“People Might Understand Me Better”: Diagnostic Disclosure Experiences of Autistic Individuals in the Workplace

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Abstract

Background: Autistic individuals face challenges in the workplace, particularly related to social communication. Diagnostic disclosure may mitigate these challenges, but it also exposes individuals to potential discrimination. This study aimed to share the diagnostic disclosure experiences of autistic adults in the workplace to help employers better understand the process, and help other autistic individuals make an informed decision about disclosure.

Methods: The participants in this study were 238 clinically diagnosed, U.K.-based autistic adults with employment experience. Participants completed an online survey, comprising both open-ended and closed-ended questions, that asked about their experiences of disclosure in the workplace. Specifically, questions focused on when in the employment process participants disclosed, to whom the disclosure was made, what factors were involved in the decision to disclose, and what the impacts were of this decision.

Results: Our findings suggest that when deciding to disclose, the participants were most concerned about how this might affect the attitudes of others in the workplace. Participants most often only disclosed selectively, while over a third disclosed to everyone. Many participants chose to disclose when completing the application materials or after starting the job, but rarely in the interview process. Many also disclosed after encountering issues at work (i.e., retrospective disclosure). Just over a third of participants rated the impact of disclosing to supervisors and coworkers positively. Subsequent adjustments made were even less positively endorsed.

Conclusions: Autistic individuals must weigh the potential benefits of disclosure against the costs. This study highlights the need for organizations, rather than autistic individuals, to take more responsibility for facilitating disclosure and improving outcomes to it. Specific recommendations include the creation of clear pathways for disclosure in workplaces, and an ongoing commitment to organization-wide autism training to reduce stigma and discrimination for autistic employees.

Keywords: autism, employment, disability, discrimination, diagnostic disclosure

Lay Summary

Why was this study done?

Autistic individuals face challenges in the workplace. Telling someone that you have an autism diagnosis (disclosure) might be one way of addressing these challenges (e.g., by increasing the understanding of others). However, the literature on disclosure shows mixed outcomes and rarely gives voice to autistic people.
What was the purpose of this study?
The purpose of this study was to explore the disclosure experiences of autistic job seekers and employees and gain insight into their decision-making.

What did the researchers do?
We conducted an online survey with 238 clinically diagnosed autistic adults with employment experience. Our participants answered some questions about their personal information (e.g., age) and their past work experience before completing survey questions about disclosure. We read through everyone’s answers to open-ended questions and put the answers into groups, such as “Reasons to disclose” and “Reasons not to disclose.”

What were the results of the study?
When deciding whether or not to disclose, our participants were most concerned about what other people they worked with would think. Most of our participants only told some people at work about their diagnosis, and many only disclosed after issues arose in the workplace. Over a third, however, disclosed to everyone. Participants said they were most likely to disclose on the application materials or after starting a job, not during a job interview. Just over one-third said that telling their supervisors or coworkers they were autistic had a positive impact, and that the changes made by their supervisors afterward were positive. Over a third said the changes made by their coworkers were neither positive nor negative.

What do these findings add to what was already known?
This is the first large-scale U.K.-based study on the disclosure experiences of autistic adults in the workplace. Our findings suggest that autistic people focus most on what other people will think and how others will treat them if they disclose. We found that disclosure during interviews is unlikely—contrary to what previous studies focused on—and that we need to conduct research looking at disclosure in more likely scenarios.

What are potential weaknesses in the study?
Most of our participants were white and female, but in the wider autistic population that isn’t the case. We had many more participants who had told people at work about their autism diagnosis than those who had not. We also could not ask any follow-up questions about our participants’ experiences because the survey was online.

How will these findings help autistic adults now or in the future?
Knowing more about the experiences of autistic people can help individuals to make an informed choice about disclosing their diagnosis. This study highlights that we need to involve nonautistic employers, colleagues, and organization leaders in the disclosure process to improve autism knowledge and acceptance, and hopefully improve outcomes for autistic people.

Introduction

Employment is a desirable achievement for some autistic adults, yet autistic individuals have the lowest employment rate of any disability group in the United Kingdom. Although current figures may be an underestimation (due to those who do not disclose or who are not diagnosed), the National Autistic Society estimates that only 32% of autistic adults are in any sort of paid work. When compared with 47% for other disability groups and 80% employment for the nondisabled population, these numbers reflect a crisis of unemployment for autistic adults that must be addressed. The impact of unemployment can be severe; research shows that employment not only improves quality of life for autistic adults but also encourages personal dignity, reduces social isolation, and increases cognitive performance.

Although every autistic person is unique, many will face obstacles throughout their employment journey, from the recruitment stage until well into their employment. For example, sensory sensitivities (e.g., sensitivity to certain types of lighting and noise) can make the workplace environment challenging. Social communication is another area in which autistic employees experience difficulties at work. Negatively perceived social communication behaviors, such as interrupting or abruptly terminating a conversation, have been linked to low job retention and workplace difficulties, particularly in interacting with colleagues. Social communication differences also appear to impact the process of seeking employment, with autistic adults frequently reporting difficulties with social interaction during job interviews.

Research outside of employment-based settings shows that one way to mitigate social communication challenges is via diagnostic disclosure. First impressions of autistic adults, as rated by nonautistic participants, improved with disclosure.
and were even more favorable when the nonautistic raters had more autism knowledge. Teachers also more frequently chose positive behavioral supports (i.e., inclusion, choice, and participation) over punishment in a hypothetical situation when they were informed of the student’s autism diagnosis.

The issue of disclosure, however, is intrinsically linked with that of stigma. Sadly, there remain many negative stereotypes and preconceptions associated with an “invisible” disability. Autistic individuals may have experienced stigma surrounding their diagnosis in the past, especially while at school, leading them to choose not to disclose based on these negative experiences. Disclosure of an autism diagnosis may even result in both positive and negative stereotyping (i.e., making generalizations about autistic individuals that may either be positive or negative, but are still harmful because they may not be true) from the same individual, making outcomes more unpredictable for autistic people. Autistic adults who choose to disclose must therefore strike a careful balance between embracing awareness and increased understanding, and avoiding harmful stereotypes. Research from education settings confirms this conflict. A study involving 250 adolescents in a U.K. secondary school found that disclosure of an autism diagnosis had no significant effect on the stigmatizing attitudes of nonautistic peers toward socializing with an autistic peer. However, participants did tend to attribute less personal responsibility to the autistic peer for their negatively perceived behavior after the disclosure of a diagnosis.

In the workplace, the decision to disclose may be even more complex, as challenges such as social communication difficulties are compounded by the natural pressures of a work environment. Research has shown that fear of discrimination from employers and colleagues is a common reason why autistic individuals choose not to disclose their diagnosis at work. Indeed, this fear of discrimination, particularly against autistic job candidates, is not unfounded. In a hypothetical situation, participants were asked to make a hiring decision about autistic and nonautistic job candidates based on video excerpts of their job interviews, where candidates either disclosed an autism diagnosis briefly or in detail, or did not disclose any diagnosis. Across disclosure conditions, participants were over four times more likely to hire the nonautistic candidates after viewing the videos. Similarly, participants were not required to give any other evidence of a diagnosis. The present study used a bespoke questionnaire administered via Qualtrics that asked about their disclosure experiences in the workplace. The term “disclosure” was introduced to participants at the beginning of the survey, and defined as telling people at work about one’s autism diagnosis. The benefits of disclosure, however, may depend on how knowledgeable the potential employer is about autism, with employers who have more knowledge about autism more likely to want to hire autistic individuals.

At present, there is insufficient evidence to support autistic individuals in their decision-making about disclosure in the workplace. The current study aims to establish the perspectives of U.K.-based autistic job seekers and employees on the extent and experience of disclosure in workplaces—and its outcomes—with the goal of helping autistic individuals make an informed decision about disclosure.

Methods

Participants

Autistic adults (aged 18 years and older), based in the United Kingdom, took part in this study. All participants had previous or current employment experience, and reported that they had received a clinical diagnosis of autism; participants were not required to give any other evidence of a diagnosis. We chose to exclude self-diagnosed participants from this study. A formal diagnosis can be used as a means to seek legal entitlements, and we therefore predicted that those who were self-diagnosed would have different reasons for disclosing, and different outcomes when doing so. The group of self-diagnosed participants was not large enough to consider separately or make any statistically significant comparisons with the participants who were clinically diagnosed. We hope that in future research we are able to highlight the workplace experiences of those who self-identify as autistic.

We recruited participants online through the Centre for Research in Autism and Education’s social media accounts and via email through the Discover Network, an online research networking platform run by U.K.-based autism research charity Autistica. A third avenue for recruitment was through Autistica’s corporate partners; we reached out directly to employees working with these companies to recruit participants.

Measures

The present study used a bespoke questionnaire administered as part of a wider program of research about employment experiences: the Diverse Minds Survey. The Diverse Minds Survey is a U.K.-wide online survey created as part of the Discover Autism Research and Employment (DARE) project, funded by Autistica with the aims of widening the evidence base for research on autism and employment and improving employment for autistic individuals.

All participants in the Diverse Minds Survey completed a general section on demographic and employment data. Participants in the current study additionally completed questions administered via Qualtrics that asked about their disclosure experiences in the workplace. The term “disclosure” was introduced to participants at the beginning of the survey, and defined as telling people at work about one’s autism diagnosis. The questions in the survey were designed for participants to answer based on their most relevant disclosure experiences, regardless of whether they were experiences from past or current workplaces. We did not ask them
to specify this. Items included closed-ended questions such as: “Have you ever disclosed to others in the workplace?” and “at what point in your employment journey did you disclose to others in the workplace?” Four questions on the survey asked participants to rate (i.e., using a 5-point Likert scale: 1—extremely positive, 2—somewhat positive, 3—neither positive nor negative, 4—somewhat negative, and 5—extremely negative) the impact of disclosing to their supervisor, employer, or coworkers and the subsequent adjustments made for them. The last three questions in the survey were open-ended: (1) “What factors did you consider before disclosing your diagnosis?” (2) “What external supports, if any, did you have when deciding whether to disclose your diagnosis?” and (3) “What were the outcomes of disclosing your diagnosis?”

Procedure

Participants clicked on a link to the Diverse Minds Survey, which directed them to answer general questions on demographics and employment. They had the option of answering any of the seven sections of the survey, one of which was the disclosure questionnaire, that were relevant to them. The survey instructed participants who answered “no” to the question, “Have you ever disclosed to others in the workplace?” to skip the questions that did not apply to them and proceed to the open-ended questions. The disclosure questionnaire took ~20 minutes to complete.

Ethics approval for this study was granted by the UCL Institute of Education. All participants included in this study completed and signed digital consent forms before taking part.

Data analysis

Quantitative analysis. We used IBM SPSS Statistics 26 to run descriptive statistics on responses to the closed-ended questions in the survey.

Qualitative analysis. We conducted content analysis to categorize the data collected through the three open-ended questions in the survey. We then imported the text responses into NVivo. We conducted the analysis across questions through open coding (i.e., no preexisting coding framework) initially. A.M.R. then developed a framework for use in the second round of coding. Two independent researchers (A.M.R. and J.D.) coded the text responses into the following categories: reasons to disclose, reasons not to disclose, factors considered, external supports, positive outcomes, negative outcomes, and neutral outcomes. The researchers then met to discuss and refine the subcategories before coding the responses again. Finally, the researchers generated a frequency table for responses under each category and subcategory. All study authors approved the final set of categories and subcategories.

Results

Sample demographics

The main Diverse Minds Survey was open to both autistic and nonautistic individuals. Of the 482 autistic participants and 136 nonautistic participants who had completed the Diverse Minds demographic questions when the data were extracted in October 2019, 285 navigated to the section on diagnostic disclosure. We excluded nonautistic respondents who completed the disclosure section (n=5) and self-diagnosed participants (n=12). We chose to remove participants from the sample if they indicated that they were not comfortable talking about their disclosure experiences (n=9), that the section was in fact not relevant to them (n=5) (i.e., they did not have any experience of choosing whether to disclose in the workplace), or they did not respond to the question “Have you ever disclosed to others in the workplace?” (n=16). Full demographic information for the final sample of 238 participants is shown in Table 1.

Quantitative results

Full quantitative results are shown in Table 2. The majority of participants had chosen to disclose to some—but not all—people at work and almost half of these said that they only disclosed their diagnosis after starting the job. A third of participants, however, said they disclosed to everyone. Over a third of participants felt that the impact of disclosing to a supervisor or coworker was positive. A third of participants viewed postdisclosure adjustments made by supervisors positively, but almost as many held neutral or negative opinions. Only a small number of participants said that the subsequent adjustments made by their coworkers were somewhat or extremely positive (see Table 2 for full breakdown of responses).

Qualitative results

We classified data from the open-ended questions into categories and subcategories through content analysis (see Table 3 for a list of categories, and Supplementary Table S1 for further example quotations). The participants in our study reported a range of reasons to disclose. The most common among these was the desire for increased understanding and acceptance: “People might understand me better—be able to help me if I have difficulties. Protect me if I am in a difficult situation that others to whom I have not disclosed will not know is difficult for me.” Participants wrote about disclosure to seek legal protections: “I disclosed for the protection that the autism act gave me as a worker.” They also disclosed to improve mental health and well-being: “Managing my physical and mental health became more important to me than hiding.” Participants had additional reasons for disclosing, which were to gain reasonable adjustments, as well as to manage and sustain employment: “I need accommodations in order to keep a job for more than one to six months. Not disclosing isn’t an option for me. If I don’t disclose, I will either be forced to quit or be fired.”

A common thread when talking about these various reasons to disclose was that a negative experience in the workplace had led them to feel compelled to disclose. These retrospective disclosures appeared to be used to explain or mitigate past events. One participant stated, “I was finding things very difficult at work and after having a meltdown down in my manager’s office I felt that the best option was to disclose my diagnosis.” Another explained how disclosure became necessary after repeated bullying: “In the end it got to the point where I was being treated so badly by my team and it came down to if I have to tell them I’m autistic or things will get worse.”

Some sentiments were far more positive, however, with participants disclosing because being autistic was an advantage for the job. This applied to roles where the autistic perspective
Table 1. Participant Demographic Data (N=238)

| Variable                           | Category                                      | N   | %   |
|------------------------------------|-----------------------------------------------|-----|-----|
| Gender                             | Female (including trans women)                | 137 | 57.6|
|                                    | Male (including trans men)                    | 78  | 32.8|
|                                    | Nonbinary                                     | 17  | 7.1 |
|                                    | Other (e.g., no sense of gender)              | 6   | 2.5 |
| Age, years                         | 18–25                                         | 35  | 14.7|
|                                    | 26–35                                         | 60  | 25.2|
|                                    | 36–45                                         | 55  | 23.1|
|                                    | 46–55                                         | 57  | 23.9|
|                                    | 56–65                                         | 29  | 12.2|
|                                    | 66–75                                         | 2   | <1  |
| Ethnicity                          | White                                         | 226 | 95  |
|                                    | Black                                         | 3   | 1.2 |
|                                    | Hispanic                                      | 1   | <1  |
|                                    | Mixed                                         | 8   | 3.3 |
| Education                          | Bachelor's degree                             | 67  | 28.2|
|                                    | Master's degree                               | 60  | 25.2|
|                                    | Doctorate                                     | 18  | 7.6 |
|                                    | A/AS-level (qualification at 16–18 years)     | 24  | 10.1|
|                                    | GCSEs (qualification at 14–16 years)          | 11  | 4.6 |
|                                    | BTEC (business and technology qualification)  | 13  | 5.5 |
|                                    | Higher national diploma                       | 10  | 4.2 |
|                                    | Foundation degree                             | 6   | 2.5 |
|                                    | General national vocational qualification     | 2   | <1  |
|                                    | Postgraduate certificate                       | 11  | 4.6 |
|                                    | Postgraduate diploma                          | 7   | 2.9 |
|                                    | No formal qualifications                      | 4   | 1.7 |
|                                    | Other (e.g., diploma equivalent, fellowship of professional body) | 5   | 2.1 |
| Employment status                  | Employed full-time                            | 92  | 38.7|
|                                    | Employed part-time                            | 42  | 17.6|
|                                    | Self-employed                                 | 23  | 9.7 |
|                                    | Volunteer                                     | 8   | 3.4 |
|                                    | Student                                       | 15  | 6.3 |
|                                    | Formerly employed looking for work            | 14  | 5.9 |
|                                    | Formerly employed not looking for work        | 12  | 5   |
|                                    | Retired                                       | 4   | 1.7 |
|                                    | Other (e.g., apprenticeship, freelance)       | 28  | 11.8|
| Most common employment sectors     | Education                                     | 37  | 15.5|
|                                    | Health care                                   | 31  | 13  |
|                                    | Public sector                                 | 22  | 9.2 |
|                                    | Administration                                | 14  | 5.9 |
|                                    | Information technology                        | 13  | 5.5 |
|                                    | Nonprofit organization                        | 9   | 3.8 |
|                                    | Retail                                        | 8   | 3.4 |
|                                    | Creative                                      | 8   | 3.4 |
|                                    | Engineering                                   | 8   | 3.4 |
| Current or most recent level worked at | Intern or volunteer                          | 20  | 8.4 |
|                                    | Graduate employee                             | 32  | 13.4|
|                                    | Midlevel employee                             | 80  | 33.6|
|                                    | Senior-level position                         | 106 | 44.5|
| Size of current or most recent organization (total number of employees) | 0–5                                          | 17  | 7.1 |
|                                    | 6–20                                         | 21  | 8.8 |
|                                    | 21–50                                        | 18  | 7.6 |
|                                    | 51–100                                       | 20  | 8.4 |
|                                    | 101–500                                      | 27  | 11.3|
|                                    | 501–1000                                     | 21  | 8.8 |
|                                    | 1001–10,000                                  | 46  | 19.3|
|                                    | >10,000                                      | 43  | 18.1|
|                                    | Not applicable (e.g., self-employed, freelance) | 25  | 10.5|

(continued)
was thought to be an asset, such as in autism research or supported and inclusive education. One participant stated: “I primarily work in the autism field, so disclosing my autism is positive because it shows I have a better insight. [P-80]” In some cases, participants used disclosure during the application process as a means of gauging whether the role and workplace environment were the right fit: “I used disclosing as a way of working out whether a job was for me. If potential employers reacted negatively to me disclosing my autism, how would they react to me asking for help with something or having a meltdown? [P-229]” Some participants also felt a sense of responsibility to be open about their autistic identity. One participant stated that, “I feel that older autistic people owe it to younger ones to make employers aware of the fact that autistic people are employable. I told them in order to help combat stigma for other colleagues they might work with in the future. [P-29]”

Given the complexity of the decision to disclose, participants relied on different groups of people for external support in making their decision. These included family members, particularly parents: “My parents are very supportive and did not want me to take a job without disclosing, because they knew it would end badly if I couldn’t have accommodations. [P-23]” Others referred to support from their significant others, friends, professionals, colleagues, online communities, and support groups for autistic individuals: “The online autistic community was super helpful. [P-14]” Notably, one-third of the participants said they did not feel they received any support when deciding to disclose.

Once the decision had been made to disclose, the outcomes fell into three categories: positive, negative, and neutral or no outcome. Those who referred to positive outcomes most commonly spoke about support, understanding, and acceptance from colleagues: “The co-workers were very understanding, and they made me settle in better. [P-7]” Receiving reasonable adjustments in the workplace was also a positive outcome of disclosure: “My employer was supportive and open to all suggestions of reasonable adjustments. This was more positive than I expected. [P-9]” Some participants noted that disclosure led to their successful recruitment, or to gaining legal protections. A small percentage (<1%) of the references in this category talked about how their diagnosis improved autism awareness and acceptance in their organization more generally: “In one place, I used the disclosure of my diagnosis to improve the place for our autistic students and to provide autism training and support to other staff. [P-8]”

| Variable Category | N   | %   |
|-------------------|-----|-----|
| Current or most recent income | <£10,000 | 53 | 22.3 |
|                    | £10,000–£19,999 | 57 | 23.9 |
|                    | £20,000–£29,999 | 53 | 22.3 |
|                    | £30,000–£39,999 | 23 | 9.7  |
|                    | £40,000–£49,999 | 15 | 6.3  |
|                    | £50,000–£59,999 | 9  | 3.8  |
|                    | £60,000–£79,999 | 6  | 2.5  |
|                    | £80,000–£99,999 | 2  | <1   |
|                    | £100,000–£149,999 | 5 | 2.1  |
| Prefer not to say | 14 | 5.9  |
| Other diagnosed conditions | Mental health condition | 155 | 65.1 |
|                               | Physical health difficulty | 61 | 25.6 |
|                               | Dyspraxia | 23 | 9.7  |
|                               | ADHD      | 22 | 9.2  |
|                               | Dyslexia  | 18 | 7.6  |
|                               | Physical impairment | 18 | 7.6  |
|                               | Mental impairment | 12 | 5.0  |
|                               | PTSD       | 12 | 5.0  |
|                               | OCD        | 10 | 4.2  |
|                               | Ehlers–Danlos syndrome | 7 | 2.9  |
|                               | Tourette’s syndrome | 3 | 1.3  |
|                               | Dyscalculia | 2 | <1   |
|                               | Learning condition | 2 | <1   |
|                               | Panic disorder | 2 | <1   |
|                               | Prosopagnosia | 2 | <1   |
|                               | Alexithymia | 1 | <.5  |

*Participants who chose “Mental Health Conditions” were included in this category; only those who wrote in specific conditions on the survey were separated into the categories for specific mental health conditions.

A/AS, advanced level qualification; ADHD, attention deficit hyperactivity disorder; BTEC, business and technology education council qualification; GCSEs, general certificate of secondary education; OCD, obsessive-compulsive disorder; PTSD, post-traumatic stress disorder.
also referred to the lack of reasonable adjustments after anything about autism. [P-66]’’ Another negative outcome and no one even bothered to read up and teach themselves and acceptance from their colleagues: ‘‘No one understood referring most often to the lack of support, understanding, sure that were reversals of the positive outcomes. They

| Variable                                                                 | n  | %   |
|--------------------------------------------------------------------------|----|-----|
| Have you ever disclosed to others in the workplace?                      |    |     |
| Yes, I disclosed to everyone                                             | 83 | 34.9|
| Yes, but only to some people at work                                     | 131| 55  |
| No, I have not disclosed                                                 | 24 | 10.1|

At what point in your employment journey have you disclosed to others in the workplace?

| Event                                      | n  | %   |
|--------------------------------------------|----|-----|
| On the application materials                | 56 | 23.5|
| During the interview                       | 15 | 6.3 |
| After securing the job but before starting | 15 | 6.3 |
| After starting the job                     | 109| 45.8|
| After my organization received training on autism                             | 3  | 1.3 |
| After promotion                           | 12 | 5   |
| None of these are applicable to me         | 28 | 11.8|

Impact of disclosure and subsequent adjustments made

How would you rate the impact of disclosing to your employer or supervisor?

| Impact rating                                      | n  | %   |
|---------------------------------------------------|----|-----|
| Extremely positive                                 | 33 | 13.9|
| Somewhat positive                                  | 63 | 26.5|
| Neither positive nor negative                      | 57 | 23.9|
| Somewhat negative                                  | 34 | 14.3|
| Extremely negative                                 | 17 | 7.1 |
| Not applicable (i.e., did not disclose to supervisor) | 34 | 14.3|

How would you rate subsequent adjustments made by your employer or supervisor?

| Impact rating                                      | n  | %   |
|---------------------------------------------------|----|-----|
| Extremely positive                                 | 25 | 10.5|
| Somewhat positive                                  | 55 | 23.1|
| Neither positive nor negative                      | 65 | 27.3|
| Somewhat negative                                  | 23 | 9.7 |
| Extremely negative                                 | 31 | 13  |
| Not applicable (i.e., did not disclose or no adjustments were made) | 39 | 16.4|

How would you rate the impact of disclosing to your coworkers?

| Impact rating                                      | n  | %   |
|---------------------------------------------------|----|-----|
| Extremely positive                                 | 24 | 10.1|
| Somewhat positive                                  | 63 | 26.5|
| Neither positive nor negative                      | 76 | 31.9|
| Somewhat negative                                  | 23 | 9.7 |
| Extremely negative                                 | 14 | 5.9 |
| Not applicable (i.e., did not disclose to coworkers) | 38 | 16  |

How would you rate subsequent adjustments made by your coworkers?

| Impact rating                                      | n  | %   |
|---------------------------------------------------|----|-----|
| Extremely positive                                 | 15 | 6.3 |
| Somewhat positive                                  | 45 | 18.9|
| Neither positive nor negative                      | 99 | 41.6|
| Somewhat negative                                  | 22 | 9.2 |
| Extremely negative                                 | 17 | 7.1 |
| Not applicable (i.e., did not disclose or no adjustments were made) | 40 | 16.8|

Participants wrote about negative outcomes of disclosure that were reversals of the positive outcomes. They referred most often to the lack of support, understanding, and acceptance from their colleagues: ‘‘No one understood and no one even bothered to read up and teach themselves anything about autism. [P-66]’’ Another negative outcome was bullying and purposeful discrimination. Participants also referred to the lack of reasonable adjustments after disclosing: ‘‘Reasonable adjustments were very difficult to get put in place due to my employer not understanding ASD. [P-15]’’

In some cases, the outcomes of disclosure were mixed, leading to a neutral view overall: ‘‘The outcomes were a mix of positive and negative.’’ [P-39] For some participants, disclosure had had no perceived effect on their day-to-day work lives: ‘‘There has generally been no change.’’ [P-30]

Discussion

The results of this study highlight the complexities of disclosing an autism diagnosis within the workplace. Most of the autistic adults who took part in the present survey reported disclosing selectively, but many also disclosed to everyone. Participants most commonly disclosed after starting a job—or when completing application materials, but rarely during the interview process. Participants reported that they disclosed to be visible role models for other autistic individuals, to demonstrate an advantage associated with being on the autistic spectrum, as well as practical reasons such as to enable access to workplace adjustments. A number of participants also viewed disclosure as a route to better mental health and well-being, legal protections, and most of all a quest for better understanding and acceptance. In many cases, individuals disclosed retrospectively in an attempt to explain or mitigate a negative past event. For those who chose not to disclose, it was often a fear of discrimination that led to the decision to keep their autism diagnosis private.

It is interesting to note that when considering disclosure, the autistic people in our study were primarily concerned about how others in the workplace perceived them and behaved toward them. Our findings are in line with existing evidence from the United States that fear of discrimination from others is the most common reason why autistic people choose not to disclose at work.19,29 Furthermore, we found that the desire for increased understanding and acceptance from colleagues is often what drives disclosure in the workplace. This is contrary to the widely held misconception that autistic individuals prefer to isolate themselves socially and have little concern about the perceptions of others.40 Our results suggest that this is not at all the case; in fact, when considering disclosure, autistic people care more about others in the workplace than about maintaining the job or even asking for reasonable adjustments. Worryingly, only a minority of autistic employees in our study felt positive about the impact of disclosing to others in the workplace, and the subsequent adjustments made by their supervisors and coworkers. This, together with the examples of adverse impacts of disclosure shared by our participants, highlights the worrying prevalence of negative reactions from colleagues. We suggest that to improve disclosure for autistic individuals, nonautistic colleagues must be included in the process. Rather than the burden of responsibility falling on the autistic individual, we recommend that the onus should instead be on organization leaders to promote a more inclusive workplace culture. One way to change workplace cultures and collective attitudes toward disability may be to provide autism training to nonautistic employers and employees. Indeed research has shown that there is a strong association between the level
of autism knowledge held by a nonautistic individual and their favorable perceptions of an autistic person who discloses.\textsuperscript{22} To address the poor satisfaction regarding adjustments, employers should involve their autistic employees in deciding which adjustments are suited to an individual’s needs—a crucial factor in successful employment outcomes.\textsuperscript{11}

Many participants made statements that reflected the necessity of disclosure rather than disclosure as a choice. The fact that many participants in our study felt forced to disclose may indicate a breakdown in the organizational processes that failed to show support for autistic employees. It may also show a lack of trust toward their organizations if autistic employees only disclosed after encountering issues at work. To avoid this, one recommendation is that employers have clear proactive protocols for disclosure. These should not only make the employees aware of how they can disclose, but also confirm that the organization values diversity and has created a clear pathway for disclosure. It may also show a lack of trust toward their organizations if autistic employees only disclosed after encountering issues at work. To avoid this, one recommendation is that employers have clear proactive protocols for disclosure. These should not only make the employees aware of how they can disclose, but also confirm that the organization values diversity and has created a clear pathway for disclosure. These should not only make the employees aware of how they can disclose, but also confirm that the organization values diversity and has created a clear pathway for disclosure. However, disclosure may not be the goal for all autistic employees, and having a pathway to disclosure is just one indication that a workplace is truly inclusive. Indeed disclosure may be less necessary, and therefore, less frequent, where coworkers are accepting of different ways of working and communicating, employers allow flexible working arrangements to suit individual needs, and workplaces adhere to legal and ethical guidelines. Disclosure as a choice should mean that it is purely the decision of the autistic employee whether or not to disclose, with no external factors necessitating it.

While our participants most commonly disclosed once in a job, a substantial group chose to disclose in the application materials. This challenges the emphasis placed on job interviews in the disclosure literature,\textsuperscript{30,36,41} demonstrating that studies on autism disclosure with a focus on application materials would be more reflective of real-life situations. This new understanding of the timing of disclosure means that we can provide more targeted supports for autistic job-seekers and recommendations for employees.

One limitation of the current study is that our sample may not be representative of the autistic population in the United Kingdom. The participants in the current study were female; however, males are more likely to receive a clinical diagnosis of autism based on current screening tools.\textsuperscript{42} This overrepresentation based on gender is also common in online surveys; research has shown that females are more likely than males to participate in survey studies,\textsuperscript{43} and this was true for the larger Diverse Minds Survey. There is also no conclusive evidence demonstrating that autism varies significantly by race or ethnicity, or that there is any association between autism and race/ethnicity in the wider autistic population.\textsuperscript{42} However, our sample was 95% white; this is also greater than the percentage for the U.K. population more generally.\textsuperscript{44} We had hoped for a more diverse sample, and in future research

\begin{table}[h]
\centering
\caption{Results of Content Analysis—Categories and Subcategories with Frequency of Participant References}
\begin{tabular}{|l|l|l|}
\hline
\textbf{Categories} & \textbf{Subcategories} & \textbf{No. of participants} & \textbf{\% of participants} \\
\hline
Reasons to disclose & Increased understanding from colleagues/employers & 59 & 24.7 \\
& To gain reasonable adjustments & 36 & 15.1 \\
& Responsibility to one’s self and to others & 26 & 10.9 \\
& To manage and sustain employment & 23 & 9.7 \\
& Mental health and well-being & 14 & 5.9 \\
& Legal/policy protection & 8 & 3.4 \\
& Evaluate how worthwhile the job is & 6 & 2.5 \\
& Being autistic brings an advantage to the job & 3 & 1.3 \\
\hline
Reasons not to disclose & Fear of negative perceptions of others & 52 & 21.8 \\
& Fear of bullying and purposeful discrimination & 26 & 10.9 \\
& Disclosure is not beneficial & 12 & 5 \\
\hline
External support when deciding to disclose & No support & 95 & 39.9 \\
& Family & 55 & 23.1 \\
& Friends & 35 & 14.7 \\
& Romantic relationships & 30 & 12.6 \\
& Other sources of support & 20 & 8.4 \\
& Professionals & 17 & 7.1 \\
& Colleagues/employers & 10 & 4.2 \\
& General support & 5 & 2.1 \\
\hline
Positive outcomes & Support, acceptance, and understanding from colleagues/employers & 68 & 28.5 \\
& Reasonable adjustments & 35 & 14.7 \\
& Success in recruitment & 12 & 5 \\
& Gaining legal protection & 5 & 2.1 \\
& Provide training to improve autism knowledge & 2 & <1 \\
\hline
Negative outcomes & Lack of support, understanding, and acceptance & 70 & 29.4 \\
& Bullying and purposeful discrimination & 45 & 18.9 \\
& Lack of reasonable adjustments & 31 & 13 \\
\hline
Neutral/no outcome & & 37 & 15.5 \\
\hline
\end{tabular}
\end{table}
this should be achieved by recruiting directly within minority communities via specific online community groups and community networks. Notably, one-third of our participants also had higher education degrees (i.e., Masters degree or higher). While a growing number of autistic students are enrolled in higher degree programs across the United Kingdom, the latest available government statistics estimate that less than 1% of people in the United Kingdom have postgraduate degrees; even fewer postgraduates are autistic individuals, who make up an estimated 1% of the U.K. population. Furthermore, autistic school graduates are less likely than nonautistic graduates to pursue higher education. From this, we can conclude that our sample has a much higher representation of individuals holding postgraduate degrees than the wider autistic population in the United Kingdom.

A second limitation of the current study is possible bias that arose due to our recruitment channels. We recruited some participants through Autistica’s corporate partners, who may have more autism knowledge than most U.K. employers. Consequently, the autistic individuals in this study may have had more positive experiences of disclosure than the wider autistic adult population.

Lastly—and not unexpectedly—our sample only included a small number of participants who chose not to disclose their diagnosis at work. Such individuals may be less likely to engage with an autism research study for fear of their diagnosis becoming public. The views of those who choose not to disclose are extremely important, and future research should seek to include their voices. Future studies should also examine in more detail what determines a positive or negative outcome of disclosure, particularly in relation to the perceptions of others in the workplace.

Despite these caveats, our study is the largest study to specifically consider experiences of workplace disclosure for autistic adults in the United Kingdom and the results have implications for both research and practice. Perhaps most importantly, autistic individuals should not be solely responsible for the impact of their decision; it is also the responsibility of nonautistic individuals and the wider organization. Workplaces must focus on creating a culture of inclusion that both allows for and embraces autism disclosure, but does not necessitate disclosure in order for employees to feel supported and included. Improving autism knowledge in workplaces is a recommended first step, but it must also be followed by real changes to the workplace environment that make it truly inclusive: flexible working arrangements, physical changes that take into account sensory sensitivities (e.g., nonfluorescent or low lighting, quiet spaces), and alternatives to face-to-face job interviews during recruitment to allow for autistic candidates to show their strengths (e.g., performing actual job tasks for a potential employer). Disclosure should be a choice made solely by the autistic individual, and inclusive workplace environments should make disclosure easier but not essential to an employee’s success.

Authorship Confirmation Statement

A.M.R., B.H., and A.R. contributed to the study concept and developed the survey questions. B.H. led participant recruitment, designed the online questionnaires, and extracted the data. A.M.R. and J.D. conducted data analysis. A.M.R. and A.R. drafted the article and Z.W., B.H., and J.D. provided critical revisions. All coauthors have reviewed and approved of this article before submission. This article has been submitted solely to this journal and is not published, in press, or submitted elsewhere.

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Author Disclosure Statement

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Supplementary Material

Supplementary Table S1

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