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## Article:

Smethurst, L., Thompson, A. and Freeth, M. orcid.org/0000-0003-0534-9095 (2024) "I've absolutely reached rock bottom and have no energy": the lived experience of unemployed and underemployed autistic adults. Autism in Adulthood. ISSN 2573-9581

https://doi.org/10.1089/aut.2023.0171

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# "I've Absolutely Reached Rock Bottom and Have No Energy": The Lived Experience of Unemployed and Underemployed Autistic Adults

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#### Abstract

**Background**: Autistic adults are underrepresented in the employment market, and those in work are commonly underemployed. Our study aimed to gain an understanding of autistic adults' experiences of unemployment and underemployment.

**Methods**: Eight autistic adults who self-identified as currently unemployed or underemployed who were actively seeking to change their employment status participated in semi-structured interviews, analysed using Interpretative Phenomenological Analysis (IPA).

**Results**: Four group experiential themes were identified: '*Feeling paralysed*' (The past weighs heavy; Fragile self-confidence); '*Powerlessness*' (Lack of agency; Systemic support failures); '*Negative perceptions*' (Feeling misunderstood; Fear of judgement; Pressure to meet societal expectations) and '*Recognising our needs*' (Managing mental health difficulties; Importance of self-understanding). Participants felt paralysed by employment experiences which impacted their confidence to progress with their career aspirations. Autistic people felt misunderstood, judged, and powerless within support systems which had implications for their mental health. Participants recognised the importance of managing their mental health needs during times of unemployment and underemployment via self-care and seeking psychological support.

**Conclusion**: Putting resource into understanding, acknowledging, and addressing processes within and around employment should be priorities for policy makers if they are serious about improving support to help autistic people find and stay in work.

**Keywords:** *Autism; Unemployment; Underemployment; Interpretative Phenomenological Analysis; Qualitative research* 

## Introduction

Being in employment has many beneficial effects. It is evidently important from a personal economic standpoint but it also generally increases independence, social status, and self-esteem.<sup>1,2</sup> Employment conditions are linked to health and wellbeing, in that, high job insecurity and low-paid work have negative consequences for general wellbeing and exacerbate health inequalities.<sup>3</sup> Moreover, involuntary joblessness and underemployment are associated with adverse mental health, such as higher levels of anxiety and depression and lower perception of self-worth and self-esteem.<sup>4-6</sup> Social Identity Theory specifies that feeling part of an in-group increases well-being and self-esteem, thus increasing social functioning.<sup>7,8</sup> Hence it is not surprising that employment which fully utilises one's skills and abilities, feeling socially connected, and social support have been shown to be positive predictors of autistic quality of life.<sup>9,10</sup> Appropriate employment therefore has a range of potential benefits for autistic people.

Data published by the Office for National Statistics (2021) revealed that autistic people are among the least likely to be in employment of disabled groups in the United Kingdom (UK), finding that just 29% of autistic individuals aged 16-64 years were in employment compared to 81.6% of non-disabled people.<sup>11</sup> Further, employed autistic people were unlikely to be in senior roles, suggesting many in work are underemployed. The Labor Utilization Framework (LUF) defines 'underemployment' in three ways: involuntary part-time work (e.g., working fewer regular hours than desired), low-income work (e.g., income unable to meet basic needs), and skill mismatch (e.g., a mismatch of education and occupation).<sup>12</sup> These definitions are used in our study. Supporting autistic adults to find and stay in work is a current UK government priority as indicated by the National Autism Strategy (2021 - 2026)<sup>13</sup> and the recently published Buckland review of autism employment<sup>14</sup>. Research indicates that many autistic adults can work, have the desire to be employed and possess strengths workplaces can benefit from, yet an inordinate number of autistic people remain unemployed or underemployed compared to the general population.<sup>15-17</sup> Low employment rates may be partly attributable to autism-specific challenges such as experiencing difficulties with social communication, social relationships, adverse physical and/or mental health at work, sensory issues, and others' lack of autism awareness.<sup>18-22</sup> The 'double empathy problem'<sup>23</sup> highlights that when people with different experiences of the world interact, such as those who are autistic and those who are neurotypical, they may struggle to empathise and understand one another. Autistic adults have reported feeling it necessary to mask their authentic selves to gain employment and reflected on the challenges when trying to decode what employers were asking of them, as part of an investigation on UK hiring processes.<sup>24</sup> Thus, there is a need to support reciprocal understanding if improvements to employment rates of autistic people are to be achieved. Research aiming to gain a deeper understanding of how employment practices are experienced by autistic people will facilitate this improved reciprocal understanding.

Autistic people have explained that barriers to employment exist at a systemic level, such as societal labelling of autistic characteristics as deficits instead of positive attributes brought to the workplace.<sup>25</sup> Employers have been shown to erroneously assume that employing autistic people will increase operating costs and decrease productivity.<sup>26</sup> The minority stress model suggests that societal discrimination and difficult social situations over time impact autistic adults' well-being and self-esteem.<sup>27,28</sup> Further, the social model of disability specifies how people are disabled by physical and attitudinal barriers in society rather than their own inherent difference.<sup>29</sup> This may go some way to explaining the recruitment barriers faced by autistic people and may provide a pathway to improvement in employment experiences, to acquire insight into the impact on wellbeing, utilising qualitative methodologies.<sup>30,31</sup> Our study therefore aimed to better understand, and identify themes relating to, the lived experience of unemployment and underemployment within an autistic adult population via an in-depth investigation of lived experiences. In line with the principles of Interpretative Phenomenological Analysis,<sup>32,33</sup> the aim of our study was purposely framed broadly

and openly to enable flexible and open exploration of the area of concern, without predetermined hypotheses.

#### Method

We used interpretative phenomenological analysis (IPA) to analyse the data. This approach values the dynamic process between the participant and the researcher, engaging in "double hermeneutics". As such, participants convey meaning of their subjective lived experience through their accounts in the interview, following which the researcher attempts to make sense of and interpret the participant's accounts.<sup>33-36</sup> Features of IPA, such as its commitment to equality of voice and researcher's reflexive statements, are particularly appropriate for improving understanding of the experiences of autistic adults.<sup>36</sup>

We gained ethical approval from The University of Sheffield Department of Psychology Research Ethics Committee.

## **Participants**

We recruited eight un- or underemployed autistic adults for our study. As IPA is an idiographic approach, examining a particular phenomenon in a particular context, small and reasonably homogeneous samples are appropriate.<sup>35</sup> We excluded participants from taking part in the study if they were unable to speak English, or if they had a co-occurring learning disability or attention deficit hyperactivity disorder (ADHD) as we felt those with LD and/or ADHD may have a significantly different employment experience to those with autism without a common co-occurring diagnosis. Further, to be eligible for our study, participants needed to want to change their current employment status, as it is acknowledged that there may be a multitude of reasons for individuals to work part-time.

We asked participants at what age they received their autism diagnosis, and whether they were unemployed or underemployed. If underemployed, we asked participants to self-identify which of the three underemployment categories outlined by  $LUF^{12}$  they felt fit their current circumstances. As such, most participants (*n*=7) received an autism diagnosis in adulthood, five

participants self-identified as underemployed, and all participants stated they were actively seeking to change their employment status. See Table 1 for demographic information.

#### **INSERT TABLE 1.**

#### Procedure

We recruited participants via the Sheffield Autism Research Lab (ShARL) website, database, and twitter account. We posted brief study details online and emailed individuals signed up to the database. If participants were interested and self-identified as eligible based on the criteria stated on the study advert, they sent the first author an email confirming their interest. Following this, we sent the participant information sheet, consent form, and main interview questions. Semistructured interviews were conducted online and lasted between 26 and 91 minutes. The authors collaboratively developed the interview schedule in line with the aims of the study, and methodological guidance<sup>35</sup> (see Table 2).

## **INSERT TABLE 2**

We shared the interview schedule with participants in advance and this was supplemented by prompts as follow-ups from the interviewer to ensure clarity and to enable participant requests for further information. The interviewer debriefed participants at the end of the interview. Participants had the opportunity to ask the interviewer questions and received details of the lead researcher should they wish to ask further questions post-interview. We sent the participants a £10 e-voucher via their email address, with their permission, as a "thank you" for participating.

#### Data analysis approach

#### Reflexivity

The participant and their experiences are at the centre of IPA research. However, it is acknowledged that the interviewer and researchers play a significant part in the process.<sup>35</sup> An IPA researcher needs to be aware of their own beliefs, perceptions, and experiences so that they can enrich their interpretations rather than them presenting a barrier to making sense of the person's experience.<sup>34</sup> In our study, we aimed to remain close to the meaning-making of the individual to

offer insights into their personal experiences, whilst remaining aware of our identities as nonautistic researchers and clinicians. The lead researcher, a trainee clinical psychologist, has worked with autistic children, young people, and adults in various settings and has studied psychological theories and autism research. As such, she consciously remained reflexive about her knowledge and assumptions of the state of services accessed by autistic people in the UK and was mindful of favouring certain accounts with a mental health lens over those without. Keeping a reflective diary during each stage of the research<sup>37</sup> and engaging with supervision acted as a reminder for them to take off their 'clinician's hat' and consciously respond to participants and the data in an open, neutral, and transparent position.

## Analysis process

The first author conducted and transcribed all interviews and replaced participant names with pseudonyms. They analysed the data using IPA principles outlined by Smith et al.<sup>35</sup> Firstly, the first author read all transcripts whilst listening to audio recordings to keep the participant's voice in mind. Following this, they engaged in a detailed line-by-line annotation of the transcript using colour coding to highlight descriptive, linguistic, and conceptual aspects of the data. Then they began to generate possible interpretations, noting experiential statements from the exploratory comments to reduce the volume of detail whilst articulating the complexity of the participant's experiences. They then organised and mapped the data to consider how Personal Experiential Themes (PETs) fit together. Finally, they identified patterns of similarity and difference across the PETs to create Group Experiential Themes (GETs). All authors discussed each stage of analysis and agreed the final theme organisation. The trustworthiness of the analysed data was demonstrated via the researchers' reflective practices, supervision, and maintaining an audit trail to highlight how interpretations were grounded in the empirical data.

#### Community involvement statement

Two autistic adults, independent to the study, were recruited via the ShARL database to provide advice via email on the ethical considerations, research advert, participant information sheet

and interview schedule. Following feedback, amendments were made to the wording of several interview questions, prompts, and the participant information sheet, as some language used in the original documents was flagged as potentially being difficult to understand.

#### Results

Analysis of the data yielded four group experiential themes (GETs) and several group-level subthemes (Table 3). Verbatim participant quotes are provided to illustrate each theme. Themes are not an exhaustive account of participants' experience. They are an interpretation of prominent discourses.

**INSERT TABLE 3** 

## **Theme 1 - Feeling Paralysed**

This theme encapsulates participants' descriptions of feeling paralysed by the stress and trauma of application processes, paralysed by past experiences of marginalisation and rejection leaving feelings of hopelessness, and paralysed by lack of self-confidence.

*The Past Weighs Heavy*. Participants shared that the "*stress and the trauma*" (Ashley) begins right at the start of the application process. They spoke of the internal process of contemplating downloading an application taking "*mental energy*" (Marcus) that difficult past employment experiences have diminished. Participants recognised that a key contributor to their lack of energy for employment processes is autistic burnout stating, "*it's always been due to like burnout, so I've absolutely reached rock bottom and have no energy*" (Graham).

Furthermore, participants shared a narrative of feeling a dissonance between wanting to be within a desired and fulfilling role and not wanting to apply for jobs because "*it would put way too much of a mental burden*" (Marcus) on them, thus they remain paralysed within their current un- or underemployed circumstance.

"I'll just stick with this job and well I'll just do what I'm doing because I just can't really face the psychic trauma of getting a paper or going on the internet trying to troll jobs and then applying and feeling more debilitating" (Ashley)

Participants shared emotional distress to reminders of the traumatic experiences they have faced within employment. They described the "*terror*" (Susan) felt when considering applying for a job, sharing how it "*really is terrifying to to put yourself out there*" (Susan), and how distressing is it to feel "*that history will repeat itself*" (Susan). When feeling constant threat, participants felt unable to exit that state of mind and thus felt frozen in their current circumstance. Moreover, participants shared a sense of their life being "*defined by failure, or not getting, or knowing what to apply for and then… not getting a job*" (Ashley) and these negative thoughts and experiences present as a barrier to taking a chance and applying for desired roles.

*Fragile Self-Confidence*. Participants spoke of having limited self-confidence to apply for a role that would mean they were no longer underemployed. Subsequently, participants would elect to apply for or stay within roles that qualify as underemployed sharing "*I know I could probably do it but no, I wouldn't have the confidence to go for it [a higher role] like I have so much self-doubt*" (Grace) and "*I think that's tied in with confidence. I've always gone for jobs lesser than what I know I'm capable of doing*" (Alexander).

Moreover, one participant shared his experience of job advertisements using complex language which appeared to contribute towards an internal narrative of self-criticism and not being good enough. Despite their knowledge and qualifications, any job advertisement that triggered this feeling "*shattered my very fragile confidence and I never bothered applying*" (Alexander).

For some "*the self confidence has always been a problem*" (Ashley) and they have "*never really had a great deal of self-confidence or self-esteem*" (Graham) which appeared to stem from childhood and has consequently impacted their employment experiences. Others spoke of the damage that traumatic experiences of bullying have exacted upon their self-esteem and confidence.

These experiences have subsequently been internalised and impact upon their belief in their ability to return to work.

"I think I need more one to one support, because to be honest with you, I don't feel very much confident to get back to work, you know, especially with the bullying I had in the past" (Zayn)

## **Theme 2 - Powerlessness**

This theme covers participants' narratives of having limited power and control over their decision making and circumstances within and around employment processes and assumed support systems.

*Lack of Agency*. From the start of the participants' employment journey, they share a narrative of having no control over their own actions and being "*railroaded into other people's expectations but by accident*" (Graham) and how they *"just kind of drifted into things"* (Richard). Participants described uncertainty, not knowing, and receiving no guidance as to what they were qualified and/or able to do, which seemingly lead to the allowance of things happening to them and a sense that they were passive in decisions made.

Whilst unemployed and searching for suitable and desired employment, some participants were receiving financial aid provided by the government. However, this decreased participants' agency to make their own employment decisions and perpetuated anxiety around having to apply for unsuitable roles "*just to have a job so I'm not unemployed*" (Alexander). Participants worried that if support were to be retracted, they would be forced to apply for roles within unsuitable environments which they felt would have dire consequences for their mental health.

"I can't just go and get any job... if the government turned round to me tomorrow and said we're stopping your benefit you've got to get a job in [supermarket name]... then I would be probably dead within the year" (Susan) *Systemic Support Failures*. Support systems and services for autistic people in either unemployed or underemployment circumstances were described as "*non-existent*" (Alexander) and "*slim to none*" (Marcus). Participants were unsure or unable to find services that could guide them toward their desired employment, alongside considering and advocating for their needs as an autistic person through the employment processes (application, interview, in-role).

"there isn't really a strong support structure there to to guide erm adults and late late diagnosed... so it's really debilitating" (Ashley)

Moreover, the few services that participants were directed to were described as unsupportive. Specifically, several participants highlighted their difficulties with the job centre, which is a service set up to help individuals find appropriate employment.

"I'd rather lose my house, I'd quite happily live in my tent and wait until the winter takes me in the middle of you know, the Scottish highlands than rely on that [the job centre]" (Graham)

Participants also described feeling on the edge of support, specifically financial support. One participant explained that their "*wage is low, but then it's not low enough to ever receive any like support or benefits because I do work, so yeah, it's hard especially at the moment*" (Grace) and another described themselves as "*living like a hollow life where I'm just existing*" (Marcus) due to financial insecurity. Subsequently, participants shared the implications of such financial difficulties.

"I cannot afford to 'join in' as it would be such a big chunk of my disposable income which I need to save instead for financial security due to underemployment. This does affect friendships that are more activity based." (Graham)

## **Theme 3 - Negative Perceptions**

This theme encompasses the negative perceptions of others in society and the workplace, the feared negative perceptions that autistic people worry they will receive, and negative perceptions

that participants hold of themselves. Such perceptions impacted autistic people's well-being and motivation to return to work or to progress within their employment.

*Feeling Misunderstood*. Bullying experiences in the workplace were highlighted within several participants' narratives. For many these experiences appeared to stem from others showing limited understanding and compassion. As such, participants were labelled as "*weird*" (Zayn) and "*rude*" (Grace) and assumptions were made about them being "*difficult on purpose*" (Grace). Disclosure of their autism diagnosis also appeared to have some disadvantages with one participant sharing they had to continually "*justify*" (Ashley) their need for reasonable adjustments, and another stated that their diagnosis appeared to place a "*limit on what they [employer] think I can actually do*" (Grace).

In addition, "gaslighting" (Richard) experiences were noted, perpetrated by managers, feeling as though they were told to do one thing when they meant something different. Some of these experiences have impacted on individuals' ability to trust others, have the confidence to return to a work environment, and appear to have precipitated mental health struggles that may require "some kind of psychological help along the way" (Zayn).

"My faith in myself has been decimated. My faith in other people has been (pause) in an employment situation has been horrific. I I I don't trust people" (Susan)

Moreover, participants shared a sense of seeking increased understanding and compassion from others, including society, colleagues, and employers. Participants felt that it would be "simple" (Marcus) for individuals within society and the workplace to make slight adjustments to how they interact, relate to, and involve autistic people including "just taking time to learn a bit more about autism" (Grace) and "embrace it [autism] as opposed to trying to fit us in a box" (Susan). As such, autistic people would feel less like they need to "camouflage your way through" (Alexander) and instead be their neurodiverse authentic self.

"Why is it that I'm treated like a neurotypical person. I'd love to be able to talk to somebody who could understand neurodiverse people" (Alexander)

*Fear of Judgement*. Despite acknowledgement that some employers were offering reasonable adjustments, participants shared that they were "*wary*" (Grace) of accepting or requesting reasonable adjustments, especially before successful appointment of a role. Participants feared that these adjustments would be perceived as "*giving autistic people an advantage*" (Grace) or "*making demands*" (Ashley). There were suggestions that reasonable adjustments could be made for everyone. However, given that this is not the case, participants spoke of struggling through the process to escape such judgement.

"If people were offering me you know some good employers do now, they say... if you need any reasonable adjustments for the application, like, I'm not sure that I would take them up on it because companies have offered these things because it's the right thing to offer and they have the disability confidence tick, but actually, that really colours their perceptions" (Graham)

Perceptions of prospective employers felt particularly important, and individuals shared feeling as though their diagnosis and needs relating to this would instantly put them on the backfoot compared to non-autistic applicants. One participant shared *"I have a lot of needs, period, and if I tried to get that across like before I'm in a job, then they will choose someone else who doesn't have those needs*" (Marcus). Consequently, individuals felt that they were unable to be open on an application form about such needs, as this would put them at a disadvantage.

Similarly, there was an expressed anxiety around how an application with multiple short-term jobs or long periods of unemployment would be perceived by employers.

"You're confronted with your past failures whenever you fill in [an application form] ... and you think gosh, what is this going to look like to the employer. I'm always thinking ahead to how is this going to be perceived." (Ashley) *Pressure to Meet Societal Expectations.* All participants shared a narrative of societal expectations for an individual to feel a "*functioning member of society*" (Susan). Participants shared that being unemployed made them feel "*worthless… like I'm not meeting people's bare minimum expectations*" (Marcus). These expected transitions were described as putting immense "*pressure*" (Grace) on individuals to get a job, often leading them to apply for inappropriate or underemployed positions to be able to say they were employed and "*not a bum sitting on my own all day*" (Zayn). Consequently, employment would often break down and individuals were left to feel as though it was their "*fault*" (Ashley) for failing to succeed in the expected transitions.

"You are just made to feel like you're dragging the country down just by being unemployed and being autistic forced into those places you just don't want to be just makes you have a mental breakdown" (Alexander)

In contrast, one individual spoke of societal pressure to be "grateful" for being in a job and feeling the "guilt of when you do feel hard done by for it [being underemployed]" (Graham) as there will always be people who are in a worse position than themselves. This minimises their difficulties with the employment position they are in and reduces their confidence to advocate for themselves and their employment needs.

#### **Theme 4 - Recognising our Needs**

This theme reflects how participants found the importance of recognising and understanding both their personal and professional needs. Further, it reflects how this increased understanding could help to support them moving forward into their desired level of employment. Participants forged positive identities via learning more about themselves, their wellbeing needs, and needs as an autistic adult, supporting them to take back some agency and power.

*Managing Mental Health Difficulties*. All participants shared difficulties with their mental health and wellbeing. Participants highlighted how their past difficulties had implications for their current

motivation and confidence to apply for desired roles which decreased their wellbeing. Moreover, feeling stuck in their current employment circumstance also negatively impacted their wellbeing which further reduced their ability and motivation to apply for a desired role. As such, participants shared how processes prior to and within employment can trigger "*fear and stress and depression as well*" (Ashley) and has often led to "*burnout*" (Graham, Marcus) and an increase in anxiety. Participants shared a narrative of needing to be proactive in managing their mental health difficulties to "*stabilise my mental health and get into a place where I can build myself back up*" (Marcus).

Participants shared multiple ways in which they were able to proactively manage their mental health needs, including accessing psychological therapy, increasing time spent on hobbies, and increasing physical exercise by going to the gym. This increased understanding of what they might need to manage their mental health was discussed as something they felt would be important to consider when contemplating changing their current employment status.

"I've got a lot of time on my hands, but a lot of that time is spent on my allotment. That is the way I feel like the world isn't quite such a bad place. If I don't go I feel it in my mood, my stress levels increase" (Susan)

*Importance of Self-Understanding.* Most participants were diagnosed as autistic in adulthood and shared that when they were "*discovered autistic*" (Ashley) this enabled them to reflect on their past and the challenges they have faced within employment through a lens of increased selfunderstanding. Prior to their diagnosis, or awareness of their needs as an autistic person, they were unable to advocate for their employment, relational, and well-being needs because they "*never thought [they] needed it to be adapted*" (Grace). With this previous lack of awareness was a shared sense of sadness. Several participants wondered whether earlier awareness may have prevented their traumatic employment experiences and enabled earlier access to essential support.

"...and now knowing that I am, because I'm autistic, but not knowing in the past, so then rethinking about the past and how I went through life and why I have ended up here [underemployed]. It's something that plays on my mind all the time" (Ashley)

Having an increased awareness of their needs did provide hopefulness to some, with the diagnosis offering empowerment to disseminate a formulation of their needs and advocate for what does and does not work for them, including requesting reasonable adjustments.

"As soon as I got diagnosed I went straight to her [manager] and said, right I'm struggling, I've got this diagnosis, you need to know... I said to her look I cannot do nights" (Alexander)

Ultimately, participants shared a narrative that looking back knowing what they know now, they can show themselves some self-compassion and understanding of what they need moving forward within employment.

"I think I think this time I think I'm not going to just accept any job like before, because I really want to want to get into work, I was desperate to get into work. Now obviously there's a condition that I have to work around" (Zayn)

## Discussion

Our study aimed to investigate the lived experience of unemployment and underemployment in autistic adults who were actively seeking to change their employment status. The analysis yielded four group experiential themes: *'feeling paralysed', 'powerlessness', 'negative perceptions', and 'recognising our needs'*. The findings demonstrate that previous negative experiences around employment can have profound, enduring effects on autistic adults. These effects led to fear of engaging with the employment process, resulted in feelings of hopelessness and decimated selfconfidence more broadly. These experiences damaged the prospect of future successful employment. Participants felt they lacked control over their employment situation, particularly due to systemic support failures experienced. There was consistent concern regarding feeling misunderstood, judged and that there was external pressure to meet societal expectations. Participants did not feel that responsibility for the situation was being taken by employers. Participants recognised the importance of understanding and managing their own mental health difficulties and a proactive approach to this was dominant in the narratives. These results demonstrate the importance of investing resource into understanding, acknowledging, and addressing sub-optimal employment processes. This will be imperative for organisations and policy makers if they are serious about improving the employment rates of autistic people.

Consideration of the findings in relation to theories and frameworks previously applied to autism provide further insight and interpretation to the results. The minority stress model suggests that societal discrimination and difficult social situations can fundamentally impact on well-being and self-esteem over time<sup>27</sup>. Previously this model has facilitated identification of minority stressors commonly experienced by autistic people, including discrimination, internalised stigma and concealment. Experience of these stressors significantly predicted poorer mental health in autistic people, even when general stress exposure was controlled for <sup>28</sup>. Experiences of victimisation, which can result from discrimination, have been shown to have enduring effects on autistic people resulting in autistic people internalising the view that they themselves are the problem<sup>38</sup>. In the current study there was clear evidence of experiences of repeated external stressors, such as discrimination and other difficult situations around employment. These experiences of external stressors were reported to result in the experience of internal stressors, such as identity concealment and masking. There was evidence of self-esteem and self-confidence being worryingly low in the current cohort. Participants shared self-critical narratives of not being good enough and being defined by past employment failures. Self-confidence is understood to be established via positive feedback about one's abilities<sup>39</sup> and is linked with self-esteem and the self-assessment of self-worth or value.<sup>40</sup> Thus, participants' lack of self-confidence may be, partly, attributable to minimal

positive feedback around employment. Principally, participants appeared to get stuck in a cycle whereby their limited self-confidence made it hard to apply for and succeed in gaining desired employment, further shattering their self-worth and confidence. Participants shared the experience of feeling frozen or stuck, with a desire to stay away from recruitment processes despite their skill set, potentially indicating a trauma response<sup>41</sup>. As proposed by others,<sup>42</sup> findings highlight the importance of acknowledging and validating individuals' subjective responses and interpretation of an event when attempting to manage the impact of trauma experienced by autistic people.

Participants referenced autistic burnout and described their limited emotional capacity to engage with employment processes. Autistic burnout is characterised by exhaustion, withdrawal, reduced functioning, and heightened autistic traits.<sup>43-46</sup>. There was evidence that participants were aware of their stigmatised status and anticipated future potential discrimination. Coping mechanisms included masking and engaging in avoidance behaviours though there was also some evidence of development of resilience. Participants felt they could not be authentic throughout employment processes and within the workplace. These findings align with previous research indicating that attempts to fit autistic people into a neurotypical world increases autistic masking, which is exhausting and inhibits autistic people from functioning at their best in the workplace.<sup>47</sup> Worryingly, multiple participants felt discriminated against and experienced bullying when trying to be authentic. There was also evidence that experiences related to exposure to stressors results in long-term adversity and may be contributing to poorer health outcomes, as suggested by the minority stress model.

Social Identity Theory explores how individuals categorise themselves and others into social groups, and how this process influences intergroup behaviour and attitudes<sup>7</sup>. Autistic adults in the current cohort reported feeling excluded from in-groups during employment despite engaging in camouflaging and masking behaviours to try to fit in. Feeling part of an in-group is considered important by Social Identity Theory in creating a sense of belonging. It has previously been shown, using Social Identity Theory as a framework, that in autistic adults, higher perceived autism stigma

predicted higher levels of self-reported camouflaging behaviour and lower mental wellbeing<sup>48</sup>. In the current cohort, there was evidence that in their employment experiences autistic employees had not benefitted from in-group biases, even when they had explicitly worked hard to try to engage in masking behaviours to try to achieve the goal of being part of an in-group. Engaging in these tiring, but ultimately unsuccessful behaviours in terms of acquiring in-group status, likely contributed to the reported experiences of burnout.

The double-empathy problem theory suggests that there is a reciprocal nature to communication difficulties experienced between autistic people and neurotypical people with neurotypical people tending to lack insight into the perspectives of autistic people<sup>23</sup>. It was clear from the experiences described that a lack of understanding of both autism in general and a lack of empathy on the part of the employer towards the autistic individuals had been experienced. However, there was no evidence of responsibility for this being taken by the employer or positive action taken to mitigate the potential effects of a lack of insight from an employer perspective.

The social model of disability proposes that autistic people are disabled by physical and attitudinal barriers in society<sup>28</sup>. Further to this, the social relational model of disability has been used to investigate how disability is constructed in the workplace<sup>49</sup>. It has been used to understand the impact of the workplace on autistic people proposing a critique of traditional approaches that place employers, managers and human resource professionals as the dominant agents of workplace decision-making rather than facilitating autistic people to be central agents of change in workplace structures<sup>50</sup>. In the current cohort there were clear expressions that employment systems experienced were not meeting the needs of autistic people and they felt a lack of control, or powerlessness. Thus, the result was the experience of being disabled by the systems themselves, which concurs with the conclusions of others<sup>47,50</sup>. Participants described worries about requesting reasonable adjustments based on fear of being judged by prospective or current colleagues and employers. Making reasonable adjustments accessible to everyone throughout employment

could reduce perceived unfairness and make the workplace environment fully inclusive.<sup>51,52</sup>. Postdiagnostic and employment support were noted as lacking within the current study. Specifically, participants experienced unsupportive and dismissive vocational support services (e.g., the job centre). The Buckland Review of autism and employment provides recommendations aimed at reducing barriers to employment for autistic people, which will hopefully facilitate organisations to improve aspects of their processes<sup>14</sup>. The national strategy supporting individuals into employment recommends ensuring the job centre welcomes and supports autistic individuals.<sup>13</sup> However, the results of the current study suggest further consideration may be required given the intensity of hesitation to access such support by the current participants.

Given the broad range of challenges experienced, as outlined in the previous paragraphs, it is imperative to work towards practical solutions. Some of these can be derived from the narratives of participants in the current cohort themselves. Participants shared a sense that neurotypical people within the workplace need to be more aware of autism-specific struggles and that there would be simple ways to increase their understanding of autism, their compassion, and kindness. Previous research has indicated that employers feel providing autism awareness training would be practical, feasible and implemented without excessive difficulty, and also that training has the potential to increase autistic people's confidence, job performance, and employer's confidence to recruit autistic people.<sup>26,47</sup>. The current findings indicate a need for the emotional loading of job applications to be considered when supporting autistic people into and within employment. However, this is not currently reflected in the national strategy.<sup>13</sup> Participants described feeling forced into roles unsuited to their needs, aligning with findings that autistic people encounter barriers to support to grow a career.<sup>30</sup> There is a need to ensure employment is aligned with the individual's strengths and interests rather than mould the person to the environment. Further consideration of ways to achieve these goals ought to be a focus of future interventions.

It is clear that the IPA approach used in the current study afforded great in-depth insight into the lived experience of the participants who generously gave their time to contribute. However, it is

important to interpret and reflect on the findings with reference to the demographics of the sample as factors such as age, gender, education and diagnosis age have been shown to be relevant in predicting employment profiles in autistic people<sup>54</sup>. This cohort of participants were not at the start of their journey into employment, most of the cohort was over 45 years of age. The sample was also well-educated and there was a lack of racial diversity in the sample, with seven of the eight participants identifying as white British. As suggested previously black autistic people may "wear a triple mask"<sup>55</sup> thus the experiences of the current cohort may differ from those from other ethnic backgrounds. Participants were predominantly recruited through the Sheffield Autism Research Lab database, and therefore this research is likely to have gathered the views of people interested in research. Finally, further research is required to explore the experience of autistic adults diagnosed in childhood to determine whether there are differences in their experiences compared to the current study whose participants were predominantly diagnosed in adulthood.

In conclusion, autistic participants shared narratives of traumatic employment experiences, both pre-recruitment and within roles. There was powerful discussion of how challenging experiences impacted self-esteem, self-confidence, and well-being. There was a desire for increased compassion and understanding from employers, colleagues, and the wider population. It was felt that without these things participants would continue to feel powerless against the systems that are supposed to enable support but had been experienced as ineffective. Finally, autistic people recognised their mental health needs were exacerbated by negative workplace practices and experiences. Participants attempted to proactively manage their well-being through self-reflection and understanding, physical exercise, therapy, and meaningful activity though this was experienced as challenging. Our study highlights the need for policy makers and clinicians working with autistic adults to be aware of these employment challenges and to provide a non-judgemental space to make sense of their experiences through a lens of self-compassion. Further, anti-stigma interventions are needed in the workplace, and an organisational commitment to inclusivity and diversity is required to enable autistic people to feel empowered from the beginning of their employment journey.

#### **Authorship Confirmation Statement**

L.J.S conceptualised this work and led the data collection, transcription of data, data analysis, and drafting of the study. A.R.T and M.F supervised L.J.S and supported the study's conceptualisation, design, and interpretation of the results. All authors revised the article and approved of the final version for publication. The article has been submitted solely to this journal and is not published, in press, or submitted elsewhere.

## Acknowledgement

We would like to thank the eight people who took the time to share their experiences with us, we are thankful for their willingness and courage to speak so openly about their experience. We would also like to thank the two autistic individuals who offered their time and guidance while developing the interview schedule and participant facing materials for our study.

## **Author Disclosure Statement**

No competing financial interests exist.

## **Funding Information**

The University of Sheffield DClinPsy programme. MF was supported by funding from the Colt Foundation

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## **Table 1. Participant Demographics**

Name <sup>a</sup>	Gender	Age Group <sup>b</sup>	Ethnicity	Elapsed Time Since Diagnosis <sup>b</sup>	Highest Qualification	Employment Status	Category of Underemployment
Grace	Female	25-34	White	2-5 years	Undergraduate Degree	Underemployed	Part-time hours (30)
		years	British				Underutilising full skills and abilities
Ashley	Other	45-54	White Irish	5-10 years	Undergraduate Degree	Underemployed	Part-time hours (22.5)
		years	white mish				Underutilising full skills and abilities
Susan	Female	45-54	White	2-5 years	Higher National	Unemployed	N/A
		years	British		Diploma (HND)		
Graham	Male	35-44	White	5-10 years	Higher National	Underemployed	Part-time hours (22.5)
		years	British		Diploma (HND)		Low-income role unable to meet needs
Zayn	Male	45-54		<b>5</b> 10	Undergraduate Degree	Unemployed	Previous experience of underutilising
		years	Arab	5-10 years			full skills and abilities
Alexander	Male	45-54	White	2-5 years	Higher National	Underemployed	Part-time hours (24)
		years	British		Diploma (HND)		Underutilising full skills and abilities
Marcus	Male	25-34	White	10+ years	Diploma of Higher	Unemployed	N/A
		years	British		Education (DipHE)		N/A
Richard	Male	55-64 years	White British	> 2 years	Higher National Diploma (HND)	Underemployed	Part-time hours (7) Low-income role unable to meet needs

Note: <sup>a</sup>All names are pseudonyms to protect confidentiality. <sup>b</sup>Exact ages and time elapsed since diagnosis are not reported to protect confidentiality.

## **Table 2. Main Interview Questions**

## Interview Questions

- 1. When you were coming to the end of your school years, what did you want to do for work?
- 2. Can you tell me about your experience of when you first started applying for jobs?
- 3. Can you tell me about your current experience of trying to gain the type of job that you want?
- 4. What has it been like for you during periods of being out of work (unemployed) and/or underemployment?
- 5. How does being unemployed / underemployed affect your day-to-day life?
- 6. What sorts of thoughts and feelings have you had about being unemployed and/or not being at your desired level of employment?
- 7. Is there anything else that you have not had the chance to tell me about today that you feel would be important for me to know about your employment experiences?

Group Experiential Theme	Group Level Subtheme			
Feeling Paralysed	The Past Weighs Heavy			
	Fragile Self-Confidence			
Powerlessness	Lack of Agency			
	Systemic Support Failures			
Negative Perceptions	Feeling Misunderstood			
	Fear of Judgement			
	Pressure to Meet Societal Expectations			
Recognising our Needs	Managing Mental Health Difficulties			
	Importance of Self-Understanding			

## Table 3. Group Experiential Themes and Group-Level Subthemes.