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Using the COM-B Model and Theoretical Domains Framework to Understand Workplace Disclosure Experiences, Influencers, and Needs Among Autistic Young Adults

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Abstract
For autistic young adults, deciding whether to disclose their autism at work is complex. Minimal research explores what they need to support disclosure and what influences decisions. To understand disclosure needs and influencers, we explored (i) disclosure decision-making experiences and (ii) perceptions of the disclosure process among autistic young adults. We conducted focus groups using the Capability, Opportunity, Motivation, Behaviour Model and Theoretical Domains Framework (TDF). We analyzed data from 23 participants and mapped onto the TDF to develop five themes: (1) workplace environment, (2) perceptions of disclosure outcomes, (3) personal factors and identity, (4) disclosure-related ambitions and determination, and (5) know-hows of disclosure. Future work should prioritize developing disclosure decision-making supports and investigate employer roles in fostering inclusive workplaces.

Keywords Disability disclosure · Employment · Autism · Young adults · Knowledge translation

The transition to employment is a momentous milestone for youth and young adults and has been linked to enhanced wellbeing and employment outcomes in adulthood (Wei et al., 2014). However, for youth and young adults on the autism spectrum, the transition to employment is often less than seamless, leading to worse employment outcomes compared to their neurotypical peers and other disability populations (Chen et al., 2015; Statistics Canada, 2017). This is evidenced by exceptionally low global employment rates or their work in low-wage, part-time, sometimes precarious jobs (Roux et al., 2013; Tint et al., 2017). Workplace accommodations may improve employment outcomes because accommodations can improve workplace inclusivity and productivity (Dreaver et al., 2020). Before accommodations are obtained, the person needs to disclose one or more of the following: (1) autism diagnosis, (2) symptoms (can be without autism diagnosis), and/or (3) their workplace challenges and needs. Deciding whether and how to disclose involves complex processes often accompanied by stress and uncertainty (Santuzzi et al., 2014). Perceptions of autistic youth and young adults regarding how to navigate disclosure at work and what they need to help with decision-making are lacking in the literature.

1 We use identity-first and neutral language (“person on the autism spectrum”) as per recommendations by the Canadian Autism Spectrum Disorder Alliance and the Autistic Self Advocacy Network USA.
Autism and Employment

Persons on the autism spectrum experience a kaleidoscopic manifestation of symptoms that can impact their ability to obtain and maintain employment (e.g., communication, sensory, and executive functioning challenges; Bury et al., 2021; Scott et al., 2019). Nonetheless, most autistic persons offer varying, invaluable benefits at work, such as trustworthiness, honesty, a higher tolerance for repetitive tasks, low absenteeism, and great attention to detail (Bury et al., 2020; Hurley-Hanson et al., 2019). Further, most autistic persons are eager to work, and have similar aspirations as their neurotypical peers, such as career goals, hopes for financial security, and independence (Anderson et al., 2021). However, autistic persons struggle to find and sustain employment and face some of the worst employment outcomes of all disability groups (Chen et al., 2015; Nicholas et al., 2019). For example, in Canada, only 33% of autistic adults report being employed (Statistics Canada, 2017). Of those who are employed, many are underemployed, meaning they unwillingly work shorter hours, receive minimal pay, and/or underutilize their skills in jobs below their intellectual potential (Ohl et al., 2017).

Even more troublesome are the pervasive unemployment and underemployment outcomes faced by autistic youth and young adults (Flower et al., 2020; Hedley et al., 2017). This is worrisome because they are at a critical developmental period to foster skills needed for future employment and adult life (e.g., executive functioning, self-advocacy; Bennett et al., 2018). Receiving suitable workplace accommodations, such as flexible work hours, quieter workspaces, and supportive equipment, can improve employment outcomes for autistic youth and young adults (Lindsay et al., 2021; Wehman et al., 2020). However, they must disclose their autism or workplace needs before receiving accommodations.

Disclosure, Autism, and Employment

Disclosure at work is when a person informs others about their health condition or symptoms and needs, which can occur at different points in the hiring process and vary on how much information is shared (MacDonald-Wilson et al., 2011; Vornholt et al., 2018). Factors shown to influence disclosure among autistic adults include past disclosure experiences, the workplace environment, relevance of disclosure to the job, severity of autism, fear of discrimination and stigma, and disclosure goals like increasing autism acceptance and receiving workplace accommodations (Lindsay et al., 2021; Romualdez et al., 2021b; Thompson-Hodgetts et al., 2020). Persons on the autism spectrum must also consider and anticipate disclosure outcomes. Positive outcomes can include enhanced inclusion and understanding at work, accommodations, catharsis, and improved first impressions, whereas, negative outcomes might involve discrimination, bullying, not getting hired, and employers curtailing workplace responsibilities (Hayward et al., 2019; O’Connor et al., 2020; Ohl et al., 2017; Thompson-Hodgetts et al., 2020).

Knowledge Gaps

Research has focused on barriers to and facilitators of disclosure, goals, and outcomes for autistic adults, with minimal focus on autistic youth and young adults. Given the array of potential outcomes, deciding whether and how to disclose could affect the work trajectory of these young people. There is a need to explore disclosure decision-making and navigation processes among autistic persons in general (i.e., how these factors are weighed and considered, how to navigate actual disclosure; Lindsay et al., 2021), and further, among understudied autistic youth and young adults.

Deciding whether and how to disclose might be difficult for someone on the autism spectrum due to challenges with decision making (Vella et al., 2011) and the social nature of disclosure (Greene, 2009). It is important to understand the nature of the relationship with the disclosure recipient and anticipate and react accordingly to potential disclosure responses. Doing so may be difficult for autistic persons as they sometimes struggle with recognizing, understanding, and responding to social cues (Davidson & Henderson, 2010; Johnson & Joshi, 2014). Research highlights the need to better understand and develop disclosure-related and vocational supports and tools for autistic youth and young adults (Migliore et al., 2014). However, before developing supports, it is imperative to understand potential influencing factors, related needs, and experiences among autistic youth and young adults that may impact disclosure.

The Current Study

We conducted a qualitative study informed by the field of knowledge translation to (1) explore disclosure decision-making experiences and (2) understand how young autistic people perceive the process and logistics of disclosure, to identify factors that influence disclosure behaviours and related needs. In this study, disclosure was defined as divulging an autism diagnosis, symptoms, or workplace needs. We defined this as being a formal process that involves planning, or an informal one, via casual, unplanned conversations. We
considered full disclosure as disclosing one’s diagnosis to everyone at work, and selective disclosure as disclosing to certain people or sharing limited information (MacDonald-Wilson et al., 2011). Disclosure behaviours comprised how disclosure choices were navigated, and the factors considered. We focused on competitive, integrated employment, which is a job within the competitive labour market, full-time or part-time; compensation commensurate with efforts; the person has promotion opportunities; and they work alongside employees with and without disabilities (Wehman et al., 2003).

Theoretical Perspectives

The Capability, Opportunity, Motivation, Behaviour (COM-B) Model (Michie et al., 2011) and the Theoretical Domains Framework (TDF) (Cane et al., 2012) from the field of knowledge translation, were used to increase understanding of disclosure behaviours, following methods of Theory Framed Research (McKenna, 1997). The developers of the COM-B Model posit that each person’s behaviour system constitutes capability (psychological or physical), opportunity (social or physical), and motivation (reflective or automatic), which interact to influence behaviours (Michie et al., 2011). Authors of the TDF amalgamated 33 psychological and organizational theories of behaviour change into 14 domains that identify individual-level behavioural influencers (knowledge, skills, social/professional role and identity, beliefs about capabilities, optimism, beliefs about consequences, reinforcement, intentions, goals, memory, attention and decision processes, environmental context and resources, social influences, emotion, behavioural regulation; Cane et al., 2012). While distinct frameworks, the COM-B and TDF are complementary (Fahim et al., 2020; Ojo et al., 2019). The TDF domains link to the broader COM-B Model categories to elucidate details of capability, opportunity, and motivation. For example, capability connects to the TDF domains of knowledge, skills, behavioural regulation, and memory, attention and decision processes. This connection helps to clarify specific influencers of behaviours.

Methods

We used a generic qualitative design to guide our data collection and analysis. This design is flexible and incorporates different qualitative methods rather than following the strict paradigmatic assumptions of one design, such as grounded theory or phenomenology, which require specific data collection and analysis approaches (Caelli et al., 2003). Generic qualitative design aligned with the postpositivist research paradigm guiding this study (Bunniss & Kelly, 2010); offered flexibility to conduct focus groups and use a deductive analytical approach, with openness to inductive interpretations; and supported translational goals that study findings inform future research and intervention development, which is often inappropriate with other qualitative designs due to assumptions that stipulate multiple realities exist, and there is no “correct” way of knowing or an ultimate truth that can be applied. Generic qualitative design also requires the use of reflexivity (Bellamy et al., 2016; Caelli et al., 2003).

We used focus groups to collect data. Focus groups are useful when the study aim is to gather a range of opinions and perceptions related to a particular topic, and not to gather in-depth experiences (Krueger & Casey, 2015); when assessing needs (Krueger & Casey, 2015; Stalmeijer et al., 2014); to understand complex interactions between characteristics (e.g., disability, gender, employment; ODay & Killeen, 2002); and have been successfully used with autistic youth and young adults (Cai & Richdale, 2016; Lambe et al., 2018). Our team received institutional ethics approval in July 2020 (REB#20–886).

Participants

Participants were included if they were aged 15–29 (Arnett, 2007; Statistics Canada, 2019) and diagnosed with autism (as identified and disclosed by the participant). Participants had to be employed (full- or part-time) or have past competitive (paid) work experience (Wehman et al., 2020) and could not have sought employment or disclosed through disability hiring agencies. Participants were excluded if they had a comorbid visible disability and/or were non-verbal, due to differing disclosure needs because their disability is evident. Finally, participants had to live in Canada, communicate in and understand English fluently, and have a technological device with internet access.

We recruited participants using purposive sampling following homogeneous and snowball techniques (Patton, 2002). Participants were recruited through a pediatric rehabilitation hospital, university-based accessibility services and autism social clubs, and over 30 Canadian autism organizations using online recruitment flyers, social media posts, website postings, newsletter postings, listservs, and participant network connections from September 2020 to February 2021. Interested participants reached out to the first author who explained the purpose of the study, provided opportunity for questions, and screened participants. All participants provided informed consent following our research institute’s COVID-19 REB protocol. Thirty-six people contacted the first author with initial interest in the study. Six were excluded since we could not re-contact them, five were ineligible (i.e., no autism diagnosis, disclosed via disability hiring agency), and two dropped out. A total of
23 young adults on the autism spectrum participated in this study with a mean age of 22.78 years (ranged between 18 and 29 years). Since all participants were 18 years of age or older, we refer to them as young adults in the remainder of this paper. All participants were verbal, cognitively able to participate independently, and spoke and understood English fluently. There were 13 men, 8 women, 1 transman, and 1 transwoman. Eleven participants were unemployed but had past competitive work experience, ten were employed part-time, and two were employed full-time in the competitive workforce (Table 1).

### Data Collection

Six online focus groups were held from October 2020 to February 2021. A flexible focus group guide was developed based on recommendations by Krueger (1998) and refinements based on qualitative research with persons on the autism spectrum (e.g., having yes/no questions at the beginning; Lambe et al., 2018). The COM-B model was used to guide question content to frame the conversation around and link to constituents of a person’s behaviour system (i.e., capability, opportunity, motivation; Supplementary File 1). The focus group guide was reviewed and revised by an autistic youth advisor.

Focus groups were conducted online via Zoom web-conferencing software due to Canadian public health COVID-19 restrictions limiting in-person research. Online data collection using audiovisual platforms like Zoom have shown to generate similar thematic content to in-person qualitative research (Abrams et al., 2015; Namey et al., 2019). Persons on the autism spectrum have also indicated benefits of web-conferencing, such as being in their familiar home environment (Zolyomi et al., 2019). The first author, who has qualitative research experience, led the focus groups and took field notes. Focus group facilitation and Zoom-based qualitative research recommendations were followed (e.g., navigating dominating and shy personalities, pilot testing of Zoom; Gray et al., 2020; Krueger & Casey, 2015). Focus groups ranged from 45 min to 1-h-30-min. Focus group sizes ranged from two-to-five participants per group,\(^2\) in which smaller group sizes are recommended for research with persons on the autism spectrum and with web-conferencing platforms (Lambe et al., 2018; Lobe et al., 2020). The focus

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\(^2\) We acknowledge the varying terminology in qualitative research. For some, two-to-three participants may be referred to as group interviews; however, for consistency, we refer to all groups as focus groups.
group with two participants was due to a last-minute participant drop-out. Data collection concluded after the sixth focus group as no new ideas surfaced (Guest et al., 2017). We used strategies to enhance accessibility and comfort for participants. For example, the first author had the questions on PowerPoint slides and shared her screen upon participant request. This allowed participants to read the questions if they required more time while still being able to interact and view each other’s cameras on the Zoom screen. The questions were also provided to participants beforehand, if requested.

Data Analysis

The first author transcribed all focus group recordings verbatim. We analyzed transcripts using NVivo 12 software following a deductive approach to Braun and Clarke’s thematic analysis. We used the TDF as the guiding framework due to its connection and expansion on the COM-B Model, which guided the focus group questions (Braun & Clarke, 2006; Cane et al., 2012). We followed additional recommendations to guide qualitative analyses using the TDF (Atkins et al., 2017). The 14 TDF domains were defined and categorized within the context of disclosure decision-making and actual disclosure or non-disclosure processes and were utilized as starting subthemes (Table 2). After reading each manuscript several times, the first author generated initial codes related to each TDF domain subtheme and developed a coding framework. One TDF domain was not relevant to the data (reinforcement) and some data were double coded as they related to more than one TDF domain. While a deductive approach was used primarily, our team was open to additional codes and did not curtail coding strictly to the TDF (Fereday & Muir-Cochrane, 2006). Upon review, verification, and discussion of the raw transcripts, coding framework, and codes by select members of the research team with qualitative analytical experience, the first author collated the codes and subthemes to develop superordinate themes. The themes were discussed collaboratively among three team members to consider their validity in relation to the data set. While some TDF domains (i.e., subthemes) may seem to display relevance to more than one theme, they were grouped, and themes were defined, based on participant quotes, codes, and TDF domain definitions to find and display the greatest connection across TDF domains to best answer our research questions.

We used different techniques to improve the credibility, transferability, and confirmability of this research (trustworthiness; Frambach et al., 2013; Rolfe, 2006). To improve credibility, the focus groups were recorded, and we had an analysis team review the codes and themes. To establish transferability, we have delineated the data collection and analysis and compare results with current evidence. To ensure confirmability, the first author practiced reflexivity to consider her potential influence on the research and kept detailed field notes and memos throughout the data collection and analysis (Rolfe, 2006).

Results

Using the TDF domains as subthemes, with openness to inductive interpretations, we developed five overarching themes. These themes are predicated upon 13 of 14 TDF domains (Fig. 1): (1) workplace environment, (2) perceptions of disclosure outcomes, (3) personal factors and identity, (4) disclosure-related ambitions and determination, and (5) the know-hows of disclosure. While all themes discuss disclosure decision-making influencers, themes are ordered by those that focus primarily on these decision-making factors (one to three) to those that also discuss navigation of disclosure logistics (four and five). There is no prescribed order in how these factors influence disclosure and/or are considered, but instead, are more dynamic and iterative in nature. The most discussed TDF domain/subtheme was environmental context and resources and the least discussed was optimism. Please see Table 2 for additional participant quotes.

Theme 1: Workplace Environment

This theme involves workplace environmental factors that influence disclosure behaviours, including physical, social, attitudinal, and political, as well as workplace needs and supports. The TDF domains are environmental context and resources and social influences. An additional subtheme of workplace needs was developed unrelated to the TDF. The largest contribution to this theme was environmental context and resources and the lowest was workplace needs.

Environmental Context and Resources

This TDF domain was discussed as the greatest influencer of disclosure behaviours and included the job role in the specific work environment, workplace policies, mission/diversity statements, strategic plans, the workplace culture (i.e., inclusiveness, the employer, colleagues), and available workplace supports. Regarding the job role, some participants indicated needing to disclose to receive accommodations to support their work duties, whereas others affirmed that their autism was irrelevant to their job, and thus, did not disclose. Participant 7 said, “When I was like doing cleaning, it just wasn’t relevant… But as a cashier, I was having a lot of struggles.” Some autistic young adults spoke to workplace policies, strategic plans, and mission/diversity statements and how protective and inclusive policies enabled, or would
| Theoretical Domains Framework | Domain/Subtheme | Definition (Cane et al., 2012) | Participant Quotes |
|-------------------------------|----------------|---------------------------------|--------------------|
| **Environmental context and resources** | Environmental factors that either enable or inhibit disclosure and related decisions and available workplace supports and resources | Participant 18: “I think in my restaurant jobs I would say it’s not important because I can’t really control or change anything about the conditions...It might be important if like the schedule is really overwhelming or like I do need some kind of supports.” |
| **Social influences** | Interpersonal processes that caused the autistic young adults to change their feelings around and behaviours related to disclosure; for instance, social pressures, support, comparisons, and norms | Participant 15: “They should be uh sensitive in a respectful way to those workers with autism. That’s another quality. Being sensitive in a respectful way.” |
| **Workplace Needs** | Supports, accommodations, and/or adjustments indicated by autistic young adults’ that would help them perform their best at work | Participant 13: “I need good clear instructions, support when I’m training, um notes that I can look at when I work, and the opportunity to get out of a busy environment.” |
| **Beliefs about consequences** | Perceived negative outcomes of disclosure at work | Participant 12: “I feel like people hear the word autism, they start projecting all these assumptions onto me, and it’s actually like more difficult for them to read me.” |
| **Optimism** | Autistic young adults’ confidence that the desired disclosure outcome would be obtained and beliefs around positive disclosure outcomes | Participant 16: “It’s also a way for your employer to get to understand you better, and... they might be an individual who is really passionate about autism.” |
| **Emotion** | Experiential, physiological, behavioural patterns and elements to deal with disclosure and anticipated outcomes | Participant 21: “Yeah, not getting hired is a big worry.” |
| **Social professional role and identity** | Behaviours and/or qualities in a social or work setting, such as one’s personal, social, professional, and group identity | Participant 10: “I would disclose to anyone personally, because I’m very open. Like, I don’t care if you know I have autism.” |
| **Beliefs about capabilities** | Beliefs of and acceptance around certain abilities (related to disclosure), confidence, self-efficacy, empowerment, and behavioural control | Participant 15: “If I decided to disclose, um which I usually would feel comfortable doing, the way to disclose it is to just uh be polite, be honest, and know the truth of who you are.” |
| **Goals** | Ambitions and goals related to disclosure | Participant 3: “Disclosing your disability might put you in touch with someone else at your workplace who also has the same diagnosis.” |
| **Intentions** | The conscious decision to perform a behaviour (i.e., make disclosure decisions and/or enact disclosure-related logistics) | Participant 6: “Depending on the position... I’d explain everything, in detail, in the interview.” |
| **Knowledge** | Awareness and/or understanding of disclosure, or a lack thereof, related to decision-making factors, logistics, and procedural knowledge | Participant 5: “I’m the first person who I know to go through it. So, to not even know what the process is, or like what to expect, or what that looks like, or what’s normal.” |
| **Skills** | Experience with and practice around disclosure decision-making and disclosure event(s) | Participant 12: “I just say like ‘okay I have trouble remembering written instructions or I’m really sensitive to bright lights’, like I’ll just give them the list of symptoms.” |
| **Behavioural regulation** | Managing or changing one’s behaviours related to disclosure and can involve self-monitoring and action planning | Participant 8: “I just sort of give a general like ‘I’m on the autism spectrum’, and probably just see...what their sort of feel is.” |
| **Memory, attention, and decision-making processes** | Ability of young adults to consider and weigh the numerous disclosure decision-making components to determine or anticipate their final decisions around disclosure | Participant 22: “Like before and after, maybe results could be the same, maybe it could turn horrible or could like, maybe it could turn like okay...So for me it’s hard to tell when.” |

*Not a TDF domain*
facilitate, their decision to disclose. Most participants spoke to the influence of the workplace culture and environment on disclosure decisions, such as employer leadership efforts that supported inclusivity of disabled employees, organizational values and initiatives, and whether colleagues were supportive and understanding of and educated about autism. Participant 5 spoke to her organization’s values, saying:

The company I work for has a great set of values, is constantly recognized as a top employer in X, Y, and Z, and has a group specifically for employees who are disabled…that’s a small part as to why I am comfortable entertaining the idea of disclosing.

Finally, participants spoke to workplace supports and resources, and whether supervisors and/or colleagues fostered supportive disclosure conversations. Again, participant 5 noted:

I had one manager who literally on my first day was like ‘okay we’re going to have a discussion about work styles, and what’s your best way to work and what are things you don’t want to do and what do you love doing’…so like if it’s a very frank and open discussion I’d be much more comfortable disclosing that.

Workplace Needs (Not a TDF Domain)

As mentioned briefly in the preceding subtheme, participants expressed that they were more likely to disclose if they needed accommodations. Examples of supports and/or accommodations included having explicit instructions, flexibility with deadlines, human support to ask questions, sensory adjustments (i.e., lighting and noise levels), and minimized customer contact. For example, participant 4 spoke to the need for clear instructions, saying, “Something I don’t like is like ambiguity… I really need to know what my goals are and what my specific tasks are.” Markedly, there seemed to be a disconnect between participants indicating that they needed or would benefit from accommodations and still opting for non-disclosure. This may be due to underlying fears of discrimination, a lack of autism understanding in their workplace, and participants’ uncertainties around how to disclose and request accommodations.

Social Influences

Participants highlighted positive and negative social influences and existing or past relationships with the disclosure recipient. Regarding negative influences, participants spoke to unfavourable qualities in others, which often led them to non-disclosure, such as discriminatory behaviour, being insensitive, and engaging in gossip. Participant 7 stated, “If I hear them… kind of like make these like ableist jokes, then I’m going to be more cautious in telling them.” Conversely, most of the young adults spoke to positive qualities or that they assessed for positive attributes, which facilitated disclosure. Participants 13 and 1 relayed that their manager and/or colleague had to be deemed “fair, compassionate, and patient” and “accepting and inclusive”, respectively, before...
they would disclose to them. Another influencer was if the disclosure recipient had autism or another disability. Participant 23 said, “It’s sort of cool because um my employer is also autistic, so, it just sort of came up in conversation and then she mentioned she had it too.” Some participants noted not having to make disclosure decisions in past jobs or the entirety of their employment experiences due to prior relationships with the disclosure recipient. Some participants spoke to disclosing to their colleagues because they became friends, or that friendship was a prerequisite to disclosing.

**Theme 2: Perceptions of Disclosure Outcomes**

Perceptions of disclosure outcomes, and whether these were positive or negative, were discussed as influencers of disclosure decisions. The TDF domains that comprised this theme include beliefs about consequences, optimism, and emotion. The TDF domain with the largest contribution was beliefs about consequences, with the lowest being optimism.

**Beliefs About Consequences**

All autistic young adults spoke to potential negative outcomes, which included discrimination, stigma, bullying, infantilizing, lack of understanding, increased pressure to prove oneself or educate others about autism, negatively impacting workplace relationships, and/or not getting hired. Anticipated stigma, discrimination, and a lack of understanding were discussed most frequently. For example, participant 13 said, “I might not tell people I have autism because I know they might not understand, or they may not even know what autism is or might not give me the job, or they may assume that I’m not capable.” A few participants discussed perceived pressure after disclosure to educate others about their autism. Finally, autistic young adults expressed the adverse impact disclosure could have on workplace relationships: “You may also not mention that you have autism because you don’t want it to be all that is talked about…you also want to bond over other interests that make you, you” (Participant 16).

**Optimism**

Participants spoke about anticipated positive outcomes of disclosure, including accommodations, enhanced acceptance and understanding, reduced stress and anxiety, increased workplace success, and trust in their manager, human resources, and employer to support them at work after disclosing. However, this was the least discussed TDF domain across all themes. Participant 15 spoke to disclosing to increase workplace success: “We autistic people, we have the right to be successful… It is important to tell people, your boss, or your fellow coworkers that you have autism, so we can all have a chance to succeed”.

**Emotion**

Emotional responses were discussed as influencing non-disclosure, and were categorized as negative (i.e., worry, fear, stress, anxiety) or related to past experiences, which festered negative feelings. Participant 22 spoke to his fears around disclosure, expressing, “I feel a bit afraid because you know, I fear of … people, at work may use that information of mine, to use it as my weakness.” Participant 18 spoke to worries around the impact on her job: “I would worry about being fired or having my shifts reduced.” Some participants spoke to past negative experiences of disclosure at work and/or more generally, which precipitated future non-disclosure and negative feelings about disclosure. For example, participant 12 relayed her experiences expressing, “Well sometimes I’ve disclosed, and people don’t believe me. They’re like ‘oh you don’t have autism, like you’re social’ or whatever.”

**Theme 3: Personal Factors and Identity**

This theme refers to factors of oneself (confidence, identity) that enable or inhibit disclosure decisions, and includes the TDF domains of social and professional role and identity and beliefs about capabilities. The largest contributor was the TDF domain social and professional role and identity.

**Social and Professional Role and Identity**

Autistic young adults spoke to the influence of other identities and whether autism was a part of their identity. Participant 10 spoke to how autism was part of her identity and that this made her more likely to disclose: “Yeah, it’s part of my identity. I always tell people. Bring on the questions—whatever you want to ask!” Conversely, while participant 14 expressed that autism was part of her identity, she was not more likely to disclose: “We’re ourselves whether we talk about it or not. Like you’re not faking if you don’t say that you have autism—you’re going to be you no matter what.” Some participants spoke to other identities related to their sexual orientation, gender identity, and other disabilities, and the impact this had on disclosing their autism. Participant 23 spoke to feeling that autism disclosure was more cumbersome than disclosing other identities: “It’s almost easier to disclose the fact that I’m gay, the fact that I’m trans, then to say hey, I’m autistic.” In fact, both transgender participants spoke to preference in disclosing their transgender identities over their autistic identities.
Beliefs About Capabilities

We categorized participants’ responses around their perceived confidence and competence of disclosure, or lack thereof. Most participants who contributed to this subtheme possessed confidence around disclosure and future disclosure decision capabilities (i.e., who they would disclose to, when they would disclose, information shared, requesting accommodations), which also relates to participant knowledge of the process and their skills (subthemes of Knowledge and Skills in Know-How of Disclosure); however, only some participants contributed. Participant 5 expressed confidence in their abilities to disclose if needing accommodations:

I was prepared to disclose at one point when asking for accommodations. It never came up but that’s sort of how I always imagined it, like ‘hey, I need X’ and then they ask why, then I’d say, oh actually this is why.

However, some participants explicitly expressed uncertainties and a lack of confidence around their capabilities, questioning their responses to focus group questions or being uncertain in their abilities to effectively disclose at work. Participant 3 was unsure about future disclosure decision capabilities, thinking that he would not be able to remember who he disclosed to: “I would have a lot of problems remembering who I’ve told and all that stuff, so I generally avoid that by just not telling people.”

Theme 4: Disclosure-Related Ambitions and Determination

Theme four encompasses autistic young adults’ goals, motivations, and logistical intentions, and how these might influence disclosure decisions and navigation, and include the TDF domains of goals and intentions. The largest contributor to this theme was the TDF domain of goals.

Goals

We categorized goals as self-focused, other-focused, or no related goals (i.e., participants felt disclosure was unimportant). For self-focused goals, participants identified goals related to themselves and/or their specific needs. For instance, disclosing to connect with other autistic employees, enhance support systems, reduce anxieties of concealing, and receive accommodations, which was discussed the most. For example, participant 6 said, “I would disclose to [employer] as early as I can...so that way, they’ll provide accommodations for when I’m working.” Participants also identified goals focused on others, such as to catalyze dialogue about autism in the workplace, be a support for other autistic employees, explain aberrant behaviours, and increase autism acceptance and understanding. Participant 5 highlighted using disclosure to facilitate conversations about autism in the workplace: “Being an advocate or trying to start that conversation in your organization is a worthwhile reason to disclose.” While most participants had disclosure-goals, some affirmed that disclosure was irrelevant and unimportant to them and had no disclosure goals (i.e., felt their autism was a private matter, they did not require accommodations).

Intentions

Participants spoke to their primary intentions around how they would approach disclosure scenarios, such as when they would disclose, who they would disclose to, and how they would disclose. This relates to participant knowledge of the process (subtheme of Knowledge in Know-How of Disclosure). Although there was a mixture of intentions around selective and full disclosure, most participants noted selective disclosure as their preference. While some participants intended to disclose to colleagues first, most participants intended to disclose to their manager or human resources first. For example, participant 15 said, “I would tell simply my supervisor or manager or boss, that I am different than him or her.” Further, most participants noted that they would disclose only after getting hired, with a few noting they would disclose during or before the interview.

Theme 5: The Know-How of Disclosure

This theme constitutes participants’ actual knowledge, skills and/or strategies, or lack thereof, related to making disclosure decisions and navigating disclosure logistics. The TDF domains are knowledge, skills, behavioural regulation, and memory, attention, and decision-making processes. The largest contribution was knowledge and the lowest was behavioural regulation.

Knowledge

Many participants displayed relevant knowledge regarding the overall disclosure process, for instance, options of who they could disclose to (i.e., human resources, managers, colleagues), the types of disclosure (i.e., selective vs. full disclosure), content of the disclosure message (i.e., highlighting needs, strengths, accommodation solutions), factors to consider (i.e., workplace culture and climate), and/or disclosure timing options (i.e., resume/cover letter, during interview, after getting hired). Even those who had not disclosed in the past portrayed some foundational knowledge about disclosure; however, several participants indicated a lack of knowledge and/or being unsure of how to find relevant information. For example, participant 18 epitomised this finding, saying, “This is interesting because I didn’t
really consider that these were options before, a lot of these times to disclose.”

Skills

Several participants had experience with formal disclosure, a few with informal disclosure or had past relationships with their employers and did not have to disclose, and many had never disclosed. For participants who disclosed, they spoke to actual experiences relating to the type of disclosure, who they disclosed to, what they disclosed, and when. Participant 9 spoke to disclosing in his cover letter: “Actually I wrote it in my cover letter too, because it kind of also… touched on one of the topics that my company likes to do.” For participants who did not have experience with disclosure, some spoke to needing guidance and support to develop relevant skills. For example, participant 5 said, “Even like seeing a before and after like, ‘Becky before she told everyone about what is happening and now after—oh life is the same for her but now better because she has all of these things she needs.”

Behavioural Regulation

Many participants discussed how they managed and regulated their disclosure decisions, actions, and related behaviours with multiple strategies. For example, assessing reactions after disclosing, bringing up autism in casual conversations, identifying the values and personal qualities of the disclosure recipient, waiting for their colleagues and employer to form opinions about their work ethic, and disclosing their autism to examine reactions to determine whether they want to work with that employer. Participant 12 discussed bringing up autism in casual conversations: “I’ll bring up autism in a general sense and… get an idea about their perceptions on it.” Participant 20 spoke to disclosing his hearing loss first, to assess reactions before disclosing his autism: “A couple of times I’ve gotten a really weird or negative reaction to that and it’s like okay well I’m definitely not telling them about the autism.”

Memory, Attention, and Decision-Making Processes

We noticed that participants were either extremely certain about the factors considered in disclosure, or uncertain and perplexed. Participants spoke to several factors that would be considered, which related to their knowledge and skills of the disclosure process and contextual factors (e.g., job role, relationship with disclosure recipient, workplace policies, culture), how they would determine this, and how this led to final decisions. Most participants who contributed to this subtheme showed certainty in and clarity around their considerations during the decision-making process and how they arrived or would arrive at final decisions. For example, participant 16 spoke to how and why she would decide to disclose approximately one-to-two weeks after starting a job:

Probably within the first week or two of learning the ropes at the job…It’s a high time of learning, training, and prep for everyone… so, once you’re past that initial stage of all that learning, that might be a good time to mention that you have autism.

However, some participants were not as certain in or aware of the factors to consider and/or were unsure of what their final decisions would be. For example, when asked when they would disclose, participant 22 said, “It’s a hard question because it’s really hard to know when I would tell them.”

Discussion

We explored workplace disclosure experiences among autistic young adults, to better understand influencing factors of disclosure and what might be needed to support navigation of decisional and disclosure processes. Our findings revealed multifarious factors that inhibit or enable disclosure, based on the TDF. The TDF domain of environmental context and resources was discussed most, with optimism being discussed least. These findings highlight the profound impact of the workplace environment on disclosure decisions, and the underlying fear and beliefs of negative disclosure outcomes. Future work should prioritize developing disclosure decision-making supports for this population and explore employer roles in fostering inclusive environments that enable autonomous disclosure decisions.

The workplace environment, including culture, policies, job roles, social influences from managers and colleagues, and autistic young adults’ workplace needs, were discussed as disclosure influencers. Our findings corroborate prior research across autistic adults and other disability populations regarding the ubiquitous influence of the workplace environment on disclosure (Bonaccio et al., 2019), putting the onus on organizations to create environments that support disclosure. Whether autistic young adults felt that disclosing was relevant to their job influenced disclosure, which is also seen among autistic adults (Huang et al., 2022; Romualdez et al., 2021a, 2021b). Participants identified qualities and characteristics of the disclosure recipient that made them feel more comfortable disclosing (e.g., if understanding, had autism, had a past relationship or current friendship, trustworthy, patient, compassionate). This finding is unique because the qualities and characteristics of the recipient have not been explored greatly in the autism literature beyond perceptions as to whether the disclosure recipient is trustworthy (Thompson-Hodgetts et al., 2020). While participants indicated needing workplace accommodations
and/or supports, there was a disconnect between identifying these needs and still thinking disclosure was unimportant and/or opting for non-disclosure. Equivalently, this was seen among youth with disabilities who did not disclose despite job coaches noting that they would benefit from accommodations due to their workplace needs (Lindsay et al., 2013).

Our study revealed the rife nature of perceptions around negative disclosure outcomes and the underlying emotional drivers, with very few participants noting positive outcomes. Beliefs of discrimination and stigma dominated discussions of why participants would not disclose. Most perceptions of undesirable outcomes were linked to negative emotions like fear, worry, and anxiety. Relatedly, current research highlights the extensiveness of fear and beliefs around negative disclosure outcomes among autistic adults and employees with other disabilities across age groups (Hanson et al., 2018; Kaushansky et al., 2017; Romualdez et al., 2021b). While most participants did not mention the benefits of disclosure, those who did, discussed accommodations, increased acceptance, workplace success, and reduced stress and anxiety. Unsurprisingly, our participants focused on negative outcomes, were unaware of disclosure benefits, and/or displayed skepticism of positive outcomes, as the literature highlights that youth and young adults with disabilities are often unaware of disclosure benefits in post-secondary and employment settings (Lindsay et al., 2019; Nuske et al., 2019). This is distinct from current evidence among autistic adults, where they have expressed extensive knowledge of the benefits and risks of disclosure (Raymaker et al., 2022; Romualdez et al., 2021b).

Personal factors, such as confidence, capabilities, and identity were discussed as important influencers of disclosure choices. Some participants embraced their autism as a critical component of their identity and indicated wanting to disclose. Research highlights the prominence of autistic identity and its connection to disclosure, with some persons being prideful of their autism (Botha et al., 2020), which can enhance the odds of disclosure within post-secondary (Frost et al., 2019) and workplace contexts (Cage & Troxell-Whitman, 2020). However, some participants who identified as autistic still expressed inclination towards non-disclosure. This was seen in a survey with autistic adults where despite participants identifying as autistic, other complex factors like fear of discrimination, inhibited disclosure (Cage & Troxell-Whitman, 2020). The relation to autistic identity might be particularly relevant for youth and young adults, as seen in post-secondary literature (Frost et al., 2019), specifically those with a recent autism diagnosis who are still grappling with their identity (Huang et al., 2020; Romualdez et al., 2021b). Another consequential finding was the noting of other identities like sexual orientation, gender, and other disabilities. Participants expressed greater comfort disclosing other identities either before, or in place of, their autism. This amplified risk of autism disclosure was expressed among autistic adults of racial, gender, and/or sexual minority groups (Raymaker et al., 2022).

Goals were identified as a major influencer of disclosure and intentions was discussed less frequently. Disclosing to receive workplace accommodations was discussed the most across participants, which corroborates prior research with autistic adults (Romualdez et al., 2021b; Whelpley et al., 2020). Goal setting may be important to determine disclosure likelihood and approaches to disclosure. Most participants intended to disclose to their managers first, however, some indicated disclosing to colleagues first if they were friends. Research with youth with disabilities highlights similar findings of primary workplace disclosure to managers (Kaushansky et al., 2017) with some to colleagues (Hanson et al., 2018). Regarding timing of disclosure, most participants conveyed that they would disclose after getting hired. Timing intention and certainty seemed dependent on abounding factors, such as whether they required accommodations, precarious nature of job role, and the fear of not getting hired.

Participants displayed a mixture of disclosure procedural knowledge, skills, and strategies. Most participants expressed foundational disclosure knowledge, with some having disclosure experience. Some participants employed strategies to help them make disclosure decisions, such as disclosing other diagnoses or identities first, bringing up autism casually, and disclosing to assess reactions and determine suitability of that employer. The latter was found in a survey study with 238 autistic adults, where some participants disclosed to determine whether they wanted to work at that company (i.e., dependent on disclosure reaction; Romualdez et al., 2021a). While most participants in our study possessed some disclosure knowledge, others noted confusions. This is similar to other young adults with disabilities, where they note confusions around disclosure logistics and how to ask for accommodations (Hanson et al., 2018; Kaushansky et al., 2017; Lindsay et al., 2013). While not in the employment context, autistic young adults expressed having minimal disclosure knowledge in post-secondary settings (Nuske et al., 2019). Knowledge and skill barriers seem to be more prevalent among the youth and young adult population in employment and post-secondary settings, as this has yet to be reported among the autistic adult disclosure literature. In fact, recent studies reported that autistic adults were well aware of the factors to consider and the disclosure process (Farsinejad et al., 2022; Raymaker et al., 2022).

Limitations

First, since we could not access medical records, we did not have information about autism characteristics or severity and
relied on autism self-disclosure, which limits credibility of participant demographics. Second, we included participants across Canada to gauge diversity of needs; however, this is also a limitation because accommodation and accessibility legislations differ provincially, which might influence disclosure (Caivano, 2016). Third, while we purposefully took a deductive analytical approach, we recognize that deductive analyses might curtail data interpretations; to mitigate this, we were open to inductive codes. Fourth, due to having only 23 participants, all from Canada, aged 18-years or older, and we did not have information about autism characteristics, broader applicability of these findings should be approached with care. Finally, we may have missed perspectives from non-English autistic Canadians and/or those who did not have computer and internet access.

Future Research & Implications

First, future research should explore how autism intersects with social categories and identities like race, gender, sexual orientation, and education level to influence autism disclosure (Cascio et al., 2021). Second, using the TDF allowed us to outline disclosure influencers that can be targeted in interventions via intervention functions, which are categories of an intervention that comprise behaviour-change techniques and link to the TDF domains (e.g., education intervention function links to the TDF domain of knowledge) (Michie et al., 2011). Due to the various disclosure factors, it is pertinent to develop targeted interventions to help this population cultivate decision-making skills, build confidence, enhance knowledge, and find autonomy to make informed disclosure choices and navigate disclosure. Professionals who support autistic young adults the transition to employment (e.g., occupational therapists) should receive training on the conglomerate factors that influence disclosure so that they can support them when navigating these processes. Third, since the TDF domain of environmental context and resources was discussed predominantly, future work should target related factors. We suggest developing and implementing industry-tailored organizational training about autism, disclosure, and accommodations to create more inclusive, accepting workplaces that enable safe disclosure discussions and provide suitable, sustainable accommodations. Finally, longitudinal studies, across other countries that explore disclosure experiences could serve useful to understand how disclosure perspectives evolve as autistic young adults gain more workplace experience, and differences across countries and cultures.

Conclusions

Our study highlighted the disclosure experiences, needs, and influencers among autistic young adults. Influencers of disclosure behaviours were predominantly discussed at the workplace environment level, emphasizing the role of the employer to create inclusive and accepting environments. Findings also revealed the importance of knowledge/skills, relation of goals to disclosure choices, emotional drivers, social influences, relevance to job role, autism identity and intersectional identities, and the need for education of disclosure benefits. We believe that our findings, grounded in the TDF, provide newfound understandings of the disclosure needs of autistic young adults to inform future research and practice (e.g., among occupational therapists and vocational rehabilitation professionals; targeting employer-level factors). Seemingly unique to autistic young adults, we suggest that particular attention be made to cultivate disclosure knowledge, skills, and capacity among this population.

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Data Availability The datasets generated and/or analyzed during this study are not publicly available due to institutional ethics guidelines and the constituents of the approved ethics application. Data generated may be made available from the corresponding author on reasonable request after consultation with the institution’s ethics board.
Declarations

Conflict of interest The authors have no conflict of interest, financial or otherwise, to declare.

Research Involving Human and Animals Rights This study involving human participants was conducted in accordance with the ethical standards of the institutional research committee and national guidelines. The study was approved by the Research Ethics Board at the Bloordview Research Institute in July 2020 (REB#20–886) and followed institutional COVID-19 specific protocol regarding data collection.

Informed Consent For this study involving human participants, informed consent was obtained from participants following institutional guidelines at the time of study approval due to COVID-19 (i.e., obtaining verbal consent). Participants consented to the use of de-identified transcript data in publications.

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