Sources of Data on Employment Outcomes for Young Adults on the Autism Spectrum

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Introduction

Public policy increasingly acknowledges the importance of addressing the employment-related challenges facing young adults on the autism spectrum (for example, Autism CARES Act [2019]). 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).

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

RSA = Rehabilitation Services Administration

SSA = Social Security Administration

SSDI = Social Security Disability Insurance

SSI = Supplemental Security Income

VR = Vocational Rehabilitation

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.** The small sample size in several data sources might limit the ability to analyze experiences of young adults on the autism spectrum across different characteristics.

/ **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.

Table 1. Key features of data sets with autism and employment information for youth ages 16 to 28

Name and source	Type and access options	Sample period, unit, and population	Estimated number of observations	Autism identification	Employment-related measures	Additional content	Data considerations
Case Service Report—Rehabilitation Services Administration (RSA-911) (http://rsa.ed.gov/performance/rsa-911-policy-directive)	**Type:** Administrative data **Access:** RUFs	**Period:** 1978–2021 **Unit:** Individual **Population:** All individuals who received pre-employment transition services, applied for VR services, received VR services, or recently had their VR cases closed	**Data source:** About 362,000 individuals in 2019 (who applied to the VR program) **Intended population:** Among applicants eligible to receive VR services, 3.2% were on the autism spectrum in 2014 (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	Self-report and medical evidence in support of the disability (the assessment process and types of evidence used could vary across state agencies)	Earnings, hours worked, type of job, employment-related services, training and supports	Medical conditions, VR service use; types of VR case closure, public supports, health insurance, some demographic and socioeconomic characteristics	• 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
Disability Analysis File (DAF) (https://catalog.data.gov/dataset/disability-analysis-file-daf-public-use-file-puf-data-collection)	**Type:** Administrative data **Access:** PUFs and RUFs	**Period:** 1996–2019 **Unit:** Individual **Population:** SSI or SSDI beneficiaries with disabilities and below retirement age. DAF-PUF contains a random 10 percent sample of beneficiaries and a subset of the variables available in the DAF	**Data source:** Approximately 30 million individuals in the 2019 DAF and 3 million in the 2019 DAF-PUF **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	Medical documentation	DAF: Ticket-to-Work information DAF-PUF: suspension or termination of benefits for work, value of benefits forgone for work	Non-earned income, program participation and benefits, Medicare and Medicaid eligibility	• Universe of the population with disabilities under retirement age who participated in SSI and/or SSDI • Easy access to public file that combines multiple SSA administrative data sources (annual downloadable file) • Recent data (2019) • DAF-PUF cannot be linked to other data sets • Employment information is limited to earnings and employment that might affect the receipt of SSI or SSDI benefits • Individuals who receive SSI or SSDI might not be representative of other individuals on the autism spectrum • The DAF-PUF groups individuals on the autism spectrum with individuals with developmental disorders or childhood and adolescent disorders not elsewhere classified
Medical Expenditure Panel Survey (MEPS), Household Component (http://meps.ahrq.gov/survey_comp/household.jsp)	**Type:** Survey data **Access:** PUF and RUF	**Period:** 1996–2019 **Unit:** Individual; household **Population:** U.S. civilian non-institutionalized population; each panel sample is interviewed in five rounds across two years	**Data source:** 11,924 families in 2019; 27,648 individuals in 2019 **Intended population:** Estimated 32 individuals ages 16–28 with a diagnosis in the pervasive developmental disorders category in 2018, which includes individuals with autism	Self- or proxy-reported survey responses, coded to the International Classification of Diseases diagnosis codes	Job-level information (earnings, hours worked, start and end dates, reason for leaving job)	Medical conditions, health status, health care receipt, health care charges and payments, health insurance coverage, non-earned income	• The PUF and RUF can be linked to the National Health Interview Survey using a restricted-use crosswalk, which enables exploring several health issues that can be correlated with employment • The National Health Interview Survey includes a question about autism diagnosis in the child questionnaire • Detailed information on medical expenditures for the individual and their household members • Recent data (2019) • Panel design features five rounds of interviews over two years • The sample size of individuals on the autism spectrum is small

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National Beneficiary Survey (NBS) (https://catalog.data.gov/dataset/national-beneficiary-survey-nbs-round-1)	**Type:** Survey data **Access:** RUFs	**Period:** 2004, 2005, 2006, 2010, 2015, 2017, 2019 **Unit:** Individual **Population:** Adult SSDI beneficiaries and SSI recipients	**Data source:** 9,092 in 2019 **Intended population:** Approximately 63 adults aged 18–25 with intellectual disabilities in 2019	Self- or proxy-reported survey responses	Earnings, hours worked, occupation, industry, experience at the job, employment-related services, training and supports	Medical conditions, health status, health insurance, income, program participation and benefits, service use	• 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)
National Core Indicators (NCI) Adult In-Person Survey (https://www.nationalcoreindicators.org/)	**Type:** Survey data **Access:** RUFs; payment required to access RUFs	**Period:** 2008–2021 **Unit:** Individual **Population:** Adults ages 18 and older who receive publicly-funded Developmental Disability services	**Data source:** 25,671 individuals in 2017–2018 **Intended population:** 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	State records	Earnings, hours worked, job industry, type of job (for example. community job, job with and without publicly funded supports)	Medical conditions, health status, service use, community participation, self-determination, training	• 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
National demonstration data set: Promoting Readiness of Minors in Supplemental Security Income (PROMISE) (http://ssa.gov/disabilityresearch/promise.htm)	**Type:** Survey data **Access:** RUFs are expected to be available in late 2022	**Period:** 2014–2016; 2015–2017; 2019–2021 **Unit:** Individual; parents/guardians **Population:** Youth ages 14–16 receiving SSI who enrolled into PROMISE and their families, interviewed at baseline and two follow-up surveys	**Data source:** 9,377 youth and 9,202 parents/guardians **Target population:** about 12% of youth in the data are on the autism spectrum (about 1,125 youth)	Self- or proxy-reported survey responses	Earnings, hours worked, occupation, reasons to leave job, employment-related services, training and supports	Medical conditions, health status, health insurance, service use, participation in public assistance programs, education	• 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

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National Longitudinal Study of Adolescent to Adult Health (Add Health) (http://addhealth.cpc.unc.edu/)	**Type:** Survey data **Access:** RUFs; payment required to access restricted files	**Period:** Wave 4: 2008–2009; other waves: 1994–1995, 1996, 2001–2002, 2016–2018 **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[a] (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 different 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) (http://ies.ed.gov/ncser/projects/nlts2/)	**Type:** Survey data **Access:** RUFs	**Period:** 2001, 2003, 2005, 2007, 2009 **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 have a lower proportion of youth on the autism spectrum who need fewer supports (Roux et al. 2015)
National Longitudinal Transitional Study 2012 (NLTS 2012) (https://ies.ed.gov/use-work/evaluations/national-longitudinal-transition-study-2012-nlts-2012)	**Type:** Survey data **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 have a lower proportion of youth on the autism spectrum who need fewer supports

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National Survey on Health and Disability (http://ihdps.ku.edu/nshd)	**Type:** Survey data **Access:** RUFs	**Period:** 2018, 2019/2020, 2021, 2022 (planned) **Unit:** Individual **Population:** U.S. adults ages 18–64	**Data source:** 2,175 individuals in 2019/2020 **Intended population:** About 8% (174) with intellectual and developmental disabilities (Down syndrome, fragile X syndrome, autism, and others)	Self- or proxy-reported survey responses	Hours worked, job tenure	Health insurance, health care, service use, SSI and SSDI status, community participation	• 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
Transformed Medicaid Statistical Information System (T-MSIS) Analytical Files (TAF) Research Identifiable Files (TAF-RIFs) (http://medicaid.gov/medicaid/data-systems/macbis/medicaid-chip-research-files/transformed-medicaid-statistical-information-system-t-msis-analytic-files-taf/index.html)	**Type:** Administrative data; **Access:** RUFs	**Period:** 2014–2019 **Unit:** Individual **Population:** Medicaid and Children's Health Insurance Program beneficiaries	**Data source:** About 88 million individuals in 2019 **Intended population:** About 1% of Medicaid participants had a claim with an autism diagnosis in 2012 (Schott et al. 2021), which suggests a sample of about 880,000 participants on the autism spectrum in 2019	Autism diagnosis in claims data files	Claims related to employment-support services	Medical conditions, demographics, program enrollment, diagnoses, service use, and payment	• 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

[a] 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.

References

Antaki, Danny, Adam Maihofer, Marieke Klein, James Guevara, Jakob Grove, Caitlin Carey, Oanh Hong et al. "A phenotypic spectrum of autism is attributable to the combined effects of rare variants, polygenic risk and sex." medRxiv, 2021.

Braudt, David B. and Kathleen Mullan Harris. "Polygenic Scores (PGSs) in the National Longitudinal Study of Adolescent to Adult Health (Add Health) – Release 2." Chapel Hill, NC: Carolina Population Center, University of North Carolina at Chapel Hill, 2020.

Burghardt, John, Joshua Haimson, Stephen Lipscomb, Albert Y Liu, Frank Potter, Tiffany Waits, and Sheng Wang. "National Longitudinal Transition Study 2012: Design Documentation. NCEE 2017-4021." Washington, DC: National Center for Education Evaluation and Regional Assistance, 2017.

Callahan, Ryan, Eric Grau, Aleks Wec, Kim McDonald, Bevin Mory, Leah Pranschke, Jason Markesich, et al. "National Beneficiary Survey—General Waves Round 7 (Volume 3 of 3): User's Guide for Restricted Access and Public Use Files." Mathematica, 2021.

Duncan, L., H. Shen, B. Gelaye, J. Meijsen, K. Ressler, M. Feldman, et al. "Analysis of Polygenic Risk Score Usage and Performance in Diverse Human Populations." *Nature Communications*, vol. 10, no. 1, 2019, p. 3328.

Grove, J.S. Ripke, T.D. Als, M. Mattheisen, R.K. Walters, H. Won, et al. "Identification of Common Genetic Risk Variants for Autism Spectrum Disorder." *Nature Genetics*, vol. 51, 2019, pp. 431–444.

Martin, Alicia R., Christopher R. Gignoux, Raymond K. Walters, Genevieve L. Wojcik, Benjamin M. Neale, Simon Gravel, Mark J. Daly, Carlos D. Bustamante, and Eimear E. Kenny. "Human Demographic History Impacts Genetic Risk Prediction Across Diverse Populations." The American Journal of Human Genetics, vol. 107, no. 4, 2017, pp. 788–789.

Martin, Alicia R., Masahiro Kanai, Yoichiro Kamatani, Yukinori Okada, Benjamin M. Neale, and Mark J. Daly. "Clinical Use of Current Polygenic Risk Scores May Exacerbate Health Disparities." *Nature Genetics*, vol. 51, no. 4, 2019, pp. 584–591.

Migliore, Alberto, John Butterworth, and Agnieszka Zalewska. "Trends in Vocational Rehabilitation Services and Outcomes of Youth with Autism: 2006–2010." *Rehabilitation Counseling Bulletin*, vol. 57, no. 2, 2014, pp. 80–89. Available at https://doi.org/10.1177/0034355213493930.

Roux, A.M., P.T. Shattuck, J.E. Rast, J.A. Rava, and K.A. Anderson. "National Autism Indicators Report: Transition into Young Adulthood." Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, 2015.

Roux, Anne M., Jessica E. Rast, K.A. Anderson, and Paul T. Shattuck. "National Autism Indicators Report: Vocational Rehabilitation." Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, 2016.

Schott, Whitney, Kate Verstreate, Sha Tao, and Lindsay Shea. "Autism grows up: Medicaid's role in serving adults on the spectrum." Psychiatric Services 72, no. 5, 2021, 597–597.

Shenk, Marisa, Andrew Krantz, and Paul Shattuck. "Evidence on the Effectiveness of Programs, Models, and Strategies to Support Employment Outcomes of Young Adults on the Autism Spectrum: A Review of the Literature." Washington, DC: Mathematica, March 2022.

SRI International. "The National Longitudinal Transition Study-2 (NLTS2): Conceptual Framework and Research Questions." Menlo Park, CA: SRI International, 2000.

United States Congress. "H.R. 1058 - Autism Collaboration, Accountability, Research, Education and Support (CARES) Act of 2019." 2019.

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