Autistic adults' priorities for future autism employment research

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Abstract

Background: A growing body of research has sought to understand autistic people's research priorities. Several of these studies have identified employment as a key research priority. Yet, there have been few attempts to identify specific, fine-grained priorities within this area.

Methods: Using an online survey, we asked 197 autistic people in the UK about their priorities for future autism-employment research.

Results: Participants spoke of their challenges in gaining and sustaining meaningful employment and called for researchers to conduct research that results in direct improvements to employment experiences. Regarding their research priorities, participants indicated a need for research covering all aspects of the employment lifecycle from accessing employment to transitioning out of employment. Importantly, participants also discussed *how* such research should be conducted: with autistic people as co-researchers and ensuring a diverse range of autistic people are listened to.

Conclusion: While much existing autism-employment research appears to align with the priorities outlined in this study, seemingly minimal attention has been paid to later stages of the work lifecycle (e.g., progressing into more senior job roles or transitioning out of work). By identifying disparities between autistic people's priorities and the research being conducted, we can support autistic people to drive the research agenda and ensure autism-employment research positively impacts the community it aims to serve.

Lay Summary

Why was this study done?

Currently, very little autism research is on topics that autistic people think is important. More researchers are asking autistic people what they think their research should look at, so they can make sure they research topics that are important. Employment has been highlighted as an important topic by autistic people in many studies. However, we don't know what specific topics employment research should look at.

What was the purpose of this study?

We wanted to know which employment-related topics autistic people think are important to research and understand why.

What did the researchers do?

We created an online survey to ask autistic people about what employment research should look at. The survey asked participants about themselves (e.g., their age) and their employment experience (e.g., if they were employed or not). We also asked questions about what employment topics should be researched, why these topics are important, and what changes employment research should lead to. In total, 197 autistic people responded. We read through all the responses and grouped similar responses together.

What were the results of the study?

Lots of our participants found it hard to find and keep a job. They wanted research to make autistic peoples' experiences of employment better. For example, by making hiring processes better, and by making workplaces more inclusive. They also said that research should look at all parts of employment from getting a job, to leaving a job and retiring. Participants also talked about how research should be done. They said more autistic people should be included as researchers, and we should include different autistic people from different backgrounds.

What do these findings add to what was already known?

Our findings show that lots of autism-employment research is on topics that autistic people think are important. However, not much research has looked at later stages of employment, such as getting a promotion or retiring.

What are potential weaknesses in the study?

Most of our participants were white, employed and had a degree, but in the wider autistic population that isn't the case. People from other backgrounds may have different experiences of employment, and therefore want different research. We also don't know which topic is the most important because we didn't ask participants to rank the topics they spoke about.

How will these findings help autistic adults now or in the future?

This study highlights key topics that autism-employment researchers should look at. By showing where the gaps in research are, we can make sure that all the employment topics autistic people think are important, are researched.

Autistic adults' priorities for future autism employment research

Between the years 2001 and 2011, the number of annual autism research publications across the globe more than tripled (Pellicano et al., 2013), coinciding with worldwide increases in funding for autism research (Autistica, 2016a; Interagency Autism Coordinating Committee, 2012). Investment in autism research in the United Kingdom (UK) grew by 200% between the years 2013 and 2016, increasing from just £5 of research funding per autistic person in 2013 to £15 per person in 2016 (Autistica, 2016a). Prompted by the exponential growth in research funding, recent work has sought to assess the distribution of research funding across topic areas (e.g., Autistica, 2016a; Daniels & Warner, 2018; den Houting & Pellicano, 2019; Harris et al., 2021; Office of Autism Research Coordination, 2019; Pellicano et al., 2013). Common across the findings of these studies is the preponderance of research on the biology and causes of autism, across the Western world. For example, a recent report comparing the autism research landscape in the United States (US), the UK, Canada, and Australia found the largest proportion of research funding in all four countries (between 17% and 64%) was distributed to biological research, with up to an additional 24% being distributed to research regarding potential causes (Office of Autism Research Coordination, 2019). In comparison, only between 2% and 11% of research funding was distributed to lifespan issues, and only between 1% and 11% to the services that autistic people and their families receive (Office of Autism Research Coordination, 2019).

Furthermore, evidence suggests that the current allocation of autism research funding does not align with community research priorities. For example, a large-scale consultation with 1,517 autistic people and community members (family members, peers, researchers, and those that work closely with autistic people) in the UK indicated that research on life skills and services and lifespan issues were a high priority for the autistic community, despite not being prioritised by research funders (Pellicano et al., 2014a). A more recent consultation (*n*

= 1,266) by the UK autism research charity Autistica painted a similar picture, with most of the top ten research priorities being grounded in a need for more support across the lifespan (Autistica, 2016b). For example, interventions to improve mental health (priority 1) and support to help autistic people maximise their potential and performance in the workplace (priority 8). Similar findings have been replicated in other countries, including the US and Australia, with members of the autistic and autism communities prioritising research designed to improve the services available to autistic people, as well as to understand issues across the lifespan (e.g., Frazier et al., 2018; Gatfield et al., 2016). A recent report further highlighted the disparity between research funding and the priorities of autistic people, showing that only a small portion (~27%) of the research aligns with the top 10 priorities of autistic people (Autistica, 2016a). Such a disparity is concerning and can lead to frustration and a lack of trust in autism research (Pellicano et al., 2014b).

To address this disparity – which has resulted in significant frustration among the autistic community (Pellicano et al., 2014b) – there have been calls for greater involvement by community members in the research process – including at the point of setting research priorities (Clark & Adams, 2020; Frazier et al., 2018; Pellicano et al., 2014a; Roche et al., 2021; Tomlinson et al., 2014). Priority setting is common practice within healthcare research, with researchers establishing the common research needs and wants of the community they serve, and using these priorities to guide the direction of future research (Rudan, 2016). Despite its potential utility, research concerning the autistic and autism communities' priorities for future autism research is in its infancy. Indeed, in a recent systematic review exploring key stakeholders' priorities for autism research, Roche and colleagues (2021) were only able to identify seven relevant academic publications – all of which emphasised the need for more research that examines autism across the lifespan.

One research area consistently prioritised by community members is employment (Roche et al., 2021). For example, in Pellicano et al.'s (2014a) study, autistic adults and parents of autistic children in the UK highlighted a need for research to establish "how to get [autistic] people into the workplace and keep them there" (p. 761). Similarly, when asked to rate the relative importance of 15 potential research topics (e.g., education, friendships, health care), autistic adults (n = 225) in the US rated employment as the second highest research priority (Gotham et al., 2015). Similar findings have also been replicated in Australia, with recent community consultations highlighting the development of inclusive workforces as a key 'implementation research priority' (Australian Autism Research Council (AARC), 2019, 2020; Poulsen et al., 2022).

It is unsurprising that employment research has been prioritised by the autistic community, given the ongoing global autism-unemployment crisis. Fewer than 22% of autistic adults in the UK are employed (Office for National Statistics, 2021), with similar statistics being reported in Canada (14.3% employed; Zwicker et al., 2017) and Australia (28% employed; Australia Bureau of Statistics, 2015). Consequently, many autistic people and their families are left with growing concerns regarding their current and future physical and mental wellbeing, financial security and independence (Gerhardt & Lainer, 2011; López & Keenan, 2014; Nicholas et al., 2019; Roux et al., 2013). There is, however, a paucity of research that seeks to establish the specific employment-related topics that are prioritised by autistic people. In one of the only consultations to identify employment-specific research priorities, the Australian Autism Research Council (2020) held online focus groups with autistic people and their allies (family members, and/or professionals that work with autistic people) to identify key research questions in five community informed priority areas: education, health and wellbeing, employment, justice, and communication. Regarding employment specifically, the project team asked participants (*n* = 12, 9 of whom were

autistic) to engage in a prolonged discussion about their priorities for autism-employment research. Participants were then encouraged to identify a set of employment-specific research questions, resulting in a list of 10 key priority questions for future autism-employment research (AARC, 2020). The top three employment-related research priorities highlighted in this consultation included (1) understanding how the needs and preferences of autistic people can be supported in the workplace (e.g., through workplace adjustments); (2) identifying the factors that create a safe work environment and culture for autistic employees, and (3) improving recruitment processes for autistic people (AARC, 2020).

While the above consultation was useful in identifying potential priority areas for future autism-employment research, what is still lacking is an in-depth consultation with a large sample of autistic people, outside the Australian employment context. This study sought to do just that, through an online survey with autistic adults in the United Kingdom. Specifically, we asked participants (1) what they wanted future autism-employment research to cover; (2) what they wanted such research to achieve, and (3) why these topics and outcomes were important to them. Exploring *why* topics and outcomes were important provided critical context to the identified research priorities.

Methods

This study formed part of a larger research initiative, Discover Autism Research and Employment (DARE). DARE aims to explore autistic adults' experiences of employment in the UK using a bespoke national survey, called the Diverse Minds Survey. The Diverse Minds Survey was developed with autistic collaborators and includes optional modules on seven employment-related topics, including priorities for future autism-employment research. The survey was advertised via (1) social-media callouts by individual members of the research team; (2) advertisements through the Autistica Discover Network, a network of autistic people interested in taking part in research, and (3) callouts within organisations

linked to the project that were interested in learning more about neurodiversity and employment.

Participants

To take part in the Diverse Minds Survey, participants were required to be aged 18 years or older and have experience of employment, or searching for employment, in the UK. To be included in the current study, participants also had to complete all demographic questions and at least one question from the priorities for future employment research module. Participants who did not identify as autistic were excluded.

Between March 2019 and April 2020, 347 people had navigated to the priorities for future employment research survey. Of those, 150 (43.2%) were excluded because they did not identify as autistic (n = 145, 96.7%), or had not answered any of the relevant research priorities questions (n = 5, 3.3%). The final sample comprised 197 participants. Of those, the majority had a formal autism diagnosis (n = 168, 85.3%), with the remaining self-diagnosing as autistic (n = 28, 14.2%) or not disclosing a formal diagnosis (n = 1, 0.5%). More than half of the sample (n = 113, 57.4%) identified as female and more than three-quarters (n = 153, 77.7%) were from a White ethnic background. Many participants were in full-time (n = 75, 36.5%) or part-time (n = 42, 21.3%) employment, or were self-employed (n = 16, 8.1%). Less than half of the sample (n = 86, 43.7%) reported being satisfied with their current employment. See Table 1 for a full breakdown of demographic information.

Table 1.

Participant demographic information (n = 197)

	п	%
Gender		
Female (including trans women)	113	57.4
Male (including trans men)	65	33.0
Non-binary	13	6.6
Prefer to self-describe	6	3.0

Age category (in years)		
18 – 25	28	14.2
26 – 35	44	22.3
36 - 45	44	22.3
46 – 55	58	29.4
56 - 65	21	10.7
66 – 75	2	1.0
Ethnicity		
White	153	77.7
Mixed/multiple ethnic backgrounds	10	5.1
Black British	1	0.5
Undisclosed	6	3.0
Undetermined ¹	27	13.7
Highest level of education		
Bachelor's Degree (e.g., BSc, BA, BEd)	57	28.9
Master's Degree (e.g., MA, MSc, MEd)	54	27.4
A/AS-Level ²	17	8.6
BTEC	14	7.1
Doctorate	13	6.6
Post Graduate Certificate (PGCert)	8	4.1
Post Graduate Diploma (PGDip)	6	3.0
GCSEs ³	6	3.0
Foundation Degree	5	2.5
Higher National Diploma (HND)	5	2.5
No formal qualifications	5	2.5
GNVQ	2	1.0
Professional qualification	2	1.0
Other	3	1.5
Employment status		
Employed full-time	72	36.5
Employed part-time	42	21.3
Self-employed	16	8.1
Unemployed – looking for work	13	6.6
Student	12	6.1
Unemployed – not looking for work	12	6.1
Volunteer	6	3.0

Parent and/or carer 5 2.5 Unemployed – disabled/ill-health 5 2.5 Retired 4 2.0 Other 10 5.1 Satisfaction with current employment 5 2.79 Satisfied 86 43.7 Dissatisfied 55 27.9 Uncertain 45 22.8 Not applicable 4 2.0 Other 5 2.5 1 – 2 employers 21 10.7 2 – 4 employers 21 10.7 2 – 4 employers 38 19.3 > 6 employers 38 19.3 > 6 employers 38 19.3 > 6 employers 38 19.3 < £10,000 £13,999 23 11.7 £40,000 £19,999 4.6 25.0 2.5 £00,000 £19,999 3 1.5 2.5 £00,000 £19,999 3 1.5 2.0 Prefer not to say <t< th=""><th></th><th></th><th></th></t<>			
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¹ Participants were given a free text response option for ethnicity. Some participants chose to report their nationality as opposed to their ethnicity. These responses have been categorised as undetermined; ²

AS/A-Levels are qualifications in the UK that are typically taken between 16 and 18 years.; ³ GCSEs are qualifications in the UK that are typically taken between 14 and 16 years.

Materials

Participants completed a series of demographic questions regarding their age category, gender identity, ethnicity, highest level of education, employment status, satisfaction with current employment, number of previous employers, income range, and sector of employment. Participants also completed an optional module regarding their priorities for future employment research. The priorities for future employment research module consisted of three open-ended questions regarding (1) the areas of autism and employment they would like to see researched in the future; (2) existing autism-employment topics that should be researched from another angle, and (3) in what ways they would like to see future employment research make a difference to the employment of autistic people.

Procedure

Ethical approval was obtained through the Research Ethics Committee at UCL Institute of Education, UCL's Faculty of Education and Society (REC1149). Participants provided informed consent to take part in the research. The priorities for future research module took approximately ten minutes to complete.

Data analysis

Survey responses (average length = 46 words, range = 2 - 420 words) were uploaded to NVivo software (QSR International, 2020) and analysed using reflexive thematic analysis, within an essentialist framework (Braun & Clarke, 2013, 2019). Data analysis was led by the first author, who familiarised themselves with the data by reading and rereading responses to the three open-ended questions. Patterns in responses were identified and extracts were assigned initial codes, taking an inductive approach. Codes were recursively reviewed and refined before being organised into relevant themes and sub-themes. The first author met

with the second author on multiple occasions to discuss the findings, resolve any discrepancies and further refine the themes and subthemes. The third author completed a final round of coding to ensure the themes and subthemes were comprehensive and reflected the data. All authors agreed on the final set of themes and subthemes. Regarding positionality, all authors have been involved with the autistic community, either as a self-advocate (AD & AW), or as an ally (JD, AMR, DM, BH, EP & AR). The authors all view autism within a neurodiversity framework, and recognise that disability is at least in part a consequence of societal barriers that exclude or discriminate against autistic people, rather than inherent impairments or deficits (Shakespeare, 2006).

Community involvement

Two autistic co-authors (AD & AW) contributed to the development of the Diverse Minds Survey. This included refining the survey to improve accessibility, such as adjusting the format of the survey and the language used. AD and AW also provided feedback on drafts of the manuscript, including our key recommendations for future research.

Results

Qualitative results

We identified five themes comprising 15 subthemes from the free-text responses (see Figure 1). Themes were centred around (1) accessing employment; (2) organisational culture; (3) the employment journey; (4) the negative impact of non-inclusive workplace environments and (5) wider reflections on autism-employment research. Example research questions under each theme and sub-theme were developed by the research team, directly drawn from participants' examples and anecdotes, and can be found in Appendix A.

Theme 1. Accessing Employment

1.1 More opportunities for Suitable Employment. Participants discussed a need to understand "the reasons for the employment gap" (P090) to "increase the numbers of autistics

in employment" (P048). One possible reason was a perceived lack of opportunities for suitable and meaningful employment for autistic people. Indeed, some participants felt they had previously been "written off as only suitable for some minimum wage job" (P008). As such, many participants reported being in unfulfilling job roles that did not adequately match their capabilities or utilise their skills. Relatedly, one participant emphasised a need for researchers to move their focus from simply increasing employment rates to supporting autistic people to access more meaningful employment: "I get it, there's a need to find more jobs for people with autism, but when is there going to be an emphasis on *careers* for people with autism?" (P103). As a result of the limited suitable opportunities, some participants felt they had no choice but to turn to self-employment: "the workplace is not designed for neurodivergent people. I am extremely successful in my work ... but I am self-employed as I do not fit into a workplace" (P029).

Participants offered several suggestions for how research could support more autistic people to access suitable employment, including research highlighting the "types of jobs that suit autistics" (P044), the "fields which are more autism friendly than others" (P152) and "employers [that] actively recruit autistic people" (P144). Some participants also felt that they would benefit from research on external forms of support, such as "mentoring which employed autistic adults might give to autistic school leavers about to enter the workplace" (P018).

1.2 Autism-Employment Research Must Translate into Systemic Change.

Participants wanted wider, systemic changes such as "governmental understanding" (P118) and "government backed schemes" (P144) to make a real improvement to the accessibility of employment for autistic people. They emphasised that research must result in real, tangible change, for example, by resulting in "a [national] autism employment fund to help fund work experience, internships, and job opportunities for autistic people" (P148), or by resulting in

direct improvements to current UK laws, and the benefit and welfare system: "[the] current law needs updating as it is a sham right now, it only means employers have a duty to meet the needs as a disabled group, not individuals" (P044).

1.3 Exploring Challenges Surrounding Diagnosis and Disclosure. Participants also felt it was important for research to examine the implications of diagnostic disclosure to access 'reasonable adjustments'. For example, some participants highlighted that there are likely many autistic employees "working without a diagnosis ... [and] employers will very likely be employing people who are autistic but don't know it, so don't know even to ask for adjustments" (P171). Indeed, participants noted that the lack of adjustments for people without an autism diagnosis often led to unique "difficulties in securing or retaining paid employment" (P132). As such, participants suggested that research should examine "how [autistic people] can best get what they need without having to disclose personal information to an employer that [they] don't fully trust" (P050). For some autistic people, however, disclosure was an important goal: "I would like people to feel safe and comfortable disclosing" (P053). Research targeted to this issue was therefore perceived to be an important catalyst for change, potentially providing autistic people with "different ways of disclosing autism in the workplace" (P163) as well as making "it normal for people with autism to be able to disclose their diagnosis from the outset, just like someone might say that English is their second language, or that they are left-handed" (P088).

1.4 The Impact of Intersectional Identities on Employment Experiences. Some participants were particularly interested in understanding how having an intersectional identity may exacerbate some of the barriers that autistic people face in accessing employment. For example, one participant explained: "I want [researchers] to examine how more than one 'persona-trait' (e.g., being autistic *and* being a woman, *and*/or being of non-white ethnicity, *and*/or being physically disabled) [may] impact even more negatively on

judgements in employment situations" (P137). Indeed, participants shared anecdotes of subgroups in the autistic community that were perceived to be doubly disadvantaged because of their intersectional identity:

[Autistic people] from middle class families are supported to achieve an education, often through home-schooling. Those from working class backgrounds but of similar intelligence, often end up as 'school refusers' and reach 18 without a single qualification. This obviously has a big impact on employment. My sense is there is appalling inequality based on family class and resources. It would be interesting to see this researched. (P008)

1.5 A More Inclusive Recruitment Process. Typical recruitment processes, including interviews and group tasks, were thought to be "the most significant barrier [to employment] for many neurodivergent individuals" (P188). Participants reported that "more [autistic people] could be employed if recruitment processes and workplaces were more autistic friendly" (P173). As such, participants felt it was important for research to highlight "autism friendly recruitment best practice" (P171) and indicate "how application [and] recruitment processes could be made easier and more practical for people with autism" (P093). Participants hoped that research in these areas could result in "easier and fairer [recruitment processes], because it does always feel like people with Asperger's and autism are at a disadvantage" (P079).

Theme 2. Organisational Culture

2.1 Exploring Stigma, Discrimination and Exploitation in the Workplace. As a result of differences between them and their non-autistic colleagues, many autistic people reported experiencing stigma, discrimination, and exploitation in the workplace. For example, one participant explained:

Employers have the habitual predisposition to make use of hyperfocus, it produces excellent results ... Unfortunately, in my experience, this is an opportunity for exploitation. Management [and] colleagues will often take advantage of my work ethic and weak social skills, i.e., not understanding when to say no. This has occurred in every job I've had. (P167)

Participants wanted research to quantify the extent to which autistic people face such experiences of stigma, discrimination and exploitation ("[research] the level of stigma and discrimination autistic people encounter in the workplace", P037) and to determine "how far discrimination is responsible for the appallingly low rates of employment among autistic people" (P008). Relatedly, participants expressed a need for research to contribute to the development of "interventions and schemes (and not just compulsory e-learning) which reduce the likelihood of bullying of autistic people in the workplace" (P113). Ultimately, participants hoped that research could help to "remove the judgement and discrimination" (P181) that autistic people face in the workplace, and "drive changes that make autistic employees feel welcomed, valued and advocated for" (P171).

2.2 Improving Understanding and Acceptance from Others. Participants repeatedly reported finding the predominantly neurotypical norms and expectations of the workplace confusing and difficult to navigate. Participants highlighted differences in communication as a pertinent barrier to successful employment: "I was diagnosed with Asperger's due to a long-term pattern in losing my job. It was never due to my work being bad ... but [because] I'd offended someone/said the wrong thing/looked at someone the wrong way" (P042). As such, participants called for research to "question the neurotypical style and methods of communication as being the 'default' against which autistic people are judged" (P077) and "raise better awareness [of autism]" (P191). They felt such research

could result in a "better understanding amongst neurotypicals of how to make autistic employees feel included and how to interact with us effectively" (P129).

Practically, some participants hoped autism-employment research could contribute to the development of "up-to-date autism training which challenges stereotypes" (P013), including, for example, by providing employers with information regarding the strengths of autistic employees ("it would be excellent if neurotypical employers became more aware of what autistic people have to offer and accept them as being of equal worth", P018) and how these strengths could be harnessed: "it would be great if researchers would be able to prove that employing people on the spectrum is beneficial and how" (P022). Participants felt, however, that it was important for research to evaluate the impact of such training ("does autism training improve autistic people's experiences in the workplace?", P152) to ensure such education leads to meaningful change: "training can be given to give people knowledge but how do we measure if their attitudes have changed?" (P156). Some felt that research should also result in more practical support to help autistic people navigate the predominantly neurotypical workplace: "[I would like to see] training programs for autistic students about office politics and networking skills, and how they can use these to advance their careers" (P163).

2.3 Better Networks of Support. A common method autistic adults used to alleviate work-related stress, and thus sustain employment, was support from colleagues, advocates, and champions: "things like workplace coaching and mentoring help to keep people in jobs" (P143). They felt it was important for research to show autistic people "they have available resources and services to protect them in the workplace" (P053). Nevertheless, many felt that existing support was lacking and indicated this may be a fruitful area for research to explore: "[I would like to see research on] how to best support professionals in the workplace. I can

find quite a bit of information about starting jobs or support in non-professional level jobs but not that much that's been helpful for me" (P123).

2.4 Access to Workplace Adjustments. Workplace adjustments were perceived by many as an integral component in supporting autistic people to sustain employment. Yet, many participants reported experiencing being "made to feel inadequate" (P029) for requesting adjustments or felt that organisations were simply offering adjustments "to earn some sort of invisible 'good company' points" (P088). Indeed, one participant noted that "wheelchair users need ramps, wide doors, disabled bays etc and this is now implemented as law" (P010) but felt that equal measures were not in place for people with more 'hidden' disabilities. As such, participants said it may be beneficial for research to identify the workplace adjustments that may be particularly beneficial for autistic people ("[I would like research to identify] what accommodations are the most widely used [and] most effective", P039) so autistic people can advocate for the adjustments they may require. Yet, others felt it was important for employers to take ownership of implementing adjustments: "It shouldn't be about putting all the onus on autistic people. We are already made to feel that everything we do is putting people out" (P038). As such, participants wanted research to demonstrate the wide-reaching benefits of adjustments to encourage employers to improve implementation: "Quantifying how [productivity] improves when adjustments are made would also be very helpful. Being able to tell a company that they can expect a certain percentage improvement in productivity by making adjustments is very powerful" (P188).

Theme 3. The Employment Journey

3.1 Experiences of Career Progression. While participants appreciated the prospect of employment research that aligns with their priorities, many indicated that current autism-employment research lacks "the whole life perspective" (P195). This gap left participants with many unanswered questions about autism and employment, for example: "what do

autistic careers/professional lives/jobs over a lifetime look like?" (P195) and "what does successful work look like for autistic adults?" (P191). Unfortunately, many participants were concerned that autistic people may not be given the same chances to progress within their careers as non-autistic people: "so many of us are underemployed because we can't do workplace politics or read people well enough to get along" (P128). They expressed explicit concerns about "the impact of 'being different' on [the likelihood of receiving a] promotion" (P087). Accordingly, participants wanted research to address questions such as "do people on the spectrum get paid fairly? [And] do we get promoted at the same rate?" (P034). Indeed, some participants highlighted that many senior positions entail management responsibilities, and this was perceived to be "very difficult, time consuming and tiring" (P023). As such, participants wanted research to result in "more guidance about how autistic people can successfully progress" (P127). Conversely, some participants felt that there are likely many "undiagnosed autistic people [that] have successful careers" (P008) and wanted research to highlight more successful case studies to "figure out what went right. How did they find a rewarding career that didn't involve playing the corporate game of thrones? What career guidance did they get? Where did they find out about the opportunities they took?" (P103).

3.3 Transitions Out of Employment. Participants also indicated that transitions out of employment may be particularly challenging, albeit common, for autistic people. Relatedly, participants reported wanting more research aiming to understand such transitions, including "how did the job end? Why did the job end?" (P102) and "the experiences of autistic people who have lost their job as a result of their autism" (P048). Participants also highlighted a need for more research examining the transition to retirement, and how autistic people can be best supported in "preparing for retirement" (P195).

Theme 4. The Negative Impact of Non-Inclusive Workplace Environments

4.1 Mental-Health Related Consequences of Employment. While employment was a desirable outcome for many participants, employment was also felt to negatively impact people "physically, mentally, and emotionally" (P062), with participants reporting specific "burnout issues related to work" (P074). Accordingly, participants reported a need for research to highlight "the effect of corporate culture on mental health" (P021) and "inform changes to enable all autistic people to be able to work if they wish ... in physical and cultural work environments that have a positive – rather than detrimental – effect upon their mental health" (P116).

4.2 Workplace Masking as a Perceived Necessity. Participants also discussed the perceived need to mask in the workplace and were concerned about "the toll it takes" (P063). They reported that they "would like to feel that it is not so necessary to have to mask in the workplace" (P021) and called for research to "make it so we don't have to mask, so we can have a job and feel like we are being part of the world like everyone else" (P019). One participant noted, however, that "despite the stresses of masking, I think it is important to try to fit in, and maybe more people could secure and maintain employment if they did. Perhaps this needs to be looked at more?" (P095).

Theme 5. Wider Reflections on Autism-Employment Research

5.1 The Need for Coproduced Autism-Employment Research. Participants made important reflections about the approach researchers should take to autism-employment research, and the importance of involving the autistic community at the heart of research. For example, many highlighted the importance of "utilising the experiences of [those with lived experience] as key employed researchers" (P002) and explained that "involvement of autistic people at every stage of the research is critical. We are the experts on autism, and too often our voices are ignored" (P077). Participants noted that involvement in research should

extend beyond simple participation and should involve autistic people "as co-researchers or advisors ... ask autistic people about their research priorities, like you are doing" (P175).

5.2 The Importance of Including Seldom-Heard Groups Within Autism-

Employment Research. Participants also indicated the importance of exploring the workplace experiences of autistic people that are often missed in autism research. For example, one participant reflected how "undiagnosed autistic adults... those who have learned to mask... [and] those who are not in mental health crisis are underrepresented" (P147). Accordingly, participants felt "a bit more balance" (P023) in future research would be an important step to ensure findings are relevant for as many autistic people as possible.

Discussion

This study sought to identify a set of fine-grained priority areas for employmentrelated autism research, according to autistic people, and to understand *why* these topics were prioritised. Our findings indicate that autistic people want to see research at every stage of the employment process, including, but not limited to: (1) the initial stages of applying for and gaining employment; (2) sustaining employment (e.g., through workplace adjustments and inclusive organisational culture); (3) progressing in one's career, and (4) transitioning out of employment. Importantly, our participants also highlighted *how* such research should be conducted: working directly with autistic people as co-researchers and ensuring the full range of the autistic population is well represented. Below, we discuss the specific topic areas that our participants wanted research to cover, with reference to existing literature and potential avenues for future research.

The first topic identified by our participants was autistic people's access to employment. Specifically, participants wanted research to (1) highlight current opportunities for suitable employment (e.g., Remington & Pellicano, 2019); (2) explore autistic people's experiences of disclosing their diagnosis (e.g., Huang et al., 2022; Lindsay et al., 2019;

Romualdez et al., 2021a, 2021b); (3) explore the impact of having an intersectional identity on employment experiences (e.g., Hayward et al., 2018; Nagib & Wilton, 2020), and (4) highlight how hiring processes may be improved (e.g., Davies et al., under review; Maras et al., 2021; Vincent, 2020). Encouragingly, research concerning autistic people's access to employment appears to be growing, with a wide range of initiatives, driven by researcherindustry partnerships, aiming to support autistic people in obtaining employment (e.g., Munandar et al., 2021; Strickland et al., 2013; Wehman et al., 2013, 2014, 2020). Yet, evaluations of such initiatives are limited. A systematic review exploring transition to employment programmes for autistic youth concluded there is an "absence of a scientifically rigorous literature base", with no firm conclusions about which programmes are (not) effective able to be drawn (Westbrook et al., 2015, p. 15). As such, there is a need for more rigorous testing of such initiatives to establish which, if any, achieve the outcomes they purport to achieve, and thus identify the most effective ways of supporting autistic people to obtain employment. Further, evidence regarding the impact of having an intersectional identity on employment experiences appears to be in its infancy, with existing research focussing on gender as opposed to other intersectional identities. This may be an important avenue for future research.

The second topic identified by participants focused on the need for research to consider not just employment rates but the *sustainability* of employment as it relates directly to autistic people. Our participants highlighted that organisational culture often acts as a barrier to sustainable employment for autistic people. Participants therefore wanted more research that might lead to meaningful organisational change. Examples of suggested research topics included: (1) autistic employees' experiences of stigma and discrimination at work (e.g., Johnson & Joshi, 2016); (2) how to improve non-autistic employees' attitudes toward autistic people (e.g., Scott et al., 2018); (3) how autistic people can be better

supported at work (e.g., through supported employment, mentors, and/or job-coaches; Müller et al., 2003; Nicholas et al., 2018; Vogeley et al., 2013), and (4) which workplace adjustments may be useful for autistic people (e.g., Davies et al., in press; Khalifa et al., 2020; Petty et al., 2022). While research in this area is progressing, once again, the evidence base remains somewhat underdeveloped. In particular, there appears to be a paucity of research that goes beyond describing people's employment experiences and moves toward the development and, importantly, evaluation of programmes that make a meaningful difference to autistic people's employment experiences – especially at the level of organisational culture. One proposed method for facilitating such change was the use of autism-specific training programmes (cf. Hendricks, 2010; Lindsay et al., 2021; Petty et al., 2022). Currently, however, there remain few empirical evaluations of the effectiveness of workplace disability-training programmes (Phillips et al., 2016) and, to our knowledge, only one evaluation of an autism-specific training intervention (e.g., Scott et al., 2018). The development and empirical testing of autism-specific workplace training programmes should therefore be a key avenue for future research.

Third, our participants said they wanted more research to examine the full employment lifecycle, not just research on the early stages of one's career. They highlighted autistic people's experiences of career progression and transitioning out of employment (e.g., due to termination of employment, or retirement) as key topics for future research. They also identified aspects of employment that may be particularly challenging for autistic people, including potentially unique barriers related to career progression, such as poor job matching by job coaches and/or employers (c.f. Sharpe et al., 2022). Yet, seemingly minimal attention has been paid to this aspect of autism-employment research. Indeed, to our knowledge, no research has directly examined autistic people's experiences of career progression, and only one paper has explored, using a single case study design, an autistic person's experience of

the transition from work to retirement (Hodges et al., 2004). The dearth of research in this area makes it a worthy candidate for future research.

Finally, participants discussed at length the negative impact that non-inclusive workplace environments have on autistic employees and said they wanted more research in this regard. Specifically, they wanted research to examine mental health in the context of employment (e.g., Hedley et al., 2019), and the extent to which autistic people must mask in the workplace to succeed, including the ramifications of such workplace masking (e.g., Pryke-Hobbes et al., under review). While initial research in this area is emerging (e.g., Harmuth et al., 2018), more research is needed, especially as autistic people are more likely to experience co-occurring mental health conditions than the general population (Lai et al., 2019).

Our findings largely map onto the findings of a recent consultation by the Australian Autism Research Council (2020). For example, participants in both consultations highlighted key topics such as a need for: (1) more meaningful employment opportunities; (2) improved hiring processes; (3) improved systemic processes (e.g., disability employment services); (4) improved workplace cultures and attitudes toward diversity, and (5) improved understanding about workplace adjustments. Unique to the current study, however, was the apparent need for more research exploring later stages of the employment journey, such as experiences of career progression and transitioning out of employment. Similarly, participants in our study shared concerns about the consequences of negative workplace experiences (e.g., impacts on mental health) and, unlike those in the Australian Autism Research Council (2020) consultation, prioritised research that meaningfully addresses these concerns.

In addition to identifying key autism-employment research priorities, our participants provided invaluable insights regarding *how* such research should be conducted. One key issue in this regard was the importance of listening to, and including, seldom-heard groups within

autism research. Indeed, some of our participants suggested it may not be uncommon for research to involve the same autistic people, or for research samples to fail to represent the diversity that exists within the autistic population. These claims are not unfounded: evidence suggests that autistic people with an intellectual disability, and those from ethnic minority backgrounds are all-too-often overlooked in current autism research (Hilton et al., 2010; Russell et al., 2019; West et al., 2016). Similarly, and perhaps somewhat inevitably, research may fail to reach those who are not interested in the research topic, or participating in research in general, as well as autistic people for whom being autistic is not central to their identity. As such, our participants wanted researchers to make concerted efforts for more diverse participant samples, so that they could make more meaningful recommendations for different groups of autistic people.

Based on these findings, we make two key recommendations. First, we suggest that researchers should involve autistic people in each aspect of the autism-employment research process, from conceptualisation to data collection and analysis. While the involvement of autistic people in autism research is gradually becoming more commonplace, genuine co-production whereby autistic people and non-autistic researchers share power in the research decision-making process is still rare, or rarely reported (den Houting et al., 2021; Fletcher-Watson et al., 2018; Pellicano 2014a, 2014b; Jivraj et al., 2014). Indeed, evidence suggests that autism researchers may lack a genuine understanding of participatory research (den Houting et al., 2021) and, furthermore, that the nature of academic research (e.g., funding constraints) could preclude the meaningful involvement of autistic people (Pickard et al., 2021). Overcoming these barriers could involve tailored training for autism researchers at any stage of their career, as well as more systemic changes to research processes to allow for the increased time and cost of participatory research (Pickard et al., 2021). Second, we suggest that autism researchers make greater efforts to reach people who are currently under-served

in autism research. Such efforts would also mean actively engaging with marginalised groups within the autistic and autism communities, including those with minority traits and/or characteristics. Researchers should also be transparent in the reporting of participant characteristics and acknowledge the limitations of their sample.

Limitations

Most notably, our own sample was not representative of the autistic population. For example, most of our participants were employed, educated to a Bachelor's Degree level or higher, and identified as coming from a White ethnic background. Similarly, given that our participants were required to complete a survey reflecting on their experiences, and considering future avenues for research, autistic people with intellectual disabilities were likely precluded from participating in this research. As a result, the research priorities outlined above only reflect the priorities of a sub-group of the autistic population and not those of all autistic people. People from minority ethnic backgrounds, and those with an intellectual disability, are likely to have unique experiences of employment (Merrells et al., 2019; Rafferty, 2012) and may have alternative priorities for future research. It is also worth noting that, unlike other priority-setting exercises (e.g., AARC, 2020), we did not ask participants to rank their priorities, which means we are unable to ascertain which of the identified priorities are the most pressing for autistic people.

Despite these limitations, this study clearly outlined the priorities of autistic people for autism-employment research moving forward. We hope that, by clearly presenting what the autistic community needs and wants from employment research, more studies will be conducted in response to and in close collaboration with autistic people, who should have the power to drive research that aims to benefit them.

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