilityresearch/promise.htm</a>)</td>
<td><strong>Type:</strong> Survey data Access: RUFs are expected to be available in late 2022</td>
<td><strong>Period:</strong> 2014–2016; 2015–2017; 2019–2021  <strong>Unit:</strong> Individual; parents/guardians  <strong>Population:</strong> Youth ages 14–16 receiving SSI who enrolled into PROMISE and their families, interviewed at baseline and two follow-up surveys</td>
<td><strong>Data source:</strong> 9,377 youth and 9,202 parents/guardians  <strong>Target population:</strong> about 12% of youth in the data are on the autism spectrum (about 1,125 youth)  <strong>Self- or proxy-reported survey responses</strong></td>
<td><strong>Earnings, hours worked, occupation, reasons to leave job, employment-related services, training and supports</strong></td>
<td><strong>Medical conditions, health status, health insurance, service use, participation in public assistance programs, education</strong></td>
<td>• Recent data (2021)  • Longitudinal data for most sample members  • Individuals who receive SSI might not be representative of other individuals on the autism spectrum  • Data available only for the states where PROMISE programs were implemented: Arkansas, Arizona, California, Colorado, Maryland, Montana, New York, North Dakota, South Dakota, Utah, and Wisconsin  • Although a PUF exists, individuals on the autism spectrum are identifiable only in the RUF</td>
<td></td>
</tr>
</tbody>
</table>
## Sources of Data on Employment Outcomes for Young Adults on the Autism Spectrum

<table>
<thead>
<tr>
<th>Name and source</th>
<th>Type and access options</th>
<th>Sample period, unit, and population</th>
<th>Estimated number of observations</th>
<th>Autism identification</th>
<th>Employment-related measures</th>
<th>Additional content</th>
<th>Data considerations</th>
</tr>
</thead>
</table>
| National Longitudinal Study of Adolescent to Adult Health (Add Health)  
([http://addhealth.cpc.unc.edu](http://addhealth.cpc.unc.edu)) | Type: Survey data  
Unit: Individual  
Population: Students in high schools and middle schools in 1994 | Data source: About 15,000 individuals in 2008  
Intended population: Not available | PRS+ (Braudt and Harris 2020) | Hours worked, earnings, occupation, industry | Medical conditions, health status, education, social network, reproductive health, risk behavior | • Longitudinal data with long follow-up period (more than three decades)  
• Rich demographic, social, familial, socioeconomic, behavioral, psychosocial, cognitive, and health survey data from participants  
• Unique in the offering of additional data from parents, schools, neighborhoods, and geographies of residence; and in-home physical and biological data from participants  
• Although a PUF exists, PRS are available only in the RUF from Wave 4 (completed in 2008)  
• No data on autism identification; PRS only indicate “risk” (or probability) of autism and might be noisy  
• PRS have poor cross-population transferability (Martin et al. 2017, 2019; Duncan et al. 2019); the PRS for autism in these data were derived from an analysis of individuals of European genetic ancestry (Grove et al. 2019), which limits their use for diverse populations  
• PRS are continuous, so researchers would have to select a cutoff score to identify a sample at risk for autism; there is limited evidence to guide this choice and how it could be tailored to other characteristics (Antaki et al. 2021) |
| National Longitudinal Transitional Study 2 (NLTS2)  
Unit: Individual  
Population: Youth ages 13–16 in 2000 who received special education services in school | Data source: About 11,500 individuals initially sampled  
Intended population: 1,012 students on the autism spectrum (SRI International 2000) | School designation of special education exceptionality category | Hours worked, wages, information on school-sponsored jobs, transition services, employment-related services, training and supports | Medical conditions, health status, health care, service use, community participation, education | • Large sample of individuals on the autism spectrum  
• Longitudinal data with almost a decade of follow-up period  
• Information on school-sponsored jobs  
• Not recent data (2009)  
• Includes only those receiving special education, which might under-represent youth on the autism spectrum who need fewer supports (Roux et al. 2015) |
| National Longitudinal Transitional Study 2012 (NLTS 2012)  
Access: RUFs | Period: 2012 (follow-up survey underway)  
Unit: Individual  
Population: Youth who were 12–23 years in high school in December 2011, both receiving and not receiving special education services | Data source: 11,128 youth  
Intended population: 1,648 students on the autism spectrum (Burghardt et al. 2017) | School designation of special education exceptionality category or parents’ report of an autism diagnosis | Hours worked, wages, information on school-sponsored jobs, employment-related services, training and supports | Medical conditions, health status, health insurance, service use, expectations for the future, education, household income | • Large sample of individuals on the autism spectrum  
• Information on school-sponsored jobs  
• Not recent data (2012)  
• Includes only youth receiving special education, which might under-represent youth on the autism spectrum who need fewer supports |
## Sources of Data on Employment Outcomes for Young Adults on the Autism Spectrum

<table>
<thead>
<tr>
<th>Name and source</th>
<th>Type and access options</th>
<th>Sample period, unit, and population</th>
<th>Estimated number of observations</th>
<th>Autism identification</th>
<th>Employment-related measures</th>
<th>Additional content</th>
<th>Data considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Survey on Health and Disability (<a href="http://ihdp.ku.edu/nshd">http://ihdp.ku.edu/nshd</a>)</td>
<td>Type: Survey data; Access: RUFs</td>
<td>Period: 2018, 2019, 2021, 2022 (planned)</td>
<td>Data source: 2,175 individuals in 2020</td>
<td>Self- or proxy-reported survey responses</td>
<td>Hours worked, job tenure</td>
<td>Health insurance, health care, service use, SSI and SSDI status, community participation</td>
<td>Recent data (2021 available and 2022 planned); Sample size of individuals on the autism spectrum is small (about 45 in one wave); the sample size will be even smaller when limited to young adults</td>
</tr>
<tr>
<td>Transformed Medicaid Statistical Information System (T-MDIS) Analytical Files (<a href="http://medicaid.gov/medicaid/data-systems/marcbis/medicaid-chip-research-files/transformed-medicaid-statistical-information-system-t-msis-analytic-files-taf/index.html">TAF</a>)</td>
<td>Type: Administrative data; Access: RUFs</td>
<td>Period: 2014–2019</td>
<td>Data source: About 88 million individuals in 2019</td>
<td>Autism diagnosis in claims data files</td>
<td>Claims related to employment-support services</td>
<td>Medical conditions, demographics, program enrollment, diagnoses, service use, and payment</td>
<td>Recent data (2019); Data are not available for all states in all years (19 states in 2014; all states and District of Columbia in 2016 and forward); Access to the autism and employment information in the data requires combining different administrative files; Employment-related outcomes are limited to employment-support services, which Medicaid does not offer in all states; Population is not fully comparable across states due to different Medicaid eligibility requirements and is not necessarily representative of all young adults on the autism spectrum</td>
</tr>
</tbody>
</table>

*Polygenic scores (PRSs), sometimes referred to as polygenic risk scores or genetic risk scores, represent a general measure of the influence of additive genetics on a specific phenotype.*
Sources of Data on Employment Outcomes for Young Adults on the Autism Spectrum

References


