Workplace and Job Search Disclosure Strategies for Adults with Autism Spectrum Disorder: An Analysis of Applicant and Employee Experiences

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Abstract

Adults with Autism Spectrum Disorder (ASD) face increased barriers in obtaining and maintaining employment when compared to other groups, including those with and without disabilities (Roux et al. 2015). Research has pointed to disclosure as an area of interest toward addressing those barriers, but notes that there may be pluses (i.e., workplace accommodations) and minuses (i.e., stigma, discrimination) to disclosure of one's ASD diagnosis (Solomon, 2020; Johnson and Joshi, 2014). This survey-based study analyzed the responses of 31 adults with ASD, their employment status and history, and their strategies toward disclosure, including whether they disclose in the job search process and/or during employment and to whom they decide to disclose. In addition, this study also considers differences in employment and disclosure experiences for individuals with ASD who have intersectional marginalized identities within the LGBTQ+ community.

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Background/Introduction

Disclosure amongst individuals with Autism Spectrum Disorder (ASD) of one's ASD diagnosis in the workplace and other domains has been identified by researchers as an area for further study (Sasson & Morrison, 2019; Johnson & Joshi, 2014; Davidson & Henderson, 2010), and advocates call for the voices of autistic individuals to be a driving force in such research (Autistic Self Advocacy Network, 2012). One in 59 children in the U.S. receive a diagnosis of ASD, a number that has steadily increased since an estimate of 1 in 150 children in 2000 (Maenner et al., 2020). This means that each year increasing numbers of autistic individuals are participants in or are looking to be participants in the workforce. As research has shown that increased barriers exist for adults with ASD to gain and maintain employment (Harmuth et al., 2018; Ohl et al., 2017; Roux et al., 2015; Chen et al., 2015), learning more about the experiences of adults with ASD with disclosure in the workplace and in the job search process may offer insight into addressing these barriers.

Individuals with ASD have increased difficulty finding employment when compared to individuals with and without disabilities. For individuals with all types of disabilities in the U.S., as of April 2021, the estimated rate of unemployment for individuals with disabilities was 10.4%, almost double the rate of unemployment for individuals without disabilities (5.7%; U.S. Department of Labor, 2021). Research has shown that amongst individuals with disabilities, autistic individuals fair worse in employment obtainment than those within other disability categorizations. Roux et al. (2013) found the just over half of young adults with ASD (53.4%) post-high school had worked outside the home for pay. In a 2015 study by Roux et al., the estimation of young adults with ASD who had worked outside the home had moved upward to 58%, which although increased, the researchers found was the lowest percentage amongst other groups of individuals with disabilities. Roux et al. (2015) found that, in their early twenties, individuals with learning disabilities worked outside the home at a rate of 95%, and those with speech and language impairments and those with emotional disturbances both worked at a rate of 91%. Individuals with intellectual disabilities worked at a rate of 74%. At 58%, adults with ASD were employed at a significantly lower rate (Roux et al., 2015).

Researchers speculate that part of the cause of this comparatively low employment rate for adults with ASD may be due to the social impacts of the disorder in finding and maintaining employment (Ohl et al., 2017; Scott et al., 2019; Solomon, 2020; and others). The clinical diagnosis of Autism Spectrum Disorder contains two main criteria, which must cause clinically significant impairment, and include: 1) "Persistent deficits in social communication and social interaction across multiple contexts", and 2) "Restricted and repetitive patterns of behavior, interests, or activities" (APA, 2013). It is this "persistent deficit in social communication and social interaction" that, as Solomon (2020) and Johnson and Joshi (2014) suggest, may cause discrimination, stereotyping and stigma from neurotypical individuals toward those with ASD, and cause individuals with ASD difficulty in understanding how to navigate interactions with neurotypical individuals. This can cause issues in the interview process, which has been found to be a major hurdle in job procurement for individuals with ASD (Nicholas et al., 2018; Smith et al., 2014), as well as in the social aspects of work, i.e., engaging with coworkers and supervisors. Johnson and Joshi (2014) suggested that more research on the social demands of disclosure and how to navigate them for individuals with ASD may help reduce employment barriers.

In terms of disclosing ASD diagnoses to neurotypical individuals, research has indicated that neurotypical individuals rate higher first impressions of certain individuals with ASD when their diagnosis is known as compared to when the diagnosis for that individual is not known. Sasson and Morrison (2019) conducted a study in which neurotypical observers (n = 215) watched mock recorded auditions for an unscripted television show with "auditioners" who were neurotypical individuals (n = 20) and autistic individuals (n = 20). Observers then rated auditioners on various subjective metrics related to the first impression they made on the subjects. When the auditioners were not given a diagnosis label, the participants rated individuals with ASD on average with lower first impression scores than neurotypical auditioners. When auditioners were labeled during their mock audition viewings as having or not having ASD, the average first impression score for auditioners with ASD significantly increased. Notably, when neurotypical auditioners were mislabeled to raters as having ASD, their scores also improved.

The takeaway from these results could be suggestive that disclosure could be positive for individuals with ASD when interacting with neurotypical individuals, although the study is isolated to "first impressions" and does not address real-world applications that go beyond split-second decisions. Notably as well, as raters marked improved scores for those who did not have ASD but were marked as such, it seems in some ways the reaction is divorced from what the auditioner did or who they were, but instead, how the rater *perceived their label*. Other studies, such as Sasson et al., 2017, Brosnan and Mills, 2016, and Butler and Gillis, 2011, have found similar results in college samples. This present study seeks to learn more about the real-world experiences of adults with ASD around disclosure in regard to employment, including strategies and consequences (positive, negative, or neutral) of the personal decisions made around disclosure of one's ASD status in the workplace and job search process.

An additional area of focus of this study is around employment disclosure for individuals with the intersectional marginalized identities of being a part of both the ASD and LGBTQQIA+ communities (with LGBTQQIA+ denoting Lesbian, Gay, Bisexual, Transgender, Queer, Questioning, Intersex, Asexual, and with the plus sign indicating the inclusion of additional nonheterosexual and non-cisgender identities). Individuals with ASD are estimated to be around three times more likely to identify as members of the LGBTQQIA+ community (Hillier et al, 2020; George & Stokes, 2018; Øien, Cicchetti, & Nordahl-Hansen, 2018; Dewinter, de Graaf, & Begeer, 2017; Bennett & Goodall, 2016; Jacobs et al., 2014). The LGBTQQIA+ community is also a group that has been shown to be the subject of stigma and discrimination in the workplace and for whom disclosure, i.e., "coming out", is also a point of individual decision-making. For example, in terms of employment ramifications, prior to the U.S. Supreme Court decision in June of 2020, an individual who is LGBTQQIA+ could have their employment terminated on the basis of their LGBTQQIA+ identity (Liptak, 2020). A Supreme Court ruling one month later upheld a "ministerial exemption" that allows employers to fire LGBTOOIA+ employees based on their identity if the employment is affiliated with a religious institution (Liptak, 2020b). For these reasons, and that there is a gap in the literature involving employment for individuals with this intersection of identities, the present study also includes inquiry into the nature of employment status and disclosure for individuals who identify as both autistic and LGBTQQIA+.

Methods

Design

Participants were asked to complete an online survey, which included 28 questions and opportunities for both qualitative and quantitative responses. The first third of the survey was demographic in nature, including questions related to age, diagnoses, race/ethnicity, Social Security benefits usage and/or eligibility (including those who denoted they were eligible but were not receiving benefits), gender, sexuality, and other related questions. The second section of the survey was related to employment status and history. The final third of the survey was related to disclosure choices and strategies, and related questions. Inclusion criteria included that participants be 18 years of age or older, and had a diagnosis of Autism Spectrum Disorder or a related diagnosis given prior to the DSM-5 classification (i.e., Asperger's Disorder). As the study focuses on disclosure, individuals who did not complete the final third of the survey which included questions regarding disclosure were not included in the final analyses. Participants were recruited via email to organizations and individuals who have a focus in working with persons with ASD, including non-profits, Vocational Rehabilitation organizations, advocates and other professionals, across the U.S. All research activities were approved and overseen by the Institutional Review Board at The George Washington University.

Participants

Fifty-eight total individuals interacted with the online survey. Twenty-six individuals did not complete the survey and were excluded. Thirty-three participants completed the survey, and of those 33, 2 participants reported no Autism Spectrum Disorder diagnosis and were excluded. Thirty-one individuals reported an Autism Spectrum Disorder diagnosis and were included in the below analyses (n = 31). Of the 31 participants, 12 reported to be female, 17 male, 1 agender, and 1 gender-fluid. Twenty-four participants reported to be White; 1 Black or African American; 1 Hispanic, Latinx, or of Spanish Origin; 1 American Indian of Alaskan Native; and 3 reported to be of more than one race (1 Black or African American and American Indian or Alaska Native; 1 White and American Indian or Alaska Native; and 1 White, Black or African American, and American Indian or Alaska Native). One participant preferred not to answer. Regarding ethnicity, 28 participants reported to be Not Hispanic or Latinx, 1 Hispanic or Latinx, and 2 provided no response. Participant ages ranged from 18 to 55 years of age, with an average age of 33.6 years with a standard deviation of 11.4 years. The average age of participants when they received their ASD diagnosis was 19 years old, with a standard deviation of 16.3 years.

Of the 31 participants, 20 participants identified as heterosexual, 4 as asexual, 1 as bisexual, 2 as questioning, and 4 listed their sexual orientation as "Other". "Other" included the written responses of: "heteroflexible", "demisexual", "not really interested", and no response given. Toward investigating the experiences of those with ASD who also have a marginalized sexual orientations, individuals who identified as having a sexual orientation other than "heterosexual" were grouped in analyses and in discussion below as LGBQQA+ (denoting Lesbian, Gay, Bisexual, Queer, Questioning, Asexual and with the "+" indicating inclusivity of additional non-heterosexual identifies) with 35% of participants identifying within this group. Unfortunately, due to the low number of recruited participants who identified as a minority

gender identity, quantitative analyses were not possible in this study for individuals with gender identities within the LGBTQQIA+ community.

In regard to receipt and/or eligibility of Social Security benefits, 9 participants indicated "Yes" they were currently receiving Social Security benefits, 17 indicated "No" they were not receiving benefits, and 2 participants indicated "I do not know" in regard to eligibility for and/or receipt of benefits. Two participants indicated the choice: "I was eligible as an adult, and am now receiving SSDI due to past work and trying to work above the Substantial Gainful Activity (SGA) threshold." One participant indicated the choice: "I am eligible, but job seeking to avoid applying for or using SSA benefits." Including detailed responses, 35% of participants were receiving Social Security benefits (11 total), and 58% were not receiving benefits (18 total). The 2 who provided no response made up the final 7% of participants.

Data Analysis

Data was analyzed in two ways for quantitative and qualitative responses respectively. Quantitative analyses included analyzing demographic statistics, frequencies, and odds ratios (Norton et al., 2018) for groups and questions of interest, including related to employment status, the likelihood of participants' eligibility for and/or use of Social Security benefits, and frequency of reports of disclosure of ASD status in the workplace, in employment interviews, and in job search documents. Odds ratios were used to analyze group differences between participants who identified as heterosexual and those who identified as having a minority sexual orientation. Qualitative responses of participants related to disclosure strategies and experiences were coded for themes and analyzed for similarities, differences, and other pertinent information as reported below.

Results

Thirty-one participants were included in the final analyses (n = 31). Nineteen participants were currently employed (61%), and 12 were not currently employed (39%). Of those who were not currently employed, 8 indicated they were currently looking for employment. Of those who were currently employed, 7 indicated they were searching for other employment. The odds of being employed were higher for those who identified as LGBQQA+ compared with those who identified as heterosexual (OR = 1.16; 95% CI = 0.25, 5.3).

Nine participants endorsed "Yes" regarding the current use of Social Security benefits. Seventeen participants endorsed "No" to current use of Social Security benefits. Two participants endorsed "I do not know." Additional responses included two participants endorsing "I was eligible as an adult, and am now receiving SSDI due to past work and trying to work above the Substantial Gainful Activity (SGA) threshold;" and one participant endorsing "I am eligible, but job seeking to avoid applying for or using SSA benefits." LGBQQA+ participants were 2.4 times more likely to be utilizing and/or eligible for Social Security benefits than heterosexual participants (OR = 2.4; 95% CI = 0.51, 11.19).

Participants responded to questions related to their decisions to disclose or not disclose while employed, during the job search process via job search documents (i.e., resumes, cover letters) and/or during the interview process. The three tables below capture the collected responses to if and when participants choose to disclose their identity as a person with Autism Spectrum Disorder. Participants who answered "Sometimes" to any of the three questions were

given an opportunity to expand on their choice with a write-in answer. These write-in answers were also analyzed for common themes in responses.

T	able 1		%			
	Do you disclose your status as a person with Autism Spectrum Disorder at your current place of employment and/or at past jobs? (n = 31)					
Γ	12	Yes, always.	39			
Γ	15	Yes, sometimes.	48			
Γ	2	No.	6			
	1	I have never had a job.	3			
	1	No response.	3			

As shown in Table 1, participants were much more likely to disclose in their place of employment at some point in their career than to have never disclosed. Most participants (48%) stated that they disclosed "sometimes" as opposed to "always" (39%). Four participants who endorsed that they sometimes disclose reported qualitative answers that included either fear of negative outcomes or having experienced discrimination as motivation for their response. The next most frequent write-in response for sometimes disclosing was related to trust or telling only select individuals in the workplace, with four participants including that theme in their response. Three participants cited accommodations when needed as reasons for disclosure. Two reported advocacy as part of the reason for their response.

Of the 27 participants who indicated they do choose to disclose in the workplace either sometimes or always, the most common person to whom they disclosed was their supervisor with 22 participants (84%) indicating this choice. The next most common was to co-workers, with 19 participants (70%) indicating this response. Just below half of the respondents (13; 48%) indicated they disclosed to Human Resources. 4 participants (15%) chose "Other", and indicated write-in options that included "participants", "trainees", and "graduate school admin" (the fourth participant noted "not sure").

The odds of individuals with ASD who are LGBQQIA+ always disclosing their ASD status in their place of employment versus sometimes disclosing their ASD status in their workplace was 2 times greater than for heterosexual participants (OR = 2; 95% CI = 0.42, 9.42). No LGBQQIA+ participants stated that they never disclose versus 2 heterosexual participants who stated that they never disclose.

]	Table 2		%
	Do you disclose your status as a person with Autism Spectrum Disorder in your job search documents (i.e., resume, cover letters)? (n = 31)		
	4	Yes.	13
	7	Sometimes	23
	17	No.	55
	2	I do not have job search documents.	6
	1	No response.	3

As shown in Table 2, most participants did not disclose their status as a person with ASD within their job search documents, which include resumes and cover letters (55%). The next most frequent responses in order of their frequency were: "Sometimes" at 23%; "Yes" at 13%; and "I do not have job search documents" at 6%. Participants who answered that they sometimes disclose their status, most often stated that they disclose that they have a disability or are a disability advocate, but not their ASD status.

The odds of individuals with ASD who are LGBQQIA+ disclosing their ASD status in their job search documents was over 5 times higher compared to heterosexual participants (OR = 5.2; 95% CI = 0.92, 29.26). Participants who are LGBQQIA+ were also more likely to always disclose their ASD status in job search documents versus sometimes disclose it (LGBQQA+ participant responses = 3 yes, 3 sometimes, and 3 no, vs. heterosexual participant responses = 1 yes, 4 sometimes, 13 no).

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Have you disclosed your status as a person with Autism Spectrum Disorder during an interview(s)? (n = 31)				
15	Yes.	48		
3	Sometimes.	10		
11	No.	35		
1	I have not been on an interview.	3		
1	No response.	3		

As shown in Table 3, participants were most likely to disclose their status as a person with ASD in interviews (48%) than any other selection provided, increasing to 58% with the inclusion of those who "sometimes" disclose in interviews. The next most frequent response at 35% was "no," participants who do not disclose their status in interviews. Those who sometimes disclose (10% of respondents) cited reasons in their write-in responses that included experience with discrimination, speaking about the topic in an interview as a strength, and disclosing only if it "comes up" during the interview.

The odds of individuals with ASD who are LGBQQIA+ disclosing their ASD status during interviews (yes = 6 participants; sometimes = 1 participant) versus not disclosing (4 participants) was slightly greater than for heterosexual participants (9 yes, 2 sometimes, 7 no) (OR = 1.1; 95% CI = 0.23, 5.25).

Of the full study population, 24 participants responded "yes" to the question "Do you have any strategies regarding disclosure of your diagnosis with Autism Spectrum Disorder in regard to employment?" (77%). Seven responded "no" they did not have disclosure strategies. Participants who answered "no" were asked if they would be interested in learning disclosure strategies in regard to employment. Three participants responded "yes" to this question, 2 responded "no", and 2 responded "I don't know."

Participants who identified that they had strategies for disclosure in the workplace were asked to describe their strategies if the participant wanted to do so. Responses were coded and analyzed for themes. These themes were related to time-based strategies, negative experiences related to disclosure, and positive experiences related to disclosure. Each theme is explored below.

Thirteen participants' statements included one or more time periods during which the participant stated engaging in disclosure in the job search process or once hired. These participants noted either disclosure of their status as having ASD or disclosure of having a disability without specifying an ASD diagnosis. These time periods included: during the job application process if/when the applicant is asked if they have a disability or accommodation needs (2) or by disclosure in their job search documents, including in the form of listed advocacy and other ASD-affiliated work, or phone communications (2); during the interview process (2); after a job offer has been made (1); soon after acquiring the job (3); and four reported to disclose during the course of employment, including: "as needed", "if it comes up", "openly...so there are no misunderstandings" and one participant who responded they "go as long as possible" at their place of employment without disclosing. The means of disclosure for these participants included through face-to-face communication, phone calls, online job application portals, and written letter given to the hiring team.

This language noted above related to attempting to not disclose "as long as possible" in an employment setting seems to suggest either a personal history of negative consequence following disclosure, fear of future or possible negative consequence from disclosure, or not receiving accommodation despite disclosure. This was a theme that arose explicitly in five participants' responses, including comments on not receiving interviews or call backs after interviews (2), not receiving accommodations or support following workplace disclosure (2), and an experience described using the single word "nightmare" following disclosure to colleagues (1).

Six participants listed one or more positive results from their experiences with disclosure, including success in job obtainment (3), and receipt of accommodations that had positive impacts on their work, work environment and, in one participant's statement, was attributed to the receipt of a promotion (4). Disclosure that was attributed to avoidance of negative consequences was also included in this theme, including disclosure as a means to avoid "misunderstanding" or "burning out" (2). Accommodations that participants discussed included informing employers of the need for feedback, minimization of sudden changes, accommodations related to auditory processing including as relates to loud environments, breaking instructions on large tasks into specific steps, and requesting breaks for purposes including stimming and to step away from large social gatherings. One participant discussed disclosing their diagnosis in a strengths-based

approach, noting in their response: "I usually just tell people that I'm autistic and I let them know that it makes me very organized at work and very good at paperwork. It also helps me to think outside of the box in some jobs because I see patterns that others don't see."

Participants who had strategies around disclosure were also asked in what ways and/or from whom or what they learned these strategies. The most frequent response was that strategies had been learned from personal experiences and observations (5 responses). Other responses included learning strategies from professionals, such as vocational rehabilitation specialists (2), non-profits (2), therapists (2), a job coach (1), and in school settings (2). Participants had also learned strategies from self-advocates (2) and family members (2). Other ways of learning disclosure strategies had come from books (2), media including podcasts and articles (1), and presentations (1).

Discussion

This research represents a small start to capturing some experiences of individuals with ASD with disclosure in the workplace and in the job search process. Overall, findings suggest that individuals more often choose to disclose in their workplace than not to disclose, and that they are most likely to disclose to their supervisor than any other individuals in the workplace. While some participants felt comfortable being open about their identity as a person with ASD in their workplace, some expressed having experienced stigma and discrimination as a result of disclosure.

Stigma and discrimination are byproducts of how others view individuals or groups of individuals, and are not rooted in the individuals themselves. While research points to individuals with ASD facing issues in the workplace due to *their* communication-styles (Johnson and Joshi, 2014), it is important to note that communication is by its very nature an endeavor between individuals, and that discrimination and stigma do not come from a communication style, but from the outlook of the other person, who in this case, is likely to be neurotypical and used to neurotypical expectations of communication. Some participants in this study spoke to advocacy as reasons for their disclosure and attempts to educate and/or normalize features of how they experience ASD in their workplace. These participants reported varying results, including positive experiences (i.e., better work environments and job procurement/promotion) and negative experiences (i.e., conflict with coworkers). In future research, it is recommended that further opportunities for exploration of these experiences and their impacts on the individuals who experience them are built into research regarding employment and individuals with ASD, as well as an increased centering of voices of individuals with ASD in the literature.

In regard to employment frequency, the findings of this study were similar to research in terms of percentage of adults with ASD who were currently employed, with 61% of participants reporting employment at the time of study. In addition, research estimates of a higher likelihood of individuals with ASD also being part of the LGBTQQIA+ community when compared to the general population were evidenced in this sample as well, with 35% of participants identifying as members of both the ASD and LGBTQQIA+ communities. In terms of the exploration of potential impacts of multiple marginalized identities on employment status, in this sample there was found to be no negative effect on current employment status as individuals who were LGBQQA+ were more likely to be employed than heterosexual participants. Notably this study is limited in further extrapolation of data to this effect as questions regarding disclosure and its impacts were only related to ASD and did not include questions related to LGBTQQIA+ identity

disclosure in the workplace or job search process. This is a recommended area for future research. However, this research did identify that there is a higher likelihood for autistic individuals with marginalized sexual orientations to be eligible for and/or utilizing Social Security benefits, which may speak to an increased need for knowledge about and implementation of services for this population. Recommendations include training on the needs of the LGBTQ+ and other marginalized populations, and the increased use of LGBTQ+- inclusive forms and materials, such as demographic forms that include pronouns and extended options for gender identity and sexual orientation reporting.

Further limitations of this study include a small sample size of 31 participants, with 11 identifying as LGBQQA+. A larger sample size of both groups of participants would increase the confidence of the odds ratios, and offer opportunity for more individuals to share their experiences with employment and disclosure. A further limitation was the lack of racial and ethnic diversity of participants in numbers high enough to be included in additional analyses. With 77% of participants identifying as White as their sole racial background, analysis of further intersectional marginal identities of participants related to race and ethnicity was not possible in the present research. This is an additional area recommended for future research. Finally, as previously noted, there was a lack of gender diversity of participants in the present sample, which made analyses of the experiences of transgender, genderqueer, non-binary and other individuals not possible in this study, and is also a recommended area for future research.

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