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The Lived Experience of Autistic Adults in Employment

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Abstract

Background: Employment is a critical factor contributing to the wellbeing and quality of life of autistic people of working age. Historically, research has tended to focus on interventions and employment-related outcomes, typically generated without the input of autistic workers. Interventions often work to help the autistic worker fit into the working environment rather than it being adjusted for the autistic worker. However, a growing body of research reflects autistic workers' experiences of employment with consideration given to how the workplace should change to reflect the differences of this historically marginalised group.

Methods: The current study is a systematic analysis of existing research that focuses on and prioritises autistic workers' experiences of employment. Our analysis draws on the social relational model of disability (SRMD), an approach increasingly applied in contexts of autism and employment. We systematically searched five journal databases, resulting in 34 papers which reflect the lived experience of autistic people in employment.

Results: We identified four themes through narrative synthesis: *Navigating Social Demands; the Disabling Nature of the Work Environment designed for neuro-typical workers; Adapt to Me;* and *Understanding, Knowledge, and Acceptance*. The results draw on the SRMD, revealing nuances to inclusionary and exclusionary employment for the autistic workforce.

Conclusion: Our findings encourage the prioritisation of the voice of autistic workers when designing working environments. They also function as a critique of the traditional approaches which placed employers, managers, and human resource professionals as the dominant agents of decision making. In these traditional practices, the burden of making employment viable was on the worker, rather than the employer. The results of the current study framed through the SRMD allowed for enhanced understanding of the barriers and new insights into how to improve the employment experience for autistic adults.

The lived experience of autistic workers in employment: A systematic search and synthesis

Background

Employment rates are low for autistic working people despite several legislative and human resource (HR) efforts. Recent United Kingdom (UK) employment records show only 22% of autistic people are employed, compared with 52% of disabled people.¹ Internationally, the picture is similar. Australia reports 27% of autistic people are employed.² In the United States of America (USA), although 58% of autistic people aged 18–25 work for pay, only 21% of those are in full-time employment.³ These statistics, while striking, only reveal the lack of employment for autistic workers^a. What is less well understood are the experiences and challenges for autistic workers in employment,^{4,5} such as adapting to workplace culture and communication.^{4,6}

Interest in employing neurodivergent workers, including autistic people, is increasing.^{7,8} For instance, some employers are attracted to the cognitive profile of autistic workers, in that autistic people are characterised by an ability to pay close attention to detail and they may bring different and valuable perspectives to issues.⁹ In addition, autistic workers may enjoy the tasks other workers find repetitive and unengaging.^{9,10} Employers view autistic workers as trustworthy, reliable, efficient, and honest.^{11,12} They also associate autistic people with having a strong work ethic,¹³ resulting in fewer absences, and that they are less tardy compared to other workers.¹⁴ Interest in employing autistic workers may also be driven by a moral and legal obligation for businesses to make workplaces accessible to disabled workers. Indeed, under the UK's Equality Act (2010), the USA's Disabilities Act (1990), and a range of EU policies,¹⁵ autistic workers are protected from discrimination. This means autistic workers can demand that employers make workplace adjustments.

Research on the employment of autistic people has included the perspectives of family members,¹⁶ employers,¹⁷ and various other stakeholders¹⁸. The focus has traditionally been on employers' perspectives about why they choose, or refuse, to employ autistic workers and what benefits or challenges the employers foresee.^{19,20} A larger body of literature has also focused on outcomes, for instance, gaining employment and employment duration, while the lived experience of autistic workers during employment has been neglected.²¹ Lived experience refers to how workers live through and respond to the challenges associated with employment,²² including a consideration of the experiences of the worker rather than just a descriptive account of such experiences.²³ For example, someone's lived experience account might include how the sensory experience of getting to and from work, and being at work, can affect productivity.²⁴ The literature regarding lived experience is growing, however, the discussion remains limited to experiences following the implementation of adjustments or interventions,²⁵⁻²⁷ factors impacting success,²¹ or the strengths autistic workers bring to work.²⁸ Recognising the often missing voices of autistic workers, our current review exclusively focuses on autistic workers' interpretation of their employment experiences.^{18,29} Our focus reflects the growing autism self-advocacy movement, including the 'nothing about us without us' campaign, that appreciates the value the autistic perspective brings.³⁰

This current review draws on the social relational model of disability (SRMD),^{31,32} which is a theoretical advancement on the social model of disability. The SRMD has been used to

^a In the paper, we use the term 'worker' instead of 'employee', as we believe it captures the full range of ways autistic people engage with paid work, such as employee, self-employed, or casual worker.

investigate disability in employment moving beyond individualistic models and allowing reflection of how disability is constructed in the workplace.³³ We apply the SRMD to understand not only the disabling environmental, attitudinal, and social barriers faced by those living with impairments, but also the ‘impairment effects’. Impairment effects include the material effects of a condition or impairment, for instance, autism is associated with sensory sensitivity, therefore an impairment effect would be difficulty hearing in a busy environment or headaches from lighting. The SRMD makes the case for impairment effects as not inherently disabling, but may impact the way the environment or society disables the individual.³² The SRMD can be drawn on to support a wider, yet unique understanding of how autism is constructed in employment contexts and how ableist practices may disable or discriminate. For instance, the unique social profile of autistic individuals may limit the ability to communicate with non-autistic colleagues in the workplace due to the use of communication methods which are unsuitable for the autistic person. Employment for autistic adults has been significantly influenced by environmental and attitudinal factors,^{34,35} thus, the SRMD offers a beneficial perspective, which is translatable into practice, to investigate autism employment and potential to provide new insights into the phenomenon.

The current review provides a qualitative evidence synthesis (QES) based on the first-hand experiences of employment from autistic workers.³⁶ A QES goes beyond the findings of a single qualitative study and draws conclusions that may be overlooked in a single study.³⁷

Our study identifies what the first-hand experiences of employment are for autistic workers, analysing experiences by drawing on the SRMD. In this review, we use identity first language, for example, ‘autistic worker’, rather than ‘worker with autism’, both to align with the social model of disability,³⁸ and with how autistic workers consistently express a preference for identity-first language.³⁹

Methods

Our methods followed the guidelines for systematic reviews, including the use of protocol and quality assessment, following the Preferred Reporting Items of Systematic Reviews and Meta-Analyses (PRISMA),⁴⁰ and utilised QES guidelines.³⁶ The extraction and synthesis we adopted followed the methods outlined by Thomas and Harden,⁴¹ identifying the key categories of experience. We conducted additional steps of synthesis and analysis to explore the data reflexively and produce more in-depth results.

Search strategy

We conducted a broad search across the years 1990–2022 and a range of journal databases. Databases included: Education Resources Information Center (ERIC), Medline, PsycINFO, Scopus, and the Web of Science, with each providing coverage of journals relevant to the research focus. We did not source grey literature. Our initial search took place on 4–13 January 2021. A follow-up search was conducted on 24 June 2021, which specifically considered papers released since the initial search. We conducted a third and final search on 24 April 2022, again considering papers released since the initial search.

Our search terms were chosen to identify papers exploring both autism and employment. Our search terms were used in conjunction with filters (when available in the databases) to identify a comprehensive collection of research. To identify the most appropriate and all-encompassing terms we used a database thesaurus. Our search terms were: Autis*; ASD; Asperger's; Pervasive developmental disorder; Neurodiver*; Work; Work*; Employ; Employ*; Occupation; Personnel; Colleague; Job; Manag*; Supervis*; Professio*. Where available, we used filters to refine the search. The exclusion filter used was: research areas – Paediatrics.

The inclusion filters were: research type – qualitative; population age – 18 years and older; language – English; timespan – 1990–2022.

We searched each term separately within the database. Following that, we combined the search terms together using “OR” to separate within population terms and context terms, and then these groups were combined using “AND”. We identified additional papers through reference sections and through correspondence with co-authors of the current research.

The inclusion and exclusion criteria we used can be found in Tables 1 and 2. We used these criteria to include papers at the title screening, abstract screening, and full text screening stages. When a decision regarding the inclusion or exclusion of a paper could not be made from the title or abstract screening, we included the paper in the full text review.

We defined an experience of employment as including any aspect of paid employment, a criterion including day-to-day working experiences, the difficulties and challenges faced, work tasks, worker strengths, the difficulties maintaining or acquiring employment, communication in employment, or any discussion on workers’ attitudes towards employment.

Figure 1 here

Tables 1 and 2 here

Study selection

Our first and second authors reviewed the literature at the abstract and full text level. All search results were initially screened by the first author through abstract review followed by full text review. Our second author provided two checks of randomised samples. Firstly, 10% of the identified papers for abstract review were screened by the second author ($n=54$), resulting in 100% agreement. Due to the high level of agreement at the abstract review level, 10% of the papers were selected for full text review by the second author ($n=15$). The full text review allowed for an in-depth discussion of the papers. The second reviewer performed the task independently to ensure the trustworthiness and accuracy of the review process. Our review process led to one discrepancy at the full text assessment level, resulting in that paper being removed. The paper in question did not contain clear first-hand perspectives from autistic individuals. As a result of the exclusion, we added a criterion to exclude studies where the origins of the data were unclear. Our review process is further detailed in Figure 1.

We conducted a critical appraisal to ensure the selected studies were free from methodological issues impacting the quality of the review findings. The method we used to exclude such methodological issues was based on the Critical Appraisal Skills Programme (CASP).⁴² We converted the criteria into a checklist and tool for assessing qualitative literature based on the work of Butler, Hall and Copnell.⁴³ Scores ranged from 0 to 10, with scores of 9 or more considered high quality, scores lower than 7.5 considered low quality, and papers with scores less than 6 recommended to be discarded. We found no papers met the threshold for being discarded. Our CASP scores are presented in Table 3.

Data extraction

As noted earlier, our method of qualitative systematic review was QES, an approach with more than 30 different published techniques to conduct extraction.³⁶ Our study used thematic synthesis,⁴¹ chosen due to its guidelines and relevance in providing a means of extraction. All data reported as ‘results’ or ‘findings’ of the selected papers, including all tables and images that are referenced within these sections, were included in the data extraction process. Our

approach includes first order constructs (participant quotes), and second order constructs (researcher interpretation).

Synthesis, analysis, and reflexivity

Our method used a three-stage process: line-by-line coding, developing codes into descriptive topics, and generating analytical themes from topics and data. We entered all data into Nvivo software, where the extraction and data synthesis procedures took place.

We coded each line of text to one or multiple categories based upon its meaning and content. We coded each sentence under a heading summarising the context of the sentence or added it to an existing code where appropriate. Once done, we coded material relevant to working experiences. Within the first stage of synthesis, we made 124 unique codes.

The data included in our process of recoding and categorising data was restricted to data discussing the autistic workers' lived experience of employment, including first-hand experiences of employment, direct discussions of the first-hand experiences of employment, and researcher analysis directly surmised from these experiences. We coded and grouped the extracted data, and a hierarchal structure created. For example, we grouped under an overarching heading of 'work environment' codes such as 'adapting to work culture', 'job demand challenges', and 'sensory experiences'. These overarching headings became the initial categories, and by the end of such grouping, five descriptive categories were identified.

We analysed the data within these categories a final time to explore new understandings and to provide analytical themes. Our final process used our lead author's interpretation of the data and the descriptive themes identified previously to interpret the experience of employment for autistic workers. Here the methodology differs from the guidelines of thematic synthesis. Our interpretation used a reflexive approach to provide reviewer insight into the topic. We acknowledge the positionality of our research, led by an autistic worker with a background of research in autism and employment, as it forms part of the process by which our analysis took place. The SRMD represents the main driver of analysis, and the lens by which to frame the entire paper. The SRMD conceptualisation of disability represents an advancement on the social model of disability, which has been widely criticised for marginalising the realities of impairment. Consequently, for those adopting the SRMD, disability is viewed as oppression through environmental factors onto an individual, but does not ignore or marginalise the lived experience of impairment effects.

Community involvement

As already noted, our research was led by an autistic person. Additionally, the focus of our research was putting the autistic voice under the spotlight. We incorporated a community focus in the review inclusion and exclusion criteria, including only the autistic community's' first-hand experiences in the analysis.

Results

Figure 1 shows our selection and screening process (PRISMA flowchart). Thirty-four papers met our inclusion criteria. We reviewed these papers for quality using the CASP.⁴² All 34 papers met quality requirements and were selected for inclusion in the systematic review. Table 3 summarises these papers. Employment experiences identified through our analysis fell within five categories: 1) Social; 2) Environmental; 3) Attitudinal; 4) Factors contributing to employment success; and 5) Disclosure and adjustment requests. Within these categories, we noted four themes highlighting autistic workers' employment experience. The

following identified themes were used to organize the results: *Navigating Social Demands; the Disabling Nature of the Work Environment designed for neuro-typical workers; Adapt to Me; and Understanding, Knowledge, and Acceptance*

Table 3 here

Navigating social demands

Description: Out of the five categories identified through our analysis, the theme Navigating Social Demands draws on experiences predominantly from the Social category. Social workplace experiences represent demands on, and challenges for, the worker, with the impact of these varying between worker accounts. The extant literature shows a complex interaction between impairment effects due to different communication styles and non-autistic (often unspoken) social norms and practices within workplaces.

Studies demonstrated how communication in the workplace was challenging for many workers.^{4,16,24,44-53} We identified several aspects of communication as challenging: ‘small talk’ and engaging in ‘social niceties’ was often difficult and tedious^{4,18,49,51,53,54}; reading body language and understanding social cues were additionally experienced as difficult.^{4,12,46,53} Our analysis revealed that while receiving feedback on performance is an important part of workplace communication, many autistic workers felt that how such information was communicated was difficult to understand or of little use.^{12,48-51,55} One challenging aspect was when there were miscommunications or misunderstandings,^{4,16,24,44,45,50,51,53,55-58} with such miscommunications often leading to conflicts at work^{4,16,46,48,50,51,55}. For example, Anderson et al. wrote:

*Gregory (CA-28) lost a position mowing lawns when two clients complained, one saying she didn’t like the way he talked to her and the other saying he was “aggressive” and “arguing with him” although he hadn’t intended to be confrontational.*¹⁶

The consequences of such conflicts impacted the employment experience.^{16,48-52,54,58-61} Social experiences were often overwhelming, distressing, or culminated in a meltdown, which could lead to a feeling of burnout.^{12,16,24,44-46,48-52,54,58-61} Due to navigating social expectations, workers reported difficulties in rejecting requests to take on more work or tasks, as they felt unable to say no.^{48,51} Individuals often experienced discrimination based on interpretations of expected social behaviour by both managers and colleagues,^{4,44-47,49-51,57,59} such as being reprimanded for asking many questions,⁴⁹ or patronised based on social abilities.^{49,52} Some workers highlighted the pressure of after-work socials which could be stressful and confusing.^{44,49-51,55} Many experienced isolation at work due to social challenges.^{4,50,51,53,57,58} Some workers reported being unsuccessful at forming work-based friendships,^{4,50,51,56} or having negative interactions with colleagues.^{4,49-51,53} Examples of where we identified such difficulties are shown in the following participant quotes from two studies:

*“Even one interaction with one person in an hour sometimes can be exhausting.”*⁴⁴

*“Sometimes they would refuse to talk to me... One lady would pretend I didn’t talk... she would ignore me, and I’m not sure why.”*⁵⁰

We saw in other instances, however, autistic workers reporting social experiences in more positive terms, indicating thriving in the social dimensions of job roles.^{24,44,52,58,61-64} Some workers considered navigating the social dimensions of work as a strength they possessed,^{4,52,61,64} valuing the friendships they made in the workplace,^{51-53,62} or because they desired social relationships.^{53,58,62} We also saw how others saw a lack of social focus to be an

advantage in the workplace, with one worker feeling being less socially focused made them more objective as they were less influenced by the group's perspective.⁶⁵ Individuals were able to utilise social skills in some aspects of their work while finding other social aspects difficult.^{24,44,61} Examples of these nuanced social experiences are demonstrated in the following participant examples from two studies:

*"I really enjoyed the tour guide just because you literally are reciting the script. I was the tour guide so it was like, 'Here is this is. Here this is what that is.' So when people ask me questions about my hometown I am like, I know all this stuff'."*⁶¹

*A teacher wrote that although being "fine with the kids", it is "exhausting being a colleague" and that she struggles "to understand the adults and some of their standards."*²⁴

The disabling nature of a work environment designed for neurotypical workers

Description: The work environment is made up of factors from environmental, social, and attitudinal categories, each having an impact on the work experience. We consider the typical work environment disabling for most autistic workers, due to the neurotypical design of work practices and environments. As such, we explored the impacts of an environment designed with neurotypical colleagues in mind.

We considered several physical aspects of the built environment affect work experiences. Of note were sensory factors, such as noise,^{4,6,12,24,44,45,51-55,63} lighting,^{4,24,44,45,54,55,63} and temperature,^{16,45,48,52} with the work environment frequently viewed as overwhelming one or more of these senses.^{4,48,51-53,55} The setting of the environment was important, with one consideration being physical separation, expressed through a dislike of open-plan offices,^{51,54,63} benefitting from physical separators, such as walls and cubicles,^{6,51,52} and favouring working alone or independently.^{6,46,51,52} Many workers felt working in settings other than the workplace offered a positive experience, including working from home or a café.^{18,51,57} When the environment was adapted to the worker, they had a more successful work experience,^{4,44,46,48,51-53,55,57} leading to improved wellbeing.^{4,16,24,45,46,48-51,57,60,63,64,66} An example of the built environment disabling the autistic worker is represented in the following participant quote:

*"They decided to pull out a couple more walls, so I have even more background noise and insane conversations to try and block out."*⁵¹

While the built environment presented many challenges, we identified mixed responses in the level of structure versus flexibility which an autistic worker would prefer in a workplace. Some favoured a flexible environment,^{4,6,18,46,51-53} while others found structure to be more important.^{4,6,24,45,51-53,62,67} Structure was tied to the concept of having clearly defined job roles and instruction,^{6,12,24,46,49,51,52,56} while flexibility was related to notions of independence.^{6,46,51,52} We found other non-physical aspects of the work environment were also important, as many valued shorter working hours^{12,51} or flexible working hours,⁵³ and discussed how transport to work could make work more difficult.⁵⁶ Company culture was described as an important predictor of work success, but it was seen as difficult to adapt to.^{4,24,45,51,54,68} For example, a supportive culture, with accommodating superiors, often led to a successful work experience.^{4,45,48,51,53,57,63} We show the contrasting effects of work cultures with the following participant quotes:

*"I like my job but I need enough to do and not feel bored. I also find it difficult to follow rules that dictate how I have to do things. Working from eight to five with exactly one hour break in the middle is hard. I also cannot leave earlier if I finish my work. So, I become bored and agitated. I really don't need this stress."*⁶

*"There were a few times where I was panicking and stimming [self-stimulating] a lot, and she (the manager) would come and help calm me down and ask me if she could help me with what was upsetting me."*⁶⁴

Aside from the contrasting and often ambiguous effects of work cultures, the work environment also generated or exacerbated negative emotions in the workplace, such as anxiety.^{16,24,47,49,51,58,68} Negative emotions in the workplace led to physical symptoms, with many studies reporting autistic workers felt exhausted due to workplace demands,^{24,46,48,49,51,67} or developed other physical symptoms, such as headaches, pains and panic attacks.^{24,48,51} The typical reaction to workplace stress, however, was burnout.^{24,51,67,68} Importantly, workplace stress was not an end in itself, often culminating in workers experiencing a shutdown^{16,51} or meltdown.^{6,16,44,48,49,51,66} Hurlbutt and Chalmers portrayed how such powerful experiences manifest for the autistic worker:

*Rosalind shared that she likes her work but finds that she is exhausted when she goes home and sometimes is "so tired that I slip into 'robot' voice or start toe walking without even realising it."*⁴⁹

Adapt to me

Description: Across all categories, a consistent theme identified in our analysis was how improvements came from adapting the workplace to the worker, rather than attempts to adapt the worker to existing expectations and environments. Specifically, adaptations were through adjustments within environmental, social, and attitudinal categories, and is considered a factor impacting success for autistic workers in the workplace.

Our analysis revealed how many autistic workers felt 'unique' or 'different' when comparing themselves to others in their workplace.^{4,18,45,51,57,68,69} These differences translated into different working habits and a need for working environments to suit the worker. Where workplaces were changed to suit autistic workers, we established how employment led to more successful experiences.^{4,16,24,44-46,51,53,55,65} The following is one example of a participant describing the value of workplace adjustments:

*"But we could work just as good as any neurotypical person, even though you sometimes need to adjust the environment a bit, like for example turning the lights off or turn the volume down."*¹⁸

Indeed, we found wider evidence of how adaptations in the working environment led to successes. For example, sensory adjustments, such as changes to lighting,^{4,18,44,63} noise control or suppression,^{4,18,44,52,63} as well as adjustments related to smells.⁶³ Alternatively, adjustments leading to positive employment-related outcomes included employing autistic workers on part-time contracts,^{12,60} or employers adjusting work schedules based on requests.^{18,49,63} The following participant quote is an example the need for an individualized schedule and approach:

*"I have a hard time getting started with my job unless I put everything in the order that they need to be in. It takes me a long time to get started."*⁴⁹

As well as allowing flexibility at the start of shifts, a range of other flexible working emerged from the literature. For example, adjusting methods of communication to suit autistic workers.^{4,45,49,50,53,54,56,62,63,69} Further success was noted when greater clarity was applied across all communication,^{4,44,46-51,53,54,56,63} specifically, clear and unambiguous workplace rules and expectations.^{4,18,46,49-51,55,63,64} Identifying and adjusting the communication method to suit the needs of the worker, such as writing things down or emailing meeting minutes, were all

reported as desirable practices.^{4,51,54,56,63} Likewise, job coaches or mentors, who help bridge communication gaps, figured prominently in positive employment-related outcomes, although such practices were rarely implemented.^{4,49,53,54,63} Alternatively, creating environments with low social demands^{4,6,16,46,48,51,62} were viewed as important ingredients for successful employment.

Understanding, knowledge, and acceptance

Description: We set out how the understanding, knowledge and acceptance theme provides insight into how workers experience the attitudes of others in the workplace and the impact of such behavioural attitudes on work experiences, as well as autistic attitudes towards important work decisions such as disclosure.

We found workers were frequently concerned about the attitudes of others in the workplace.^{4,6,24,44,45,48,49,51,53,55,57,61,62,66-71} Many negative behavioural attitudes contributed to such concerns, specifically bullying,^{4,12,24,45,47,50,51,54,55,59,66,68,69} being patronised,^{12,45,51,52,55,69} or feeling unvalued.^{12,24,45,51} Discrimination by superiors was widely reported in the literature,^{12,24,45,47,49,51,52,54,57,59,64,67-69,71} which, in some instances, led to worker dismissal or discipline.^{4,45,49,54,57,59,67,68} Such experiences demonstrate the disabling effects of colleague and manager behavioural attitudes and stereotypes of autism. The following participant quote is an illustration of how such difficulties transpired in the work setting:

“So, people think just because you have autism that you have a lack of emotion and that you want to be alone, which isn’t true.”⁵²

Our analysis revealed how the stigma related to autism is often internalised, leading to a fear of attitudes and a state of increased self-awareness.^{49,57} We found many individuals chose to mitigate that fear through masking,^{24,51,57,67,69} which can be seen as internalised ableism due to it stemming from a belief that their true self would be unacceptable to their workplace. Other expressions of internalised ableism were seen through individuals separating their self from their diagnosis,^{44,49,51,68} expressing negativity towards their abilities and talents,^{4,6,12,24,46,48,49,51,53,58} or believing negative workplace consequences are of their own making.^{24,44,46,51} We reveal how a sense of being at fault can manifest, and its consequences, through the following study extracts:

“I am so stressed... I find that because I am quite rubbish at this, I have to come home and work in the evening to catch up so that I can hit my deadlines.”⁵¹

Participants linked some of the difficulties to characteristics associated with autism that were neither recognised, valued, nor supported in their workplace. These included perfectionism, being too honest and “too nice” (leading to bullying), dealing with unexpected demands, understanding the “bigger picture”, self-organisation, as well as additional specific, diagnosed difficulties such as dyspraxia.²⁴

Unfortunately, our analysis revealed a lack of understanding of autism in the workplace.^{4,12,18,24,44-47,49,51-55,57,59,64,66,68-70} We found a desire for more understanding was regularly expressed by participants,^{4,18,24,44,46,47,51,54,56,66} with negative social experiences often stemming from a lack of understanding, awareness, or even direct discrimination.^{4,44-47,49-51,53,57} Additionally, improving awareness and understanding was perceived as one of the most important ways to improve the work experience.^{4,44,45,48,50-52,57,60,62,63,68} Indeed, a manager or colleague understanding how to work with autistic colleagues improved the workplace experience through the diminishment of disabling attitudinal barriers.^{4,16,24,44,45,48,49,51-53,56,60,62-64,66,69} Additionally, workers who felt they were accepted and did not have to conform to an unsuitable environment widely reported positive outcomes.^{4,16,24,44,45,48-51,57,60,63,64,66,69}

However, an unintended consequence of raising awareness was the creation of stigma, which has an impact on worker mental health.^{4,12,24,45,47,50,51,55,59,66,68,69} As noted here, we indicate how managers and colleagues often mis- or over-interpret the training they receive on autism, reinforcing problems with employment in a different way:

For example, an identified need for quiet time was taken to mean they wanted to withdraw completely. Consequently, some women were provided with a separate space to work. 'I'm quite a sociable person. Why do you want to isolate me and put me on my own?'⁵⁷

We observed how the often misguided attitudes of colleagues is commonly reported as a key reason why autistic workers chose not to disclose their autism or request adjustments.^{6,16,24,46,49,51,61,64,66,68-71} That said, it was common for autistic workers to experience discrimination *after* disclosure.^{24,45,51,53,54,57,59,61,64,66-69} More broadly, a fear of discrimination was the most common reason for non-disclosure.^{6,16,24,46,49,51,61,64,66,69-71} Importantly, disclosure could lead to some level of acceptance and a positive experience of employment,^{16,24,44,53,59,64,66,68,69} principally because some workers felt responsible for improving attitudes towards them.^{4,24,44,51,53,66,68,69} In some instances, we saw how research participants felt pride in their autism, further challenging discrimination and negative attitudes.^{44,61} In reality, we came to the conclusion that to disclose or not disclose posed a challenging dilemma for autistic workers, mainly because disclosure could lead to ambiguous outcomes:

"I don't just want it to tie me down to just doing autism-related work, or autism-related theatre work. There is other stuff I am interested in."⁴⁴

Discussion

In this qualitative synthesis focused on the perspectives of autistic workers, we used the SRMD³¹⁻³³ to understand the experiences and needs of autistic workers. The identified themes fit within the core principles of the SRMD, suggesting that the environment physically, socially, attitudinally, and structurally is disabling autistic workers. According to the reviewed literature, altering autistic workers' working environment via adjustments leads to raised prospects of employment success. For instance, we identified that the challenging aspects of communication disabled the individual from communicating effectively due to the interaction between an 'impairment effect' of a differing social profile and a structure built against it. However, when work structures were adapted to suit the individual, a more positive employment experience occurred.^{4,51,54,56,63}

We found how positive employment experiences were often linked to an understanding or accepting environment. When experiences within social and environmental categories were positive, it was frequently due to adaptations towards the workers' preferences. This tended to occur when workplace personnel (managers, co-workers, etc) were understanding and accepting of difference. By drawing on the work of Thomas,³¹ our review reveals how the attitudes and knowledge of colleagues and line managers disable autistic workers. Other literature which privileges employer perspectives also highlights that employers have identified that understanding and knowledge are key ways to improve the employment experience.¹⁸⁻²¹ In addition, previous literature found many employers reflected on their own position as not being informed enough and would opt for more training were it available.^{19,20} The desire for more training shows a consensus between stakeholders that improving knowledge and understanding of autism is an important area for improving outcomes for autistic workers. Despite a desire for more training, we revealed how some employers demonstrated a lack of understanding by continuing to express negative perceptions over how autistic differences may impact the working experience.^{4,19,20,51,54,56,63}

Previous research and our synthesis of such work revealed how the priorities of different stakeholders differ when considering aspects of the work experience.²⁹ Research emphasising different stakeholders offers insights into the priorities of autistic workers, for example, the dynamics surrounding disclosure and the attitudes of others is something that is rarely seen from the perspective of the employer.¹⁹⁻²¹ Disclosure of a diagnosis or a request of adjustments is necessary for workers to get the support that may enhance their workplace experiences, however, it may not always be met with a positive response. This can therefore lead to a struggle to decide whether or not to disclose. A decision about whether to disclose or not would be difficult to understand from a perspective other than that of the autistic worker themselves, as it is an internal struggle and, logically, subjects outside of the workers themselves would be unaware of the nature and detail of such a struggle. We revealed how employers are often unaware of the struggle surrounding disclosure even when actively encouraging such practice.

We saw how the major focus of previous reviews is on the outcomes of employment rather than the experience itself.^{25,72-74} We found how previous research prioritises improved outcomes for autistic workers using a medicalised approach, where interventions are aimed at changing the worker and worker differences are the focus.^{21,25,72} Such an approach constructs the autistic worker as disabled as they are expected to fit in and adjust to the norms of their neurotypical co-workers.⁷⁵ We have seen how a medicalised approach is not what autistic workers want or find effective. Many workers want the environment to be adapted to them, as expressed through the theme *adapt to me*. Workers who experienced these adaptations to their needs found a more successful work experience.^{4,51,54,56,63} Importantly, many of the adjustments for autistic workers simply represent general good practice, that is, allowing workers and managers to make largely low- or no-cost adjustments, or for managers and colleagues to be more accepting of differences, the basis of all equality, diversity and inclusion practice.

Our focus in this review on first-hand experiences revealed that autistic workers can have positive social experiences of work.^{52,53,57,58,61,62,64,65} This contrasts with previous literature that has viewed social experiences as largely negative or problematic.⁷² In line with our findings, recent research highlights the benefits and desires for social relationships,^{76,77} which is in contrast to earlier theories, such as social motivation theory.⁷⁸ For many participants in the reviewed studies, social work roles were desirable and provided positive outcomes,^{4,52,53,61} despite previous practice recommending autistic workers avoid such situations.⁷² This highlights the circumstances under which social experiences at work are positive and where they are problematic, for instance, unstructured social interactions such as small talk were noted as being difficult whereas when there was a more focused work agenda these were largely positive.⁵²

A key discussion in our analysis of the findings was the interplay of internalised ableism. When considering disclosure, there were several cases of workers choosing not to disclose as they did not want to feel different from others in the workplace, or because they felt they did not need any accommodations.^{51,61,69,71} Internalised ableism was also seen within discussions surrounding *navigating social demands*, that is, in some accounts, participants revealed social aspects as requiring skills they lacked and felt themselves incapable of obtaining.^{4,18,46,49-51,55,63} Further, we established via the final theme – understanding knowledge, and acceptance – the complex interaction between impairment effects, internalised ableism (e.g., a perceived deficit in relation to communication), environmental barriers (e.g., lighting and noise) and attitudinal barriers in the workplace. The consequences of which were worsening the work experience and damaging the mental state of the individual.^{4,6,12,24,46,48,49,51,53,58}

Future directions

Our research highlights the importance of drawing on first-hand experiences of autistic workers when designing accessible and inclusive employment. Overall, our view of privileging such first-hand experiences reflects the broad direction of the findings associated with research in the field of autism and employment in the past two years. Between January 2021 and the final search in April 2022, 14 of the 34 studies accepted into the research were published, demonstrating the exponential growth and increased value being placed upon the perspective of the autistic worker. Our paper helps distil the finer points of such trends, highlighting how steps to make employment more inclusive should avoid disproportionately drawing on the views, voices and opinions of key stakeholders such as employers, managers and HR professionals. Our research highlights the importance of co-designing workplace interventions, rather than top-down and unitarist approaches which dominated all but the most recent research.

Our analysis of the employment experiences of autistic workers was through the theoretical lens of the SRMD. As such, a further key finding is to suggest how such an approach represents an effective, yet under-applied theoretical framing of autism and employment. We believe the data identified naturally fits within social relational principles and the attitudes of autistic workers favour a focus on environmental, rather than personal, adjustments. Thus, we hold the view that future research should make more use of the SRMD in relation to inclusive employment, as well as representing a relevant approach when examining poor employment experiences.

Conclusions

The purpose of our research was to highlight and synthesize research on first-hand accounts of autistic workers through the lens of the SRMD. Departing from previous systematic literature reviews, our analysis was focused solely on research privileging the voices and lived experiences of autistic working people over that of other key stakeholders in the employment relationship.

Our approach highlighted the adjustments which need to be made, how and why they were successful, and how such workers are willing to work with the employer to determine these adjustments (e.g., Cooper et al., 2020).⁴⁵ Further, when working environments were typified by understanding, acceptance and a willingness to change and adjust, they could mitigate against many conventional disabling forces (e.g., see Goldfarb et al., 2021).⁶² Such experiences are in line with the principles that define the SRMD, and future research should further investigate the relationship between these principles and autistic workers.

A final key point is how the autistic worker needs to be a central agent in the changes bringing success to their work environment. That is, improved employment will require listening to the autistic workers' experiences, and then acting on such experiences to achieve maximum participation in employment. Paying attention to lived experiences allows for understanding of nuanced aspects of employment such as the relationship between disclosure and attitudes, or the experiences of success in and desire for social work roles. Thus, research and practice need to continue to listen and respond to the voices of autistic workers to maximize successful employment experiences.

Authorship confirmation/contribution statement

David Thorpe: Conceptualisation (lead), formal analysis (lead), funding acquisition (lead), investigation (lead), methodology (lead), project administration (lead), visualisation (lead), writing – original draft (lead), writing – reviewing and editing (equal).

Marisa McKinlay: formal analysis (supporting).

James Richards: Supervision (supporting), writing – reviewing and editing (equal), conceptualisation (supporting), funding acquisition (supporting).

Kate Sang: Supervision (supporting), writing – reviewing and editing (equal), conceptualisation (supporting), funding acquisition (supporting).

Mary Stewart: Supervision (lead), writing – reviewing and editing (equal), conceptualisation (supporting), funding acquisition (supporting).

Conflicts of interest

All authors declare that they have no conflicts of interest.

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