HHS Public Access

Author manuscript

Autism. Author manuscript; available in PMC 2023 January 01.

Published in final edited form as:

Autism. 2023 January ; 27(1): 65–75. doi:10.1177/13623613221080813.

"[I] don't wanna just be like a cog in the machine:" Narratives of Autism and Skilled Employment

Dora M. Raymaker[1], **Mirah Sharer**[1], **Joelle Maslak**[2], **Laurie E. Powers**[1], **Katherine E. McDonald**[3], **Steven K. Kapp**[4], **Ian Moura**[1,2], **Anna "Furra" Wallington**[2], **Christina Nicolaidis**[1,5]

[1]Portland State University

[2]Academic Autism Spectrum Partnership in Research and Education

[3]Syracuse University

[4]Department of Psychology, University of Portsmouth, Portsmouth, UK

[5]Oregon Health & Science University

Introduction

Employment is a key determinant of health and life outcomes (e.g., healthy relationships, stable housing, good mental and physical health) (Benach, Muntaner, & Santana, 2007). In addition to the benefit of greater financial security on quality of life, employment satisfaction is associated with improved physical and mental health, including reduced anxiety and depression and increased self-esteem (Faragher, Cass, & Cooper, 2005). For autistic people and people with mental health conditions, stable employment has been shown to improve health and life outcomes, and adaptive functioning (Taylor, Smith, & Mailick, 2014), and to reduce the cost of hospitalizations, support, and service use (Bush, Drake, Xie, McHugo, & Haslett, 2009; Howlin, Alcock, & Burkin, 2005; Taylor et al., 2014). Yet, a disproportionate number of adult autistic people are unemployed or underemployed compared with the general population (Bernick & Holden, 2015; Foden, 2008). For example, only 58% of young adults on the autism spectrum who received special education worked for pay compared with all other groups of special education recipients, including 74% of peers with an intellectual disability (The National Autism Resource & Information Center, 2018). Employment inequities may be exacerbated by the core features of autism, which can affect an individual's ability to be competitive in job interviews, as well as the types of job opportunities available (e.g., due to restricted interests or discrimination) (Bernick & Holden, 2015).

These employment disparities may also be exacerbated for individuals with advanced training seeking careers. Little information exists on the proportion of autistic people with advanced training who are competitively employed in their field. One nationally representative U.S.-based study showed that while nearly 44% of autistic people ages 19–24

Corresponding Author: Dora M. Raymaker, 1600 SW 4th Avenue, Suite 900, Portland OR 97201, draymake@pdx.edu, 503-568-4501.

had some post-secondary education, only 55% of them had held any paid employment—even that outside of their field—after high school (Shattuck & Narendorf, 2012). Many skilled jobs—defined for the purposes of this study as those requiring specialized training or certification beyond what can be obtained the first weeks on the job—have additional entry gates (e.g., obtaining auditions, entering a formal apprenticeship in a trade) which may increase barriers to employment. Further, most autism employment programs are not designed for a wide range of careers, either focusing narrowly on information technology and data management (e.g., Microsoft's Autism at Work program, Specialisterne) or on unskilled labor (Chappel & Somers, 2010; Hagner & Cooney, 2005; McDonough & Revell, 2010).

Additionally, little is known about what successful career paths look like for autistic people with postsecondary education or other skilled training, what types of jobs they might want, or what "successful employment" means to them beyond a floor (i.e., barest minimum) outcome of placement in a job. The existing literature largely focuses on transition-age youth who have not yet completed training (e.g., (Anderson, Butt, & Sarsony, 2021)) or, again, on unskilled positions. Much of the research on career pathways has focused on specific topics, such as ameliorating skill deficits in the workplace (e.g., (Lorenc et al., 2018)), with less attention to whole person and contextual perspectives (Hedley et al., 2017). Some studies have included the perspectives of autistic people in skilled positions, however the focus has been on research questions related to other topics (e.g., the experiences of autistic women at work (Hayward, McVilly, & Stokes, 2019)). Experts in the area of autism and employment are calling for more research that focuses on understanding success, engaging with the full ecosystem connected to employment, and understanding how to better support people in careers rather than just jobs (Nicholas & Klag, 2020; Nicholas et al., 2019).

Our aim was to better understand the experiences and career trajectories of autistic people with skilled training—including people who felt they were successful—and what might help facilitate skilled employment outcomes. Specifically, we aimed to 1) learn what successful skilled employment looks like for autistic employees, 2) understand barriers and facilitators of successful employment, and 3) consider what outcomes might be important to assess success in skilled employment. We used a community-based participatory research (CBPR) approach to obtain qualitative data from autistic employees/job seekers, supervisors and support professionals of autistic employees/job seekers. We also talked with key informants from within relevant systems (e.g., employment programs, disability employment policy, college internships) to further examine historical and contemporary thinking and support for autistic applicants and employees. Understanding these experiences is an essential first step in developing and evaluating effective, systems-focused interventions to improve employment outcomes for autistic people with skilled training in a wide range of careers.

Methods

Community-Based Participatory Research Partnership

CBPR is an emancipatory approach to inquiry that acknowledges lived experience as equivalent in value to academic knowledge and equitably includes community partners in all phases of the research (B.A. Israel, Eng, Schulz, & Parker, 2005; B. A. Israel,

Schulz, Parker, & Becker, 2001; C. Nicolaidis & Raymaker, 2015). The Academic Autism Spectrum Partnership in Research and Education (AASPIRE, aaspire.org) is a mature CBPR collaboration between academic researchers and the Autistic community based in the U.S. We describe our collaboration methods elsewhere (C. Nicolaidis et al., 2019; C. Nicolaidis et al., 2011).

Author Positionality and Contributions, and Community Involvement

The Principal Investigator for the study (DR), who is Autistic and an AASPIRE Co-Director, oversaw the project, conducted most interviews, led the analysis, and coded all transcripts. The other AASPIRE Co-Director (CN), who is not autistic, provided mentorship through all phases of the project. AASPIRE Autistic community members identified the topic as important, co-developed the research materials including the consent forms, fliers, and interview guides, assisted with recruitment, discussed preliminary findings, helped interpret and finalize the findings, and identified key recommendations and next steps. Academic co-investigators (KM and LP) assisted with study design and data interpretation. Non-autistic research assistants (including MS) conducted some interviews and served as secondary coders. An autistic research assistant (IM) participated in peer debriefing. All co-authors contributed to the development of this manuscript. Portland State University's Institutional Review Board approved this study.

Participants and Recruitment

We aimed to obtain in-depth data from a national sample of autistic people with skilled training, people with experience supervising or coaching autistic people in skilled settings.

Autistic employee participants had to be 18 years of age or older, reside in the U.S., and report having a professional autism diagnosis (autistic disorder, Asperger's disorder, pervasive developmental disorder – not otherwise specified, autism spectrum disorder). They must have obtained or looked for a skilled job, defined as the type of job that requires more than short-term (typically two weeks or less) on-the-job training to reach competency. Because we were interested in facilitators of success while recognizing that the perspectives of people who had not achieved success are also valuable, we purposefully sampled participants to ensure a majority (~70%) had a self-identified successful experience with a skilled job. We used maximum variation sampling (Palinkas et al., 2015) to ensure participants had a wide range of professions and demographic characteristics.

Supervisors and support professionals needed to be 18 years of age or older, reside in the U.S., work in a skilled setting or provide services to people seeking skilled employment, and report having been successful in supervising or serving at least one employee who had disclosed a professional autism diagnosis.

We recruited employees, supervisors, and support professionals through social media, word of mouth, and professional and community connections. We also asked employee participants to share a recruitment flier with their supervisors or support professionals, if they felt comfortable doing so, to generate a subsample of paired employee/supervisor-support professional participants. The study also received media attention in the Portland, Oregon area, which increased our response rate from that region.

We conducted individual, one-hour, semi-structured interviews with 45 autistic employees/job seekers and 11 supervisors or support professionals. Participants ranged in age from 21–65 years, came from all regions of the U.S., and represented a wide range of gender identities and educational backgrounds. In the autistic sample, 22% indicated that they communicated using alternative and augmentative communication (we did not ask about context or frequency), and 42% used some form of disability services. Participants represented a wide range of skilled fields: arts/entertainment, athletics, law, education, engineering, health care, information technology, public administration, publishing, science/research, social work, and trades. Although we did not collect demographic information on when participants received their ASD diagnosis, enough participants disclosed this information during their interviews to indicate our sample included a relatively balanced mix of both people diagnosed in childhood and people diagnosed in adulthood. See Table 1 for demographic details.

The supervisor/support professional sample was comprised of 3 support professionals (2 job coaches, 1 vocational rehabilitation specialist); 7 supervisors of autistic employees in jobs related to social services, mathematics, information technology, data management, and higher education; and 1 person who was both a support professional (case manager) and a supervisor. Five individuals (1 job coach, 1 VR counselor, and 3 supervisors) supervised or supported employee participants. Supervisor/supporters ranged in age from 27–48 (mean 37, std. dev. 8.5), were 55% female, and were all white.

We contextualized the data from employees, supervisors, and support professionals by speaking with eight key informants who were not otherwise involved in the study. We identified individuals with expertise and experience in a range of targeted systems related to skilled employment and autism and recruited them directly by email, telephone, or in-person conversation. Key informants included academic researchers, employment specialists, small business owners, vocational rehabilitation specialists, policy/community leaders, disability service directors, and directors of corporate autism at work programs. Expertise included high school transition programs, customized employment, small business needs, job development, service system integration, employment policy, internships, accommodations, and autism employment programs at large corporations.

Procedures

Prospective employee/job seeker and supervisor/support professional participants contacted us for more information by telephone or email from a recruitment flier which provided study and eligibility information. We then gave them a link to an online screening survey or conducted the screening survey by telephone. The first author selected people to invite to the study based on the screening data to obtain a maximum variation sample. Participants had a choice to complete the informed consent and interview by email, telephone, video conference, text-based chat, or in person (with an option to change modes if desired). Like others (McCoyd & Kerson, 2006), for over a decade we have successfully collected qualitative interview data using these multiple modalities in order to maximize accessibility and diversify the range of individuals who can participate at no cost to the richness of the data; more examples and process-related information is available elsewhere (e.g.,

(C. Nicolaidis et al., 2015; C. Nicolaidis et al., 2019; Raymaker et al., 2020)). We audio-recorded the spoken interviews. Trained research assistants deidentified and transcribed the recordings verbatim, and deidentified and reformatted email and text chat transcripts to provide consistent formatting with the audio transcripts.

Data Collection

For employees, we first asked them to tell the story of their career path, starting with when they began thinking about their career and ending with where they are now. We prompted for the following key ideas if they did not emerge organically: career timeline, successes and failures, things that helped or hurt, and whether autism or any other aspects of their identity (e.g., race, gender, sexuality, religion) had any impact on their experiences. We then asked more focused questions related to participants' insights on what successful employment means to them, what advice they would give to other autistic people and to supervisors, what they would change if they could redo things, and what services and supports they wished were available to them. For supervisors and support professionals, we asked the same questions but to relate the story of their time supervising an autistic employee and reversed the advice question (i.e., what advice would you give other supervisors and to autistic employees). We had unstructured conversations with the key informants over the telephone, asking them to frame the discussion by describing their position, and to share their ideas around autism and skilled employment given their area of expertise.

Analysis

For the employe/job seeker and supervisor/support professional interviews, we conducted a thematic analysis, using an inductive approach, at a semantic level, with a critical realist paradigm (Braun & Clarke, 2006; Robert Wood Johnson Foundation Qualitative Research Guidelines Project, 2008). Specifically, we looked for overarching meanings to emerge from people's words at face-value, acknowledging that the interviews represent a co-constructed reality by the participant and the researcher within a social context and exhibiting ontological depth. (Vincent & O'Mahoney, 2018) We focused the analysis with the central question: "what about people's skilled work experience impacts the overall outcome?" We used Atlas.ti (ATLAS.ti, 2018) software to manage data. DR did most of the initial coding for the autistic participants concurrently with secondary coding by a non-autistic research assistant. The two met to check that they were finding similar constructs; they came to consensus on the initial codes and continued using that set with MS replacing the initial research assistant as secondary coder. DR shared the preliminary themes and representative quotes with the full AASPIRE team, asking the autistic members if it felt consistent with their experiences and community conversation in a process similar to member checking. Autistic partners felt the preliminary themes were consistent with community experience and did not recommend removing any. DR completed the employee coding, DR and MS coded the supervisor/support professional and key informant interviews, and DR synthesized themes and findings across the corpus. Lastly, DR brought the findings to the full team for finalization and interpretation.

To help ensure trustworthiness of qualitative findings (the qualitative analogue to validation) (Morrow, 2005), we employed multiple coders and peer debriefing. An autistic research

assistant (IM), who was conducting a secondary analysis with the full data corpus provided detailed peer debriefing and additional checking from the perspective of lived experience. Discussions among DR and IM included, in addition to academic lenses, reflections and personal frames as autistic people with skilled training. All coders agreed that we had theme saturation from both participant groups.

We used key informant interviews to help contextualize and better understand details of our findings; we did not include key informant interviews in the primary analysis described above.

Results

Themes

The primary themes from the thematic analysis of the career story portion of the interviews were the high stakes of disclosure, unconventional pathways to careers, disconnects with service and support systems, mental health challenges from trauma and burnout, autistic advantages in the workplace, and complex dimensions of discrimination. Although the discussion of the themes here centers the employee sample, supervisor/support professional stories reinforced and supported the same themes; that is, supervisor/support professionals did not bring up substantively different themes from employees. Quotes have been edited for brevity and clarity; brackets indicate text added by the authors and an ellipsis indicates text removed by the authors.

High stakes of disclosure ––Participants described disclosure of an autism diagnosis as having a substantial impact on their employment experiences and outcomes, both positively and negatively.

Sometimes the disclosure—either to human resources or a few trusted co-workers, or to the entire workplace—is what helped the person keep or sustain employment, or feel their job was successful. Being able to receive accommodations, increased understanding from co-workers, and feeling accepted at work without the burden of masking were some of the most frequently stated reasons for positive outcomes. For example, an autistic employee explained:

> “I outed myself [as autistic] to my [supervisor] about a year [in]...and saw an immediate positive shift in our rapport, my results, and my overall demeanor. I was no longer stressed about passing. He was immediately receptive to my needs.... He showed a genuine interest in how my brain works, remained completely respectful of me, and kept an open dialogue with me about how I was doing. In turn, my mood changed and the quality of my work improved dramatically.” (employee, higher education)

Other times however, the disclosure led to discrimination and/or loss of work. Another autistic employee described:

> “I disclosed my [diagnosis] and had a group meeting with the two supervisors and the unit supervisor... I had to pay $180 out of pocket to have a phone conference

> with the psychologist who DX [sic] me and how it affected my employment. After that, they hammered me on the smallest things and I had the union rep knowing about it. She even mentioned...how that wouldn't have occurred with other employees.... I got nailed for [something perceived as petty] and fired two weeks later. I appealed the termination and lost....disclosing my DX, it has been nothing but hell when it has come to employment." (employee, photography)

Participants were well aware of the high-risk—and potentially high-reward—nature of disclosure and made complex risk assessments. An autistic participant advised employers to:

> "Recognize that the employee may be taking a massive personal risk in making their disclosure, and that they must have calculated that the extra measure of vulnerability prompted by disclosure was worth it." (employee, electrical engineering)

Unconventional pathways to career ——In relating stories of their career paths, many participants described accessing jobs in ways that bypassed typical gatekeeping processes like interviews, which were frequently noted as an insurmountable barrier. They made strategic use of special interests, took advantage of the ability to demonstrate skills, used opportunities provided by mentors or family, or found specialized niches through design or chance. One participant related that the conjunction of special interests, a mentor, and the luck of timing started them on a long-term career path:

> "[The editor] showed me…some of the basics of using like graphic design software….and it was really the earliest early days of that stuff publishing, and somehow he and this other guy talked to student congress and they gave them like ten thousand dollars…to buy this computer system, which was like gonna be a publishing system....so I learned like really early on…how to use this stuff when even professional graphic designers didn't know what to do with any of it and they're just floundering, so that gave me a step into that kind of world." (employee, printmaking)

Disconnects with service and support systems ——A number of participants related their experiences with employment service and support systems (e.g., job corps, vocational rehabilitation), most of which were challenging. Participants described how programs designed for autistic people or people with disabilities struggled to understand and connect them with skilled settings. For example, one participant related:

> "I was a highly qualified candidate for WRP [a government program for people with disabilities] positions, but I never received any offers …. I later found out the government agencies mostly use disability hiring programs such as WRP…to hire employees for unskilled positions….This is a problem, since those on the autism spectrum often do much better with positions involving analytical thinking than positions involving unskilled labor." (employee, law enforcement)

However, participants also described how programs that might have access to skilled employment opportunities struggled to understand the needs of autistic people. For example, another participant related:

> "…my VR [vocational rehabilitation] job developer found…a call center position that I think was probably an easy fit for her. Unfortunately, this job was incredibly stressful for me and my then VR counselor suggested I take Xanax during the day while at work. I eventually gave my notice as this was not the right fit for someone with my condition." (employee, literary arts)

Mental health challenges from trauma and burnout ––—Although participants described some challenges related to their autistic traits (e.g., sensory sensitivity in the workplace, meeting social expectations in job interviews), they often placed more weight on co-occurring mental health conditions and mental health needs, especially from long histories of discrimination, bullying, and abuse, both within and outside of the workplace. Even when not actively triggered, many employees struggled with enforcing work boundaries or with pervasive fear of abuse from co-workers. One autistic employee who did not feel successful summarized:

> "Finding a job…has been agony. It hurts so much to put myself out there and be tossed aside…. When I found work and tried to keep it, most times I would end up getting bullied by people there. I have a lot of PTSD [post-traumatic stress disorder] issues with bullying, so I do not take it well [and it leads to bad outcomes]." (employee, veterinary science)

This theme was echoed strongly by supervisors, many of which emphasized the need for trauma-informed approaches and mental health support when working with autistic employees. One supervisor related how this played out daily practice:

> "I felt like [the autistic employee's stress over not working fast enough even though he was] was getting better and then I figured out this big data tangle problem and his reaction was, 'Oh my gosh I made a huge mistake and now she's definitely gonna fire me.' So the other thing that I've been...helping him succeed [at]... is realizing that if you have an employee who's on the spectrum and they are—they have like a nervous kind of low self-esteem... He apologizes a lot...[and is] like, 'I'm not doing a good enough job.' So what I've tried to do...[is give] very specific positive feedback at the time that things happen." (supervisor, program evaluation)

Autistic participants also often worried about the impact of work on their mental health, including working too much without sufficient recovery time, or working in a toxic or unaccommodating workplace where they needed to expend extra effort to manage the environment. Many worried about work contributing to autistic burnout (an independent concept from professional burnout that is characterized by overall exhaustion, increased sensory sensitivity, and decreased abilities (Raymaker et al., 2020)) with its potential to destroy their ability to work. One autistic employee offered this advice for other autistic people:

> "As far as keeping a skilled job goes – I would say that the most important thing is to monitor yourself for signs of burnout and act sooner, rather than later, to thwart it…. I would suspect that burnout is by far the biggest contributor to lack of long-term success." (employee, law)

Autistic advantages in the workplace ––Participants and supervisors told stories about how special interests, autistic traits, or lived experience as an autistic person made them better at their job, love their work more, or succeed at their work. One autistic employee shared how being autistic helps them connect with others at their work:

> "From the people I've chosen to share [my diagnosis] with it's usually a positive response...like they know me and from seeing how I work with kids [with disabilities] they're like, oh that would explain why you're able to really zero in on that and you have this good rapport with that kid who's hard to reach, and I'm like oh yeah I guess so [laughs] using my superpowers [laughs]" (employee, para-education)

Another autistic employee gave an example of special interests at work:

> "In the course of my education, anatomy, physiology, pathology, and symptom pattern recognition…became a special interest. This meant I could focus my autistic superpowers on succeeding at work." (employee, nursing)

A supervisor working in a scientific field gave examples of ways they feel being autistic helped their employees excel:

> "In general [the autistic people I've supervised] have really good analytical skills. Sometimes it['s] how they quantitate...mathematical [sic], sometimes it's logic and reasoning [and] being able to see things more clearly.... [One person I supervised]...didn't have as much [sensory] filtering as most of us have, maybe that's given them some training that gives them the ability to process more information than many of us would be able to process and I think that's probably pretty useful in our field!" (supervisor, research)

Complex dimensions of discrimination ––Most people described experiences of autism-related discrimination. Experiences of ableism were pervasive, and their impact extended beyond the workplace to influencing decisions about disclosure, people's mental health, and people's ability to trust others. For example, one person discussed deciding to hide their autistic identity in the future after a particularly painful experience of discrimination:

> "I've acquiesced to the--the world view that we don't live in a... post-ableism world, and so once I acquiesced to that view... I've had to treat my disability like it's a thing that should be shamed even though I don't believe that.... I realized that once I acted like that I was able to work a lot better..." (employee, social work)

Participants who also identified as a racial, ethnic, gender, or sexual minority described additional layers of workplace discrimination, such as racial typecasting, getting fired for being gay, or navigating the amplified risk of managing gender or sexual identity disclosure

in addition to autism disclosure. For example, one participant, a white-passing transgender person of color, stated that she typically disclosed her autism even though "this can cause people to be a little worried about hiring me." Later in the interview, she discussed the additional layers of complexity she needed to navigate:

> "[After coming out trans] …I was told…that I was 'fired for being gay.' I also acknowledge that my privilege as a white-passing person has also helped me.…I feel if I had the double-whammy of being a trans woman and a person of color, I would have almost no chance of getting a job. As it is, I have only a few strikes against me in the 'not-employable identities' column." (employee, social services)

The Meaning of Successful Employment and Facilitators to Achieving it

We asked participants what successful employment meant to them and what they thought would be important to measure in order to identify employment success. Participant answers converged around: opportunities for professional growth, good work/life balance, financial independence, sense of community at work, feeling valued, doing meaningful work, and being a part of an accepting work culture. One participant summed up:

> It really helps if it means something, if I feel like what I'm doin' is meaningful to someone 'cause, I mean money's important too [laughs]...and also a job that has opportunity for growth, that can lead to somethin' else which--because people change over their lives and what's good for you at one point is not always...don't wanna do the same thing for twenty years. …[And] if it uses my skills that--or skills that I'm proud of... I guess there's a bit of, like, recognition, recognition's important and [I] don't wanna just be like a cog in the machine, like, that sounds boring. (employee, para-education)

Autistic participants made it clear that workplace cultures that allowed them to be openly autistic and in control of their work were key to their success. Supervisors supported what the employees said and further clarified strategies for success. Specifically, supervisor strategies converged around the following:

- being flexible and creative about hiring and carving job tasks to fit skills and passions
- normalizing and accommodating disability and autistic differences
- taking a trauma-informed approach and supporting employee mental health
- respecting and valuing employees, and making use of their autistic advantages
- providing authentic mentorship and friendship; and
- being direct about feedback and expectations.

We synthesized findings into a model (see Figure 1) that includes the experiences, facilitators, and dimensions of success, described by participants.

Discussion

Little is known about autism and skilled employment, despite an increasingly urgent need. Our study focused on understanding the experiences of successful skilled employment, barriers and facilitators to successful employment, and what successful skilled employment outcomes are from multiple stakeholder perspectives. At its core, successful skilled employment meant professional growth, financial security, healthy work/life balance, sense of workplace community, feeling valued, the opportunity to do meaningful work, and an accepting and non-toxic workplace; these constructs are consistent with those often measured in the general population (e.g., (Tharanga Sumanasiri, Ab Yajid, & Khatibi, 2016), (Burroughs & Eby, 1998), and (Brough, Timms, & Bauld, 2009).). Positive outcomes were achieved by workplace factors such as flexible hiring and job crafting, a culture that normalizes and accommodates autism, genuine friendships with mentors and supervisors, explicit valuing of skills, and direct communication on the job. They were also achieved by employee factors such as safe, effective disclosure, advocacy, and skills. External, mutual (i.e., both workplace and employee), or additional factors playing a role included trauma-informed mental health support, employment support services that understood both autism and skilled work, and sensitivity to employees who may be multiply marginalized.

While communication differences are a key feature of autism, no coherent themes about communication experiences emerged from participant stories. However, communication was pervasive in both strategies for successful employment (e.g., providing direct feedback and expectations) and types of reasonable accommodations employees related as being helpful to them as part of the disclosure theme (e.g., using alternative and augmentative communication in the workplace, receiving written instructions). Strategies for supervisors to accommodate communication—as well as a number of the other strategies for facilitating successful experiences—were echoed in the qualitative findings by Dreaver et al. (2020) of supervisors and employers in unskilled settings in Australia and Sweden. In addition to lending support to our findings related to communication strategies, the similarity more broadly suggests our findings related to facilitating success may be transferrable to other countries and that there is some overlap in supervisor strategies in both skilled and unskilled settings.

Our findings suggest that to be effective and inclusive, employment services must be customizable, multifaceted, and target both autistic employees/job seekers and workplaces. Multifaceted employment services currently exist, but a number of recent systematic reviews of such interventions concluded that while they showed promise, the small number of studies, lack of rigorous research methodologies, and small samples limited data on efficacy (Gross, Monroe-Gulick, Davidson-Gibbs, & Nye, 2018; Hedley et al., 2017; Nicholas, Attridge, Zwaigenbaum, & Clarke, 2015; Taylor et al., 2012). More research is needed to rigorously understand, develop, implement, and evaluate multifaceted interventions in real-world settings for autistic adults whose training and aspirations include skilled careers in a range of occupational domains. AASPIRE is currently working in this direction.

Research on autism workplace disclosure is still in its early stages, although it is increasingly pointing to its high-stakes nature and urgent need for more understanding

and tools (Lindsay, Osten, Rezai, & Bui, 2021; Romualdez, Heasman, Walker, Davies, & Remington, 2021). In contrast to research suggesting that non-autistic people are more likely to perceive the effects of disclosing autism more positively than autistic people (Thompson-Hodgetts, Labonte, Mazumder, & Phelan, 2020), we found similarities among the views of autistic employees, supervisors, employers, and other key informants. Given the impact disclosure has on outcomes, more guidance is needed for autistic employees, employers, job coaches, and other support professionals on safely and effectively navigating disclosure, especially for people navigating multiple disclosures (e.g., autistic and gay).

The general population of LGBTQ+ adults in the U.S. experiences significant employment inequities including discrimination, stigma, and loss of employment despite improving (though still limited and insufficient) protections (Human Rights Campaign Foundation, 2018); likewise, racial and ethnic minorities experience significant employment disparities in the U.S. with more than twice the rate of unemployment as white people (U.S. Bureau of Labor Statistics, 2020). Given the large number of participants who related experiences of discrimination for being racial, ethnic, gender, or sexual minorities in addition to being autistic—and the finding that gender and sexual minorities are overrepresented in the adult autistic population (Pasterski, Gilligan, & Curtis, 2014; Rudolph, Lundin, Åhs, Dalman, & Kosidou, 2018)—this points to an urgent area for more attention. Autism employment programs and initiatives need to consider race, ethnicity, gender, sexuality, and other aspects of identity affecting employment in their services, and workplaces may need to consider ways to merge siloed diversity and inclusion efforts.

Of existing disability employment approaches, customized employment (often used with, but not limited to, disability services focused on personalizing and optimizing the joint needs of employer and employee) (US Department of Labor, 2021) was endorsed as a good approach for achieving a successful employee/employer/job fit in skilled settings either explicitly by key informants and support professionals or implicitly by autistic employees and supervisors (in the very general sense of describing the value of collaborative negotiations between employers and employees). Research that focuses on the autistic population in customized employment shows some potential promise; however it remains limited and not focused on skilled work (Wehman et al., 2016). While not named, some aspects of supported employment (often used with mental health services and focused on supporting people to work concurrently with addressing other needs) (Kinoshita et al., 2013), such as integrating mental health therapy with employment coaching, could be useful for addressing trauma, and other mental health needs if integrated within a customized employment framework. Although these approaches are unlikely to provide a universal solution for all skilled autistic people, aspects of them could provide a foundation for future services, additional service components, or starting places for new solutions.

This study has several limitations. It is an exploratory qualitative study from a convenience sample and not structured to demonstrate causality, efficacy, or effectiveness. While over a third of our sample used disability services, and nearly a quarter used alternatives to speech, we did not deliberately sample for people with high support needs or who are non-speaking. Similarly, although we oversampled for racial and ethnic diversity, people who identify as Black and Latin/Hispanic are under-represented in our sample and may have

different experiences from the non-white individuals we talked to. Based on the content of the narratives, rural perspectives may be under-represented in our sample and the application of findings outside of the U.S. is unclear. Lastly, we struggled to engage supervisors despite our assurances that we were only interested in their opinions and the interview would not ask them to disclose any employee or other confidential information. Our supervisor perspectives were limited primarily to science, technology, engineering, and mathematics fields; supervisors from other professions might have offered additional insights. Despite these limitations, we feel our data displays authenticity in presenting a range of realities, provides a more sophisticated understanding of the phenomena of interest, and suggests potential actions. We encourage future research on autism and skilled employment that includes people without a formal diagnosis particularly from demographics that have more trouble obtaining a diagnosis, centers people with high support needs, or otherwise learns from demographics not reached in our study.

Implications

Employment is complex, for people with and without disabilities. Our findings highlight the need for customizable multi-faceted employment service interventions; changes to service systems to better meet the needs of people with skilled training; a more wholistic view of autistic employees including sensitivity to discrimination, trauma, and mental health; and the need for more research and resources related to disclosure. Employment researchers and service programs may want to begin including employment outcome measures related to job satisfaction, work/life balance, professional growth, and other constructs used in employment research with the general population. Our findings point to the need for a more systems-focused approach to autism and employment that engages multiple stakeholders (e.g., supervisors, co-workers, job developers), that is developed in partnership with or fully directed by the autistic employee, and that, consistent with legal definitions of disability discrimination, does not focus all the effort for remediation on the autistic employee. We recommend further work on autism and skilled employment in both research and practice be conducted in collaboration with the Autistic community.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgements:

We would like to thank the study participants and all AASPIRE team members, past and present, for their invaluable insights. We thank the Autistic Self Advocacy Network for their ongoing support of our work.

Disclosures:

This work is supported by National Institute of Mental Health grant number 1R21MH112038; by the National Center for Advancing Translational Sciences of the National Institutes of Health under award number KL2TR002370 administered by the Oregon Clinical and Translational Research Institute; and by National Institutes of Health award UL1GM118964. The views expressed in this article are those of the authors and do not necessarily represent the views of the NIH. We have no conflict of interest to report.

References

Anderson C, Butt C, & Sarsony C (2021). Young Adults on the Autism Spectrum and Early Employment-Related Experiences: Aspirations and Obstacles. Journal of Autism and Developmental Disorders, 51(1), 88–105. doi:10.1007/s10803-020-04513-4 [PubMed: 32356082]

ATLAS.ti. (2018). ATLAS.ti: Qualitative Data Analysis Retrieved from https://atlasti.com

Benach J, Muntaner C, & Santana V (2007). Employment Conditions and Health Inequalities Retrieved from http://www.who.int/social_determinants/resources/articles/emconet_who_report.pdf?ua=1

Bernick MS, & Holden R (2015). The autism job club: The neurodiverse workforce in the new normal of employment New York: Skyhorse Publishing.

Braun V, & Clarke V (2006). Using thematic analysis in psychology. Qualitative research in psychology, 3(2), 77–101.

Brough P, Timms C, & Bauld R (2009). Measuring work-life balance: Validation of a new measure across five Anglo and Asian samples

Burroughs SM, & Eby LT (1998). Psychological sense of community at work: A measurement system and explanatory framework. Journal of Community Psychology, 26(6), 509–532. doi:10.1002/(SICI)1520-6629(199811)26:6<509::AID-JCOP1>3.0.CO;2-P

Bush PW, Drake RE, Xie H, McHugo GJ, & Haslett WR (2009). The Long-Term Impact of Employment on Mental Health Service Use and Costs for Persons With Severe Mental Illness. Psychiatric Services, 60(8), 1024–1031. doi:10.1176/ps.2009.60.8.1024 [PubMed: 19648188]

Chappel SL, & Somers BC (2010). Employing persons with autism spectrum disorders: A collaborative effort. Journal of Vocational Rehabilitation, 32, 117–124. doi:10.3233/JVR-2010-0501

Dreaver J, Thompson C, Girdler S, Adolfsson M, Black MH, & Falkmer M (2020). Success Factors Enabling Employment for Adults on the Autism Spectrum from Employers' Perspective. Journal of Autism and Developmental Disorders, 50(5), 1657–1667. doi:10.1007/s10803-019-03923-3 [PubMed: 30771130]

Faragher EB, Cass M, & Cooper CL (2005). The relationship between job satisfaction and health: a meta-analysis. Occupational and Environmental Medicine, 62(2), 105. doi:10.1136/oem.2002.006734 [PubMed: 15657192]

Foden TJ (2008). Adult employment: Strangers in a strange land Retrieved from http://www.iancommunity.org/cs/articles/strange_land

Gross JMS, Monroe-Gulick A, Davidson-Gibbs D, & Nye C (2018). PROTOCOL: Multifaceted interventions for supporting community participation among adults with disabilities: a systematic review. Campbell Systematic Reviews, 14(1), 1–31. doi:10.1002/CL2.214

Hagner D, & Cooney BF (2005). "I do that for everybody": Supervising employees with autism. Focus on Autism and other Developmental Disabilities, 20(2), 91–97.

Hayward SM, McVilly KR, & Stokes MA (2019). "I Would Love to Just Be Myself": What Autistic Women Want at Work. Autism in Adulthood, 1(4), 297–305. doi:10.1089/aut.2019.0020

Hedley D, Uljarevic M, Cameron L, Halder S, Richdale A, & Dissanayake C (2017). Employment programmes and interventions targeting adults with autism spectrum disorder: A systematic review of the literature. Autism, 21(8), 929–941. doi:10.1177/1362361316661855 [PubMed: 27542395]

Howlin P, Alcock J, & Burkin C (2005). An 8 year follow-up of a specialist supported employment service for high-ability adults with autism or Asperger syndrome. Autism, 9(5), 533–549. doi:10.1177/1362361305057871 [PubMed: 16287704]

Human Rights Campaign Foundation. (2018). A workplace divided: Understanding the climate for LGBTQ workers nationwide Retrieved from https://www.hrc.org/resources/a-workplace-divided-understanding-the-climate-for-lgbtq-workers-nationwide:

Israel BA, Eng E, Schulz AJ, & Parker EA (2005). Methods in Community-Based Participatory Research for Health San Fransisco: John Wiley & Sons, Inc.

Israel BA, Schulz AJ, Parker EA, & Becker AB (2001). Community-based participatory research: policy recommendations for promoting a partnership approach in health research. Educ Health (Abingdon), 14(2), 182–197. doi:10.1080/13576280110051055 [PubMed: 14742017]

Kinoshita Y, Furukawa TA, Kinoshita K, Honyashiki M, Omori IM, Marshall M, … Kingdon D (2013). Supported employment for adults with severe mental illness. Cochrane Database of Systematic Reviews(9). doi:10.1002/14651858.CD008297.pub2

Lindsay S, Osten V, Rezai M, & Bui S (2021). Disclosure and workplace accommodations for people with autism: a systematic review. Disabil Rehabil, 43(5), 597–610. doi:10.1080/09638288.2019.1635658 [PubMed: 31282214]

Lorenc T, Rodgers M, Marshall D, Melton H, Rees R, Wright K, & Sowden A (2018). Support for adults with autism spectrum disorder without intellectual impairment: Systematic review. Autism, 22(6), 654–668. doi:10.1177/1362361317698939 [PubMed: 28683565]

McCoyd JLM, & Kerson TS (2006). Conducting Intensive Interviews Using Email: A Serendipitous Comparative Opportunity. Qualitative Social Work, 5(3), 389–406. doi:10.1177/1473325006067367

McDonough JT, & Revell G (2010). Accessing employment supports in the adult system for transitioning youth with autism spectrum disorders. Journal of Vocational Rehabilitation, 32, 89–100. doi:10.3233/JVR-2010-0498

Morrow SL (2005). Quality and trustworthiness in qualitative research in counseling psychology. Journal of Counseling Psychology, 52(2), 250–260. doi:10.1037/0022-0167.52.2.250

Nicholas DB, Attridge M, Zwaigenbaum L, & Clarke M (2015). Vocational support approaches in autism spectrum disorder: A synthesis review of the literature. Autism, 19(2), 235–245. doi:10.1177/1362361313516548 [PubMed: 24449603]

Nicholas DB, & Klag M (2020). Critical Reflections on Employment Among Autistic Adults. Autism in Adulthood, 2(4), 289–295. doi:10.1089/aut.2020.0006

Nicholas DB, Raymaker DM, Hedley D, Randolph JK, Robertson SM, & Vincent J (2019). An expert discussion on employment in autism. Autism in Adulthood, 1(3), 162–169. doi:10.1089/aut.2019.290003.djn [PubMed: 35252769]

Nicolaidis C, & Raymaker DM (2015). Community based participatory research with communities defined by race, ethnicity, and disability: Translating theory to practice. In Bradbury H (Ed.), The SAGE Handbook of Action Research: SAGE.

Nicolaidis C, Raymaker DM, Ashkenazy E, McDonald KE, Boisclair WC, Baggs AEV, … Dern S (2015). “Respect the way I need to communicate with you”: Healthcare experiences of adults on the autism spectrum. Autism doi:DOI: 10.1177/1362361315576221

Nicolaidis C, Raymaker DM, Kapp SK, Baggs A, Ashkenazy E, McDonald K, … Joyce A (2019). The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. Autism, 23(8), 2007–2019. doi:10.1177/1362361319830523 [PubMed: 30939892]

Nicolaidis C, Raymaker DM, McDonald KE, Dern S, Ashkenazy E, Boisclair WC, … Baggs A (2011). Collaboration strategies in non-traditional CBPR partnerships: Lessons from an academic-community partnership with autistic self-advocates. Progress in Community Health Partnerships, 5(2), 143–150. [PubMed: 21623016]

Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, & Hoagwood K (2015). Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. Administration and Policy in Mental Health and Mental Health Services Research, 42(5), 533–544. doi:10.1007/s10488-013-0528-y [PubMed: 24193818]

Pasterski V, Gilligan L, & Curtis R (2014). Traits of Autism Spectrum Disorders in Adults with Gender Dysphoria. Archives of Sexual Behavior, 43(2), 387–393. doi:10.1007/s10508-013-0154-5 [PubMed: 23864402]

Raymaker DM, Teo AR, Steckler NA, Lentz B, Scharer M, Delos Santos A, … Nicolaidis C (2020). “Having All of Your Internal Resources Exhausted Beyond Measure and Being Left with No Clean-Up Crew”: Defining Autistic Burnout. Autism Adulthood, 2(2), 132–143. doi:10.1089/aut.2019.0079 [PubMed: 32851204]

Robert Wood Johnson Foundation Qualitative Research Guidelines Project. (2008). Critical or subtle realist paradigm Retrieved from http://www.qualres.org/HomeCrit-3517.html

Romualdez AM, Heasman B, Walker Z, Davies J, & Remington A (2021). "People Might Understand Me Better": Diagnostic Disclosure Experiences of Autistic Individuals in the Workplace. Autism in Adulthood doi:10.1089/aut.2020.0063

Rudolph CES, Lundin A, Åhs JW, Dalman C, & Kosidou K (2018). Brief Report: Sexual Orientation in Individuals with Autistic Traits: Population Based Study of 47,000 Adults in Stockholm County. Journal of Autism and Developmental Disorders, 48(2), 619–624. doi:10.1007/s10803-017-3369-9 [PubMed: 29086210]

Shattuck PT, & Narendorf SC (2012). Postsecondary education and employment among youth with an autism spectrum disorder. Pediatrics, 129(6), 1042–1049. [PubMed: 22585766]

Taylor JL, McPheeters ML, Sathe NA, Dove D, Veenstra-Vanderweele J, & Warren Z (2012). A systematic review of vocational interventions for young adults with autism spectrum disorders. Pediatrics, 130(3), 531–538. doi:10.1542/peds.2012-0682 [PubMed: 22926170]

Taylor JL, Smith LE, & Mailick MR (2014). Engagement in vocational activities promotes behavioral development for adults with autism spectrum disorders. Journal of Autism and Developmental Disorders, 44(6), 1447–1460. doi:10.1007/s10803-013-2010-9 [PubMed: 24287880]

Tharanga Sumanasiri EG, Ab Yajid MS, & Khatibi A (2016). Organization-Based Self-Esteem (OBSE) And Its Influence On Self-Perceived Employability (SPE) Of IT Export Sector Employees In Sri Lanka. *European Scientific Journal*, ESJ, 12(14), 124. doi:10.19044/esj.2016.v12n14p124

The National Autism Resource & Information Center. (2018). Employment Research and Reports | Autism NOW Center Retrieved from http://autismnow.org/on-the-job/employment-research-and-reports/

Thompson-Hodgetts S, Labonte C, Mazumder R, & Phelan S (2020). Helpful or harmful? A scoping review of perceptions and outcomes of autism diagnostic disclosure to others. Research in Autism Spectrum Disorders, 77, 101598. doi:10.1016/j.rasd.2020.101598

U.S. Bureau of Labor Statistics. (2020). Labor force characteristics by race and ethnicity, 2019 (1088) Retrieved from https://www.bls.gov/opub/reports/race-and-ethnicity/2019/home.htm: https://www.bls.gov/opub/reports/race-and-ethnicity/2019/home.htm

US Department of Labor. (2021). Customized Employment Retrieved from https://www.dol.gov/agencies/odep/program-areas/customized-employment

Vincent S, & O'Mahoney J (2018). Critical realism and qualitative research: An introductory overview. In The SAGE Handbook of Qualitative Business and Management Research Methods: History and Traditions 55 City Road, London: SAGE Publications Ltd.

Wehman P, Brooke V, Brooke AM, Ham W, Schall C, McDonough J, … Avellone L (2016). Employment for adults with autism spectrum disorders: A retrospective review of a customized employment approach. Research in Developmental Disabilities, 53–54, 61–72. doi:10.1016/j.ridd.2016.01.015

Figure 1:

Model of Findings: Experiences and Facilitators that Interact with Dimensions of Success

Table 1.

Employee/Job Seeker Demographics.

N	**45**
Age	
Mean	36
Std. dev.	11.3
Range	21–65
Gender	
Female	21 (47)%
Male	18 (40)%
Other gender identity	6 (13)%
Race/ethnicity	
Asian	3 (7%)
Black/African-American	2 (4%)
White	35 (78%)
Multiracial	4 (9%)
Latino	1 (2%)
Education	
High school or GED	6 (13%)
Associate's degree	6 (13%)
Bachelor's degree	20 (44%)
Master's degree	11 (24%)
Doctoral degree	2 (4%)
Additional training	
Professional certification/licensure	20 (44%)
Graduate certificate	6 (13%)
Formal apprenticeship	3 (7%)
Formal intern/externship	3 (7%)
Successful employment	31 (69%)
Alternative and augmentative communication use	10 (22%)
Disability service use	19 (42%)
Interview mode	
Email	22 (49%)
text chat	3 (7%)
Telephone	3 (7%)
video conference	5 (11%)
in person	12 (27%)
U.S. State	AZ (1)
	CA (2)
	CO (2)
	FL (1)
	IL (2)

N	**45**
	KS (1)
	LA (1)
	MA (2)
	MD (1)
	ME (1)
	NE (1)
	NJ (1)
	NM (1)
	NY (3)
	OR (18)
	RI (1)
	VA (3)
	WA (1)