

Disclosure and Autistic: *Young Adults in the WorkForce*


Autisme et divulgation diagnostique: Jeunes adultes en milieu professionnel

Jeanine McAdam

jeanine.mcadam@gmail.com

M.A. candidate in Disability Studies, CUNY School of Professional Studies New York,
United States.

<https://doi.org/10.65130/sK1zJpE>

Manuscrit sous licence Creative Commons Paternité - Partage des conditions initiales à l'identique 4.0 International (BY SA) 

RÉSUMÉ

Pour de nombreux jeunes adultes autistes, lors de leur transition vers le marché du travail, il y a une décision énorme et stressante à prendre : quand devraient-ils divulguer leur diagnostic s'ils choisissent de le faire? Doivent-ils le divulguer? Un diagnostic d'autisme peut entraîner de nombreuses stigmatisations sociales et émotionnelles. Il arrive souvent qu'il existe un environnement de travail dans lequel les superviseurs et les collègues pourraient percevoir la personne autiste différemment ou la dévaloriser au sein de l'équipe. La divulgation peut aider la personne autiste à obtenir le soutien et les mesures dont elle a besoin pour faire son travail plus efficacement. La divulgation peut aussi procurer un énorme soulagement émotionnel. Cet article, qui fait partie d'un mémoire de maîtrise, explore la prise de décision de cinq jeunes adultes autistes qui entrent sur le marché du travail et qui sont à la recherche d'un premier emploi professionnel. La recherche porte sur leur décision de divulguer leur diagnostic lors du processus d'embauche ou une fois l'emploi obtenu.



MOTS-CLÉS

Neurodiversité, Neurodivergent, Autisme, Autiste, ADS, Divulgateur, Emploi, Stigmatisation, Travail, Handicap, Handicap, Handicapé.

ABSTRACTS

For many autistic young adults when transitioning into the workforce there is a huge and stressful decision to make, when or if they should disclose their diagnosis? An autism diagnosis can carry much social and emotional stigma. Many times, a work environment exists where supervisors and co-workers view the autistic person differently or value them less on the team. Then again, disclosing can help the autistic person gain the support and accommodations they need to perform their job more effectively. Disclosing can also provide a tremendous amount of emotional relief. This paper, part of a master's research project, explores the decision making of five autistic young adults entering the workforce searching for professional employment. The research focuses on their decision to disclose (or not disclose) their diagnosis during the hiring process or once employment is obtained.

KEYWORDS

Neurodiversity, Neurodivergent, Autism, Autistic, ADS, Disclosure, Employment, Stigma, Work, Disability, Disabilities, Disabled.

INTRODUCTION

For many young autistic (ASD) adults (ASD) when entering the workforce there is a huge and stressful decision to make. When or if they should disclose their diagnosis? An autism diagnosis can carry much social and emotional stigma. “While accommodations may offer valuable support, they may also be viewed as stigmatizing or marginalizing among individuals with developmental disabilities” (Johnson & Joshi, 2015, p. 436).

This paper studies five autistic young adults entering the workforce. The analysis explores their decision-making concerning disclosing or not disclosing their diagnosis, also the timing of when these young adults choose to disclose, who to disclose to and if disclosure will help or hinder their job hunt, plus the emotional impact of disclosing or not disclosing. This group of young adults and the topic of study was chosen because there is a 76% unemployment rate among autistic adults with autism 4-6 years after high school (Roux *et al.*, 2015, p.2).

Before exploring disclose further, a definition of an autism diagnosis needs to be established and an analysis of the recent literature reviewed.

In 2013, the APA released the fifth edition of DSM (DSM-5). It stated that an autism diagnosis requires persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following: deficits in social-emotional reciprocity, in nonverbal communicative behaviors used for social interaction, and in developing, maintaining and understanding relationships (Autism Speaks, n. d.).

Also, it is important to note that autism is a spectrum disability, it impacts different people in different ways and with different levels of severity (Nimante *et al.*, 2023, p. 414).

LITERATURE REVIEW

Previous research on the decision to disclose among young autistic adults in a work environment shows that many are reluctant to disclose. “First, young adults did not want to be treated differently; they want to be perceived as ‘normal’ ” (Nimante *et al.*, 2023, p. 421). Nimante’s research was done in Latvia but very similar to earlier studies done in other countries. “As was the case with university students, autistic employees feared that disclosure would lead to negative assumptions of their capabilities due to stigma” (Johnson & Joshi, 2016; Romualdez *et al.*, 2021 cited in Huang, 2022, p. 5301). Huang also found that autistic people choose not to disclose because, “Many were concerned about misconceptions and stigma that may cause others to view them less positively” (Huang, 2022, p. 5304).

To explore further the question of disclosing or not in a work environment, I attended two workshops offered by career counselors virtually at Landmark College. The career counselors advised not to disclose unless the autistic candidate was applying to a company with a specific disability program. The advice centers around having a better chance of getting the job. This advice reinforces the findings in the research, as explored above there is stigma attached to autism and discrimination could disqualify a candidate during the interview. “The low numbers of employed autistic

individuals with autism suggest that many, if not most, have been unable to get beyond the initial employment interview” (Hensel, 2017, p. 88).

One of the workshop speakers suggested when interviewing and talking about accommodations to NOT say, “I’m on the autism spectrum.” The speaker clarified, “It doesn’t help, the employer doesn’t know what it means.” Instead, the speaker advised the job seeker to focus on “Disclose(ing) your needs. Specifics about yourself” (Reilly, 2023). For example, “I am a person who needs: Flexible hours, work from home two days a week, not having meetings back-to-back or shorter meetings, a quiet space to work and lighting that is comfortable” (Healy, 2023).

Before interviewing the young adults participating in this study, I analyzed employment statistics in the Northeast of the United States (Winson *et al.*, 2023). I reviewed this data to understand the employment opportunities for autistic people in relationship to people with a physical disability and those without a disability. I focused on five states: Connecticut, Massachusetts, New Jersey, New York and Vermont. The states were selected because the young adults I interviewed resided or attended college in those states.

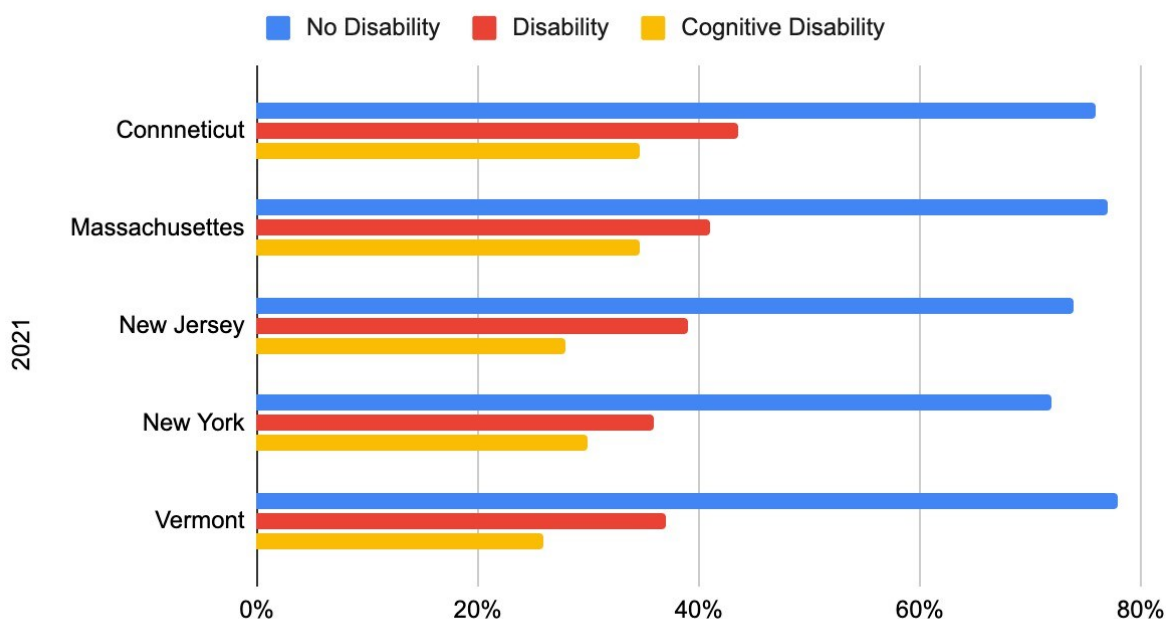
A review of the quantitative data from StateData: The National Report on Employment Services and Outcomes Through 2021 (Winson *et al.*, 2023) shows that people with cognitive disabilities have an even lower employment rate than disabled people overall. The data includes all people with neurological, intellectual or developmental disabilities under the umbrella of cognitive disabilities. There is no breakdown in this report specifically addressing autistic people. However, autism is a neurological disability and can be a developmental disability. The executive summary explains: “Overall, the findings across all four data sources suggest that people with IDD experience greater levels of unemployment, underemployment, low wages, and poverty compared to those without disabilities” (Winson *et al.*, 2023, p. 2).

The A.J. Drexel Institute data (Roux *et al.*, 2015) reflects these same findings. “Compared to their peers with other types of disabilities, young autistic adults with autism had the lowest rate of employment” (Roux *et al.*, 2015, p. 1). People with physical disabilities have a higher employment rate than people with developmental disabilities. “People with any type of disability are less likely to work (40%) compared to people with no disability (74.3%). People who have a cognitive disability are the least likely to work (32.7%)” (Winson *et al.*, 2023, p. 2). That could be because the Americans with Disabilities Act (ADA) passed in 1990 in the United States focused on employment opportunities for people with physical disabilities rather than mental illnesses. More research needs to be done on this theory and the ADA’s impact on employment and autism.

Within the specific states examined for this study, people with cognitive disabilities are on average over 50% less likely to be employed than their peers with no disability and 10-15% less likely to be employed than people with physical disabilities.

Figure 1

Employment



PARTICIPANTS

With the numerous challenges autistic young adults face while entering the workforce, I wanted to find out how a sampling of young autistic adults planned to navigate this difficult environment. The participants were five autistic adults between the ages of 21-25. The group included three men, one non-binary person and a transgender woman, all were Caucasian and lived in the northeast of the United States. Each participant had a high school diploma, and all the participants attended college with some level of educational accommodations. Two were working on acquiring a college level associates degree. Two were studying for college level bachelor's degrees and one had finished college with a bachelor's degree. Four had internship/volunteer experiences within the workforce while one had not. Three moved away from home to attend college and lived independently with academic support during college. Two of the adults lived at home and attended college virtually or in person. The group was found through the author's network in the autism community. The author reached out to several young autistic adults but only those included in this paper replied.

METHOD

The research method included the gathering of both quantitative data through yes/no answers followed by qualitative data. The qualitative data was gathered via a one-on-one interview format with open ended, follow up questions to the yes/no answers. This format enabled the adults to talk further about their thoughts concerning disclosure as they entered the workforce. The questions were asked in the third person, "How would you advise a autistic peer...?" The goal was to keep the young adults engaged with the questions and not add any personal stigma they may feel around autism while answering the questions. It was interesting, after asking one or two questions in the third person, the young adults started referring to themselves as I and answering the questions in

the first person. This could be because they became more comfortable with the questions and the style of asking, plus they could have gained more trust with the interviewer.

The reason behind only five questions was to not overwhelm the interviewees with a lot of communication challenges. The questions were kept to one sentence with a semi-structured format. From my experience as an advocate for autistic people, too many compound questions could potentially shut down the young adult and result in fewer meaningful answers. The aim was to hesitate after each question and leave a moment of silence to let the participants process the questions and formulate an answer. The interviews lasted between 10-20 minutes and were not recorded. Notes were taken and analysis performed following the interviews.

DATA COLLECTION

Table 1

Data Collection

Questions	P1	P2	P3	P4	P5
Disclose Before Acquiring Job	-	✓	-	✓	-
Disclose After Acquiring Job	✓	-	✓	-	✓
Pain of Hiding	✓	✓	✓	-	-
Fear of Disclosing	✓	✓	✓	-	✓
Relief of Getting Accommodations	✓	✓	✓	✓	✓

The first two questions addressed if and when the five young autistic adults would disclose their disability in the workplace and the timing of the disclosure. Participant Two and Participant Four stated they would disclose before acquiring the job, during or before the interview. Participant Two clarified they would include in the cover letter that they were autistic and needed support. The reasoning for both participants who answered yes to disclosing, before acquiring the job, was that they needed accommodations in the workplace and wanted to be upfront about those needs.

Participant Two who suggested disclosure in the cover letter said, “Tell people, then they know and can accommodate.” Following up on that thought I asked, “How would the autistic person disclose on their resume or cover letter?” The reply was, “There is always a section that asks strengths and weaknesses. Disclose there.” I did not ask if Participant Two perceived their diagnosis as a strength or weakness. Participant Four replied yes about disclosing during the interview and said, “Tell them first, you want them to know you have a disability.” It would, “Be a bad impression on your boss,” if you didn’t tell them.

Stigma seemed to be behind the reasons for Participants One, Three and Five to not disclose, before acquiring the job, in the cover letter or during the interview. These young adults planned to be hired first before they disclosed their disability because they didn’t want to start in a new work

environment with a label. Participant Five explained they wanted to “Get a sense of the work environment” before disclosing. Participant Three expressed, “Depends on the job and how comfortable with the employer or where it is.” Participant Three was also very clear about wanting to wait and find a supervisor or human resource person who they could comfortably disclose to. All three reflected on how disclosing depends on the work situation.

The next question was about the emotional pain of hiding their autism diagnosis within the workplace. Participants One, Two and Three agreed it was painful to hide their autism once the job was acquired. Participants Four and Five said “no it wasn’t painful”. It was interesting because Participant Four was very supportive of disclosing (question one) during the interview so that proper accommodations could be provided on the job. Participant Five who replied that it wasn’t painful to hide, seemed much more consistent with his reasoning not to disclose. He said about his potential boss, “I think it doesn’t really matter (concerning the boss). I think they have other stuff they have to deal with.” This young adult expressed they would disclose when some kind of problem that relates to his autism impacts the job. He said, “Wait until something comes up and then disclose.”

Participant Two agreed it was painful to hide and was very clear about their thoughts:

The pain of hiding would not be good. It would be like fitting a square peg into a round hole. It can’t be expected that a neurodiverse person can do the same things as a neurotypical person in the same environment. Many jobs have a very social environment. The neurodiverse person needs that safety net of accommodations so that they have the ability to disengage from that social environment (Participant Two).

Participant Three also agreed it would be painful to hide and shared the following, “If you don’t disclose it can be really frustrating and if something happens then people get frustrated or annoyed with you. That can be painful - frustrating” (Participant Three).

The next question concerned fear surrounding disclosing either in the cover letter, interview or on the job. All the participants agreed it would be frightening to disclose, except for Participant Four. Participant Three explained, “It’s scary - it’s not easy”. Participant Two said, “They could read the resume or cover letter and reject you. It does happen even though there are laws that are supposed to prevent businesses from doing this. At companies the individual is expendable.” Participant Five who felt it was important to wait until, “Something comes up and then disclose” was also fearful of disclosing. When I asked them to talk a bit more about those fears, they declined.

Participant Four didn’t feel it was frightening to disclose, the reasons they expressed were, “I want to be my best self” and they were, “willing to advocate for myself.” Participant Four finished the thought by saying, “I don’t want to worry I won’t get the job because I’m neurodiverse.”

The final question centered around the emotional outcome of disclosing an autism diagnosis. Did the young adult find relief from disclosing and getting the appropriate accommodations? All five young adults agreed that they found relief and were able to perform better in their job. Participant Four said, “It’s a relief that everyone knows you’re neurodiverse and people learn how to work with

you.” Participant Two who commented on the laws that protect people with disabilities said, “Getting accommodations creates that safety net in the work environment.”

All of these young adults expressed how they wanted to be a part of the workforce. “Most autistic persons are eager to work, and have similar aspirations as their neurotypical peers, such as career goals, hopes for financial security, and independence” (Tomas, 2022, p. 4773, cited in Anderson 2021). Many of the participants in this study had plans to live independently and understood they needed employment to accomplish that goal.

DISCUSSION

To disclose or not disclose is not an easy decision. There is much an autistic person needs to consider. If applying for a job through traditional employment channels, based on the research and advice from the college counselors and career advisors, it is best the young autistic adult not disclose during the cover letter or interview steps in the process. Chances are higher that the person will not be hired for the job which is reflected in the high unemployment rate among people with cognitive disabilities. The research also supports this conclusion.

Lindsay et al. (2019) conducted a study in which they sent out two identical job applications to multiple companies, the only difference between the two being that one discloses that the applicant has ASD. They found that the applicant with ASD received 26% fewer expressions of employer interest (cited in Cooper, 2022, p. 20)

When the autistic person does obtain employment, it is recommended that the person discloses to a trusted supervisor, co-worker or a knowledgeable person about autism in human resources. If that suggestion is not a possibility it is a good idea to get advice from someone outside the organization. “For example, getting help from employment counselors or job coaches to identify who is a trustworthy workplace ally should be beneficial to the disclosure decision-making process” (Johnson *et al.*, 2016, p. 445).

When applying for a job through an inclusion program which welcomes people with disabilities then the job seeker can feel more comfortable disclosing. However, the person or their job coach needs to do their research and determine if the company/organization has a program designed specifically for autistic people. If the program is more general for all people with disabilities the autistic person needs to communicate their specific accommodations to the potential employer. The risk always exists that they may not get hired if they communicate their needs even in a company with an inclusive environment for people with disabilities.

Considering the importance of perceived necessity in participants’ disclosure decisions, autistic people with higher support needs may need to disclose more frequently in a range of situations (Huang, 2022, p. 5306).

It was also interesting to learn that most of the young adults interviewed for this research project had the savvy and social skills to assess current and potential workplaces and understand the stigma attached to autism. They knew the timing of the disclosure, who to disclose to and method of delivering their disclosure was hugely impactful. With a diagnosis that includes impairment in

social interactions it was interesting to discover that these young adults understood the obstacles they were facing when entering the workforce.

The limitations of this study include the need for a larger sample size. Also, the participants were all Caucasian, a more diverse representation of autistic people would be important going forward. And, more women need to be included in the study. Now that the participants have finished school, analysis could be conducted concerning their success in the workforce. In addition, the focus of this study was on autistic young adults with verbal and written communication skills who were successful in obtaining a High School diploma and some college.

CONCLUSION

While doing this study it was refreshing to hear the young adults interviewed talk about their autism openly and identify their needs plus accommodation requirements in the workforce. However, because of stigma and the high unemployment rate it will be difficult for these young adults to find a welcoming workforce.

Can the workforce change? Recommendations include:

A strong diversity climate, or a climate characterized by “openness towards and appreciation of individual differences” (Hofhuis *et al.*, 2016, p. 1) could encourage workers to display their neurodivergent traits rather than mask them. Similarly, organizational initiatives aimed at increasing awareness, knowledge, acceptance, and inclusion, as well as decreasing stigma more generally, may reduce the necessity of masking behavior in the workplace (Kidwell *et al.*, 2023, p. 58).

Providing training to neurotypical co-workers about autism may help to increase understanding and decrease stigma (Romualdez *et al.*, 2021, p. 7).

In closing, there is no denying the employment data and the workforce atmosphere is discouraging. It is not easy for an autistic person to obtain and retain employment. “The problem with identifying effective accommodations for employees with ASD stems from the reality that their primary difficulties often center on social interaction and communication in the workplace” (Hensel, 2017, p. 95). It is important for the workforce to acknowledge that supervisors and coworkers should be trained in the communication style of autistic people and address their needs in the office. More research needs to be done on the workforce’s willingness to provide accommodations plus the types of accommodations that are currently being offered. Hopefully, in the near future, autistic people can join a compassionate and accepting workforce. These intelligent young adults have a lot to contribute and they deserve the opportunity.

REFERENCES

- Autism Speaks. (n. a.). *Autism diagnostic criteria: DSM-5*.
<https://www.autismspeaks.org/autism-diagnostic-criteria-dsm-5>
- Cooper, A. A., & Mujtaba, B. G. (2022). Assessment of workplace discrimination against individuals with autism spectrum disorder (ASD). *Socioeconomic Challenges*, 6(2), 19-28.
- Healy, A. (2023, March 14). *Building a neurodiversity-friendly workplace culture* [Webinar]. Neurodiversity Celebration Week.
- Hensel, W. F. (2017). People with autism spectrum disorder in the workplace: An expanding legal frontier: Harvard Civil Rights-Civil Liberties Law Review. *Harvard Civil Rights-Civil Liberties Law Review*, 52(1), 73-102.
- Johnson, T. D., & Joshi, A. (2016). Dark clouds or silver linings? A stigma threat perspective on the implications of an autism diagnosis for workplace well-being. *Journal of Applied Psychology*, 101(3), 430-449.
- Kidwell, K. E., Clancy, R. L., & Fisher, G. G. (2023). The devil you know versus the devil you don't: Disclosure versus masking in the workplace. *Industrial and Organizational Psychology*, 16(1), 55-60. <https://doi.org/10.1017/iop.2022.101>
- Reilly, J. (2023, February 7). *Neurodiversity and Employment: How do we get it right?* [Webinar]. Landmark College.
- Romualdez, A. M., Heasman, B., Walker, Z., Davies, J., & Remington, A. (2021). "People might understand me better": Diagnostic disclosure experiences of autistic individuals in the workplace. *Autism in Adulthood*, 3(2), 157-167. <https://doi.org/10.1089/aut.2020.0063>
- Romualdez, A. M., Walker, Z., & Remington, A. (2021). Autistic adults' experiences of diagnostic disclosure in the workplace: Decision-making and factors associated with outcomes. *Autism & Developmental Language Impairments*, 6, 1-12.
- Roux, A. M., Shattuck, P. T., Rast, J. E., Rava, J. A., & Anderson, K. A. (2015). *National Autism Indicators Report: Transition into Young Adulthood*. A.J. Drexel Autism Institute, Drexel University. <https://drexel.edu/~media/Files/autismoutcomes/publications/LCO%20Fact%20Sheet%20Employment.ashx>
- Tomas, V., Kingsnorth, S., Kirsh, B., Anagnostou, E., & Lindsay, S. (2023). Using the COM-B model and theoretical domains framework to understand workplace disclosure experiences, influencers, and needs among autistic young adults. *Journal of Autism and Developmental Disorders*, 53(12), 4772-4786.
- Winston, J., Butterworth, J., Migliore, A., Domin, D., Zalewska, A., Shepard, J., Kamau, E., & Wedeking, R. (2023). *StateData: The national report on employment services and outcomes through 2021*. Jeffrey Edelstein Institute for Community Inclusion (UCEDD), University of Massachusetts, Boston. www.ThinkWork.org/bluebook