

# Getting People with Autism to Work

An International Society for Autism Research Policy Brief

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## ABOUT THE ISSUE

**The right to employment for people is enshrined in Article 23 of the Universal Declaration of Human Rights; however, for many on the autism spectrum, this right is yet to be realized.**

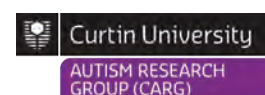
The employment rate for people with autism is between 50%-75%, lower than that for people with intellectual disability without autism and nearly all other populations with special needs.<sup>1-7</sup> This has many costs at the societal as well as individual level, as unemployment decreases quality of life, reduces financial independence and impairs dignity and cognitive abilities.<sup>8</sup> A large proportion of the lifetime cost associated with autism is, not surprisingly, incurred during adulthood, with more than a third resulting from employment losses related to lost productivity and loss of tax revenue due to unemployment.<sup>9,10</sup> Developing pathways that help autistic adolescents and adults to obtain and maintain employment should be a societal priority.

## BACKGROUND

Internationally, approaches to employment vary. In the United States, most employment opportunities for autistic people to date have been generated by family members or friends, including new businesses, models and personal investments. These approaches have led to greater awareness of the benefits of ensuring adequate employment opportunities, resulting in increasing awareness of the employment-related issues for autistic adults. In contrast, Sweden having invested significantly in state-owned companies such as Samhall (<https://samhall.se/in-english/>) and centrally mandating for the employment of people with functional impairment impacting work capacity (including autism), has one of the highest rates of employment of autistic individuals internationally. While there are several examples of excellence in the field of employing people with autism, there is a paucity of evaluation research in this field and articulation of models of service enabling the translation of successful approaches internationally.

“**Employment is important because it allows us to add value to the community, to achieve our personal best.**”

- Ellen, autistic woman



Autistic individuals show a range of abilities and disabilities within the umbrella of an autism diagnosis. The diversity of people with autism means a “one size fits all” solution to improving employment outcomes is unlikely.<sup>11-14</sup> While this policy brief outlines strategies likely applicable to many living with autism, it should not detract from the importance of flexible person-centered and individually focused approaches. **It is clear that improving the employment opportunities and outcomes for autistic adolescents and adults will have significant benefits to workplaces, the economy, the community and individuals living with autism.**

## THE OPPORTUNITY

### Why is NOW a good time to do something about this?

To better capitalize on individual strengths and disabilities, the World Health Organization’s International Classification of Functioning, Disability and Health (ICF) offers an internationally accepted, comprehensive and integrated framework incorporating personal, societal and environmental factors affecting the health and well-being of autistic individuals.<sup>15</sup> The development of the ICF core sets for ASD<sup>16</sup> provides a shortlist of categories most relevant to autism, expanding the focus from diagnosis to functioning, which is now also an essential feature of the autism description in DSM-5 and ICD-11. The ICF provides a framework for improving employment outcomes and in developing strategies supporting the inclusion of those with unique abilities, as well as profound disabilities. Many of the strengths of autistic adolescents and adults are potentially beneficial to employers, such as punctuality and attention to detail. While variations in labor markets and models of support internationally dictate differing opportunities for autistic adolescents, this policy brief outlines strategies and approaches aimed at improving employment outcomes cross-culturally.



## THE APPROACH

The authors combined three different approaches to better understand the challenges and policy implications around this issue:

- 1 First, a scoping review of the scientific literature examining employment research in autism was conducted,<sup>17</sup> revealing that the overwhelming majority of research to date has focused on approaches targeting the symptoms of autism, rather than modifying the employment or attitudinal environment.
- 2 Subsequently, a survey of 248 adults with autism, 207 family members and 33 employers across three countries (Australia, Sweden and the United States) was undertaken.
- 3 Finally, in each country, in-person meetings were held with autistic individuals, scientists, policymakers, employers, stakeholders and care providers, seeking their views in relation to issues pertinent to preparing for employment, the factors facilitating successful employment and the barriers or challenges autistic individuals face in employment.

## OVERALL RESULTS



- There is a lack of research examining the role of environmental supports in maintaining people with autism in the workplace. Preferential to the current focus on changing autism symptoms is providing resources and services, helping those with different abilities to succeed in the workplace by removing barriers and use of facilitators in the environment.
- While heterogeneous, employers and autistic people recognize the specific strengths of people with autism, including attention to detail and punctuality. These can be leveraged in employment.
- Matching the interests, skills and strengths of an autistic person with a particular job will improve outcomes. Many autistic adults bring talents, including focused attention and dedication to accuracy, skills essential for certain positions. A poor match will likely lead to failure for the employee and disappointment for the employer.
- In preparing for employment, good job coaching on interview skills and opportunities for on-the-job experience such as internships are critical. These training and coaching opportunities may include things specific to the job or support daily life skills such as transportation and self-care.
- Matching on-the-job mentors with employees with autism provides timely individualized support; however, continuous monitoring and oversight limit work performance.
- In preference to “blanket training,” targeted education of employers and co-workers on the unique needs of people with autism supports inclusion. Environmental supports are key in maximizing the functioning of people with ASD.
- Employers recognize the skills and benefits that people with autism bring to the workplace and that employing individuals with autism is beneficial to all.
- The issue of disclosure remains controversial. Disclosure should consider the unique needs of autistic employees, and individually weigh the perceived negative consequences (including stigma) and benefits of disclosing a diagnosis.

## RECOMMENDATIONS: WHAT YOU CAN DO RIGHT NOW

- **Utilize person-centered, individualized approaches** to identify needs, working to improve the quality of life of each autistic individual on their terms.
- **Environmental supports in the workplace are essential**, including modifying the task format and the work environment, such as lighting and sound.
- **On-the-job experience is key to success.** Expanding work experience programs is critical to improving employment outcomes.
- **Employers require better metrics** as to what strategies work and do not work, with ready access to resources.
- **Employers have a unique opportunity to increase understanding of ASD in the workplace** by offering educational tools to managers and those with direct contact with the employee.
- **Programs helping people get jobs and stay employed** should consider the strengths of those with ASD.
- **The process needs to start early in adolescence** to build “pathways” to employment.

These results are consistent with other national surveys in overcoming barriers in employment for autistic adolescents and adults<sup>13-14,18-20</sup>

## REFERENCES

1. Roux AM, Shattuck, Paul T., Rast, Jessica E., Rava, Julianna A., and Anderson, Kristy, A. National Autism Indicators Report: Transition into Young Adulthood. Philadelphia, PA: Life Course Outcomes Research Program: A.J. Drexel Autism Institute, Drexel University;2015.
2. Carter EW, Austin D, Trainor AA. Factors associated with the early work experiences of adolescents with severe disabilities. *Intellect Dev Disabil*. 2011;49(4):233-247.
3. Howlin P, Goode S, Hutton J, Rutter M. Adult outcome for children with autism. *J Child Psychol Psychiatry*. 2004;45(2):212-229.
4. Howlin P, Moss P. Adults with autism spectrum disorders. *Can J Psychiatry*. 2012;57(5):275-283.
5. Shattuck PT, Narendorf SC, Cooper B, Sterzing PR, Wagner M, Taylor JL. Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics*. 2012;129(6):1042-1049.
6. Lee GK and Carter E.W. Preparing Transition Age Students with High Functioning Autism Spectrum Disorders for Meaningful Work. *Psychology in the Schools*. 2012;49(10):988-1000.
7. Taylor JL, Seltzer MM. Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *J Autism Dev Disord*. 2011;41(5):566-574.
8. Hendricks, D. Employment and adults with autism spectrum disorders: Challenges and strategies for success. *Journal of Vocational Rehabilitation*. 2010. 32:125-134.
9. Jacob A, Scott M, Falkmer M, Falkmer T. The Costs and Benefits of Employing an Adult with Autism Spectrum Disorder: A Systematic Review. *PLoS One*. 2015;10(10):e0139896.
10. Scott M, Jacob A, Hendrie D, et al. Employers' perception of the costs and the benefits of hiring individuals with autism spectrum disorder in open employment in Australia. *PLoS One*. 2017;12(5):e0177607.
11. Nicholas DB, Zwaigenbaum L, Zwicker J, et al. Evaluation of employment-support services for adults with autism spectrum disorder. *Autism*. 2017;1362361317702507.
12. Chen JL, Leader G, Sung C, Leahy M. Trends in Employment for Individuals with Autism Spectrum Disorder: A Review of the Research Literature. *Review Journal of Autism and Developmental Disorders*. 2015;2(2):115-127.
13. Bell P. Autism Speaks Employment Think Tank. New York: Autism Speaks;2012.
14. Foundation K. 2015 Kessler Foundation National Employment & Disability Survey: Overview. West Orange NJ, 2015.
15. Mahdi S, Albertowski K, Almodayfer O, et al. An International Clinical Study of Ability and Disability in Autism Spectrum Disorder Using the WHO-ICF Framework. *J Autism Dev Disord*. 2018;48(6):2148-2163.
16. Bölte S, Mahdi S, de Vries PJ, et al. The Gestalt of functioning in autism spectrum disorder: Results of the international conference to develop final consensus, International Classification of Functioning, Disability and Health core sets. *Autism*. 2018;3(2):449-467.
17. Scott M, Milbourn B, Falkmer M, et al. Factors impacting employment for people with autism spectrum disorder: A scoping review. *Autism*. 2018;1362361318787789.
18. Dudley C, Nicholas, D.B. and Zwicker, J.D. What do we know about improving employment outcomes for individuals with autism spectrum disorder? 2015. SPP Research Paper 8:32.
19. Nicholas DB, Hodgetts S, Zwaigenbaum L, et al. Research needs and priorities for transition and employment in autism: Considerations reflected in a "Special Interest Group" at the International Meeting for Autism Research. *Autism Res*. 2017;10(1):15-24.
20. Society NA. Too Much Information: The Employment Report. United Kingdom: National Autistic Society.