Disclosure and workplace accommodations for young adults with intellectual/developmental disabilities and co-occurring mental health conditions

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Abstract

**Purpose:** Little is known about how young adults with intellectual/developmental disabilities and co-occurring mental health conditions navigate workplace disclosure of their mental health condition. We sought to understand the advice professionals provide regarding disclosure and the decisions young adults make about disclosure of their mental health conditions.

**Methods:** We conducted focus groups with professionals who support young adults with intellectual/developmental disabilities to attain and maintain employment (n=17) and interviews with young adults with intellectual/developmental disabilities and co-occurring mental health conditions (n=12). We conducted content analysis to identify why, when, what, and to whom young adults disclose their mental health condition and the advice provided to them regarding disclosure.

**Results:** Young adults and professionals described disclosure decisions as largely influenced by perceived needs (i.e., the need for accommodations) and anticipated positive (e.g., support) and negative (e.g., stigma, not being hired) outcomes. They largely constrained disclosure to work-relevant content. Many young adults disclosed to coworkers with whom they were comfortable, though both young adults and professionals agreed that initial disclosure should be limited to supervisors and/or human resources.

**Conclusions:** Workplaces may support disclosure—a necessity for the provision of accommodations—by cultivating an inclusive work environment and openly demonstrating familiarity and comfort with employees with disabilities.

**Keywords:** Intellectual disability; developmental disability; mental health; employment; disclosure
Introduction

Individuals with intellectual/developmental disabilities are significantly underemployed, with recent estimates of community-based employment\(^1\) at 20.2% (Bush & Tasse, 2017; Hiersteiner et al., 2018). This disparity poses significant risks to health and wellness and strains Social Security, community, and family support systems (Dewa et al., 2007; Mavranezouli et al., 2014). In contrast, employment is associated with increased independence, life satisfaction and social and community social integration, demonstrating the importance of work for overall health and quality of life (Akkerman et al., 2016; Southward & Kyzar, 2017).

Recent estimates suggest that one third of people with intellectual/developmental disabilities have co-occurring mental health conditions (NADD, 2013). While little published research has described employment outcomes for individuals with intellectual/developmental disabilities and co-occurring mental health conditions, recent research examining employment outcomes in a national sample suggests that young adults ages 23-34 with intellectual/developmental disabilities and co-occurring mental health conditions are less likely than their peers without a mental health condition to be employed. In addition, in this sample, young adults with intellectual/developmental disabilities and co-occurring mental health conditions worked fewer hours and had lower hourly wages than those with intellectual/developmental disabilities only (Schwartz et al., 2021). Thus, in order to improve employment outcomes, there is a critical need to understand the ways in which young adults with intellectual/developmental disabilities and co-occurring mental health conditions seek, acquire, and maintain employment.

As part of the processes of seeking, acquiring, and maintaining employment, individuals with disabilities continuously make decisions about disability disclosure (Brouwers et al., 2020; MacDonald-Wilson et al., 2010). Disability disclosure refers to sharing information about one’s diagnosis(es) in the workplace (MacDonald-Wilson et al., 2010). Research suggests individuals with disabilities navigate an ongoing process of appraising whether they will disclose, and if so, when, to whom, and the content of the disclosure, all while considering the potential positive and negative outcomes of disclosure (Brouwers et al., 2020; Lindsay et al., 2018, 2019a; MacDonald-Wilson et al., 2010).

Individuals with “visible” or “apparent” disabilities (e.g., use of adaptive equipment, facial features representative of a developmental disability such as Down syndrome) are more likely to disclose, and may do so earlier in the job seeking and acquisition process (Lindsay et al., 2018, 2019; Von Schrader et al., 2014). Therefore, people with intellectual/developmental disabilities and co-occurring mental health conditions may readily disclose their “visible” developmental disability so they can subvert negative associations with intellectual/developmental disabilities by asserting their strengths and how they can uniquely contribute to the workplace (Lindsay et al., 2018, 2019a). Yet, as their mental health condition may not be visible, or not immediately apparent to others, people with intellectual/developmental disabilities and co-occurring mental health conditions may take a different approach to disclosing information about their mental health condition and the types of workplace accommodations that may support their job performance.

Communication Accommodation Theory (CAT) provides a framework for understanding how people adjust communication during interactions with people with different social identities.

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\(^1\) In these studies, community-based employment was defined as integrated, paid employment in a job that does not occur in a congregate facility. This employment could be supported with public funds and could include individual jobs and individual or group-supported employment.
CAT proposes that communication is dynamic, reciprocally constructed, and occurs within sociohistorical contexts (Gallios et al., 2005). Accordingly, young adults with disabilities may bring an understanding of power differences between them and their employers and societal stigma to communicative exchanges. For example, Lindsay and colleagues (2019) discussed how CAT provides guidance for understanding how non-disabled employers may draw upon stereotypes when interacting with young adults with disabilities and that this may be anticipated and/or perceived by young adults. It is possible that young adults with intellectual/developmental disabilities and co-occurring mental health conditions may anticipate differential responses to the additional disclosure of a mental health condition. Research has not yet explored these nuanced decisions related to disclosure for individuals with intellectual/developmental disabilities and co-occurring mental health conditions.

Young Adult with Intellectual/Developmental Disabilities and Co-occurring Mental Health Conditions

Significant attention has been devoted to the employment of young adults with intellectual/developmental disabilities as they transition from high school or postsecondary education (e.g., Burgess & Cimera, 2014; Simonsen & Neubert, 2012). Many transition and vocational programs are designed to help young adults with the processes of seeking and acquiring employment. In fact, the Social Security Administration funded youth transition demonstration projects to identify interventions that would support youth with disabilities and those at high risk of receiving Social Security Income to obtain early employment (Fraker & Rangarajan, 2009). Yet, research shows that maintaining a job post-graduation can be difficult for individuals with intellectual/developmental disabilities (Chan et al., 2018; SRI, n.d., 2011), even when provided with supports (Fraker et al., 2018).

One reason may be a lack of reasonable accommodations that support job performance, and subsequently, job retention and tenure (Zafar et al., 2019), and reduced reliance on SSI (Chow et al., 2015). Accordingly, it is not surprising that a primary motivation for disclosure is provision of accommodations (Lindsay et al., 2018; Romualdez et al., 2021; Zafar et al., 2019). Young adults with intellectual/developmental disabilities and co-occurring mental health conditions may benefit from accommodations that directly address their mental health condition or symptoms, yet to receive these accommodations, disclosure of their mental health condition is necessary. In order to best support young adults with intellectual/developmental disabilities and co-occurring mental health conditions to obtain and maintain employment, it is critical to understand how they strategically disclose both their developmental disability and their mental health condition and related support needs, and the influence of these disclosures on attainment of reasonable accommodations that optimize workplace performance. Because this population often receives employment supports, their decisions about disclosure may be highly influenced by service providers, such as employment specialists and school-based transition specialists. Thus, it is also important to understand how and what professionals teach young adults with intellectual/developmental disabilities and co-occurring mental health conditions about disclosure, what guidance they provide about the disclosure process, and the rationale underlying their advice.

2 While “transition to adulthood” is commonly defined within school systems as the time period of ages 16-22, aligned with the concept of “emerging adulthood” (Arnett, 2000) there is increasing recognition that transition processes, including establishing and maintaining employment, may continue into the early 30s.
Understanding decision making around disclosure has the potential to inform interventions that support young adults with intellectual/developmental disabilities and co-occurring mental health conditions to make informed decisions about disclosing their mental health condition to increase the likelihood that their disclosure will result in needed workplace accommodations, and subsequently reduce employment disparities. The objectives of this study were:

**Objective 1:** Describe the training and guidance provided to young adults with intellectual/developmental disabilities and co-occurring mental health conditions regarding workplace disability disclosure.

**Objective 2:** Describe how young adults with intellectual/developmental disabilities and co-occurring mental health conditions make decisions about workplace disability disclosure.

**Methods**

All research methods were approved by the Boston University Institutional Review Board. We used a qualitative approach to explore this understudied topic (Maxwell, 2013). To address Objective 1, we conducted focus groups with professionals who support young adults with intellectual/developmental disabilities and co-occurring mental health conditions to acquire and maintain jobs. To address Objective 2, we conducted interviews with young adults with intellectual/developmental disabilities and co-occurring mental health conditions. For all participants, we collected demographic information, including age, gender and racial identities, and relevant work experience.

**Inclusive Research Approach**

This research was conducted using an inclusive research approach (Walmsey & Johnson, 2003), in which the research was conducted in partnership with young adult co-researchers with intellectual/developmental disabilities and co-occurring mental health conditions. While the PI developed the research questions and preliminary methods, the co-researchers co-developed the interview guide and co-facilitated interviews, and engaged in data analysis of both focus group and interview data through bi-weekly meetings; the group reached consensus through group discussions.

**Objective 1 Methods**

Employment and transition specialists work closely with young adults with disabilities to prepare them for acquiring and retaining employment. Thus, they often provide support for people with disabilities to make decisions about and plan for disclosure. We recruited participants across the United States through personal contacts, Centers for Independent Living, private employment agencies, and previous research participants. Inclusion criteria were: 1) Employment or transition specialist; employment specialists were defined as any professional providing support for people with disabilities to acquire employment, engage in job training, and retain employment. This could include individuals employed by state agencies (e.g., vocational rehabilitation), Centers for Independent Living, and/or private agencies; 2) At least 1 year of

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3 Titles include, “job coach,” “vocational/employment specialist,” “job trainer,” etc. Transition specialists include school- or community-based service providers who support young adults with disabilities to develop independent living and job skills.
experience supporting young adults with intellectual/developmental disabilities and co-occurring mental health conditions to acquire and/or maintain employment; 3) Reported having had interactions with at least 5 young adults with intellectual/developmental disabilities and co-occurring mental health conditions about their disability disclosure. Exclusion criteria were: 1) Employed in a congregate work setting (e.g., sheltered workshop); 2) Reported working with fewer than 5 clients who were individuals without intellectual/developmental disabilities

Focus groups were conducted by the PI using HIPAA-compliant Zoom. Focus group questions centered on the advice provided to young adults with intellectual/developmental disabilities and co-occurring mental health conditions about disclosing their mental health condition (e.g., when, to whom, what to disclose), accommodations that support mental health while working, and the types of supports provided to young adults to make decisions about disclosure.

Objective 2 Methods

Participants were recruited across the United States through personal and professional contacts, organizations supporting young adults with intellectual/developmental disabilities, previous research participants, social media posts, email, and word of mouth. Inclusion criteria were: 1) Self- or proxy4-reported diagnosis of an intellectual and/or developmental disability; 2) Self- or proxy-reported diagnosis of a mental health condition (e.g., anxiety, mood, or psychotic disorder as defined by the DSM-V) and/or receiving treatment for a mental health condition or symptoms5; 3) Ages 16-35; 4) Had experience applying for at least one job and maintaining the job for at least four weeks; 5) Ability to communicate in spoken or written English. Exclusion criteria were: 1) Employment history included only school or agency-assigned placements, as they may not have engaged in the interview process and/or had to make decisions about disclosure; 2) Employment history included only sheltered workshops or other congregate employment settings.

Interviews were conducted using HIPAA-compliant Zoom and were co-facilitated by a co-researcher. Interview questions addressed participants’ decision-making process about disclosing their mental health condition, including why, to whom, when, and the content of their disclosure. We also asked participants about the accommodations that supported their mental health and accommodations, had they been available/asked for them. To support the co-researcher to lead the interview as much as possible, the PI and the co-researcher simultaneously viewed a shared GoogleSlide show with the interview guide. The PI kept track of which questions were answered, and helped prompt the co-researcher to relevant slides. In addition, the co-researcher had a list of “question words” on each slide to support them to develop their own follow-up questions (Schwartz & Durkin, 2020). Interviews lasted approximately 30-80 minutes, depending how much participants shared and whether or not they needed support with the demographic form.

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4 Proxy respondents were parents or other caregivers who, in some cases, helped participants enroll in the study and complete-related study paperwork.

5 We considered prospective participants to have a mental health condition per self-report of diagnosis and/or if they receive related services, due to the difficulty in attaining accurate psychiatric diagnoses for this population (Constantino et al., 2020; Whittle et al., 2018).
Analysis

For both interviews and focus groups, we conducted thematic analysis. The PI reviewed all transcripts to become familiar with the data. The PI then assigned preliminary codes identifying data that related to broad categories (e.g., “why disclose”; “to whom”; “timing”; “work environment”). Then, she and a graduate research assistant generated more specific “open codes” that “st[uck] closely to the data” (Charmaz, 2014, p. 112). Next, the coders collaboratively organized the open codes into categories of similar meaning to define initial codes. They then applied these initial codes to the data and refined, expanded, added, and/or removed initial codes until the codes full described the data.

Simultaneously, the PI worked with the co-researcher team to elicit their interpretations of the focus group and interview data. The group used a range of accessible strategies using collaborative online tools, such as GoolgeJamboard and Miro. Each meeting, the team looked at data about one topic (e.g., “accommodations” or “what people disclose”). The PI wrote each individual quote related to the topic on one virtual “post-it” note. Then, the young adults generated a “main idea” that described the data. After each piece of data was assigned a main idea, the co-researchers organized data with similar main ideas into categories (Schwartz et al., 2020). While the co-researcher team sometimes used different words to describe the “main ideas” and categories, the organized content was very similar to the codes that the PI and research assistant had generated.

Participants

Twelve young adults participated in interviews (Table 1). They had a range of work experiences, including work at a museum, in the service industry, and childcare. Seventeen professionals participated in four focus groups (Table 2). Professionals primarily worked in a range of settings and had an average of 9 years of experience working with young adults with intellectual and developmental disabilities to acquire and/or maintain employment.

Findings

As young adults’ (Y) decision making process was in many ways aligned with the guidance provided by professionals (P), findings for both objectives are presented together. Additionally, no differences in guidance were observed across professionals’ roles (e.g., transition vs. vocational specialist). Both professionals and young adults spoke about the decision-making process for disclosure of a mental health condition being similar to that of the decision-making process for disclosure of any other disability. As described below, the decision to disclose (or not) was predicated on individuals’ perceived needs and the anticipated outcomes of disclosure. Young adults and professionals perceived mental health as a private matter, and constrained disclosure to information relevant to work. While professionals and many young adults felt they should only disclose to supervisors/managers, some young adults also spoke about experiences of disclosing to coworkers. Both groups discussed the importance of focusing on strengths and that early disclosure may have the benefit of leading to early-provision of accommodations.

Supports to Make Decisions about Disclosure

Professionals emphasized that disclosure of any condition is an individual’s choice. They described providing a range of supports to facilitate decision making. The primary types of
support were discussing pros and cons of disclosure and educating individuals about the relationships between disclosure and provision of accommodations. One professional emphasized the importance of educating young adults about disability rights, as described below:

Discussing pros and cons of disclosure:
- “I do like to kind of let them see all sides of, if they were to disclose and what kind of would happen on both ends, as it's their choice.” (P4)
- “We use [a] little pros and cons discussion worksheet, to really get into it with folks.” (P20)

Educating about the relationship between disclosure and provision of accommodations:
- “I told them that they don't necessarily have to disclose, but if they need certain accommodations, you know... they're going to want to do that.” (P1)
- “I always tell people that I’m working with, if they’re going to ask for an accommodation under ADA, you have to disclose. You can’t just say you want the accommodation without explaining why.” (P14)

Educating about disability rights:
- I explained to them too, certain questions cannot be asked, when they're at an interview... like age, do you have a disability?...” (P1)
- “[I explain that] if you wait to tell them three months down the road, they can't come back and discriminate against you.” (P1)

Professionals described supporting young adults to prepare to disclose in a variety of ways. Several helped young adults prepare for disclosure through role play/mock interviews, and some young adults recalled these experiences. Professionals emphasized that having an understanding of one’s strengths and challenges may be foundational for making decisions about disclosure. Accordingly, they worked with young adults to identity their potential needs at work. For example, one professional shared:

The most important thing I think we do is, we teach them what their understanding is, and what needs they have going forward into an employment….as they get to understand themselves, they'll understand whether or not they need to disclose, and what they need to disclose. (P11)

Another professional spoke about reflecting on past accommodations to identify future needs: “We talk about it…‘what was successful in the past?’ ‘What have you tried at other jobs?’ ‘What do you wish you had at the job before for support?’” (P20). Herein, professionals tried to provide tools and knowledge to support decision making. While they did emphasize individual choice, professionals sometimes spoke about the importance of disclosing when work performance would be greatly impacted by mental health symptoms and/or accommodations were needed, as described below.

Deciding whether to Disclose

Aligned with the perspectives of professionals, young adults described disclosure as influenced by their needs and the anticipated outcomes of disclosure. They reported learning about disclosure from job coaches, vocational specialists, and family members. Young adults emphasized the importance of disclosure to receive accommodations, or in general, be understood at work. However, they expressed concerns about stigma regarding mental health resulting in not being hired or being treated poorly once on the job.
**Work Place Support Needs**

Young adults and professionals consistently described how needs for accommodations often drove the decision to disclose. Professionals consistently shared how disclosure was linked to accommodations, as noted above. Young adults echoed these comments, sharing, “I let them know ahead of time so they can make accommodations… basically for me, they’ll be able to follow through the book of the ADA” (Y8); “[I disclosed] to see if there are any accommodations that they’d be willing to do” (Y14). In addition, young adults disclosed to seek “help” in general, often not specifically naming accommodations. For example: “So they understand…how to help” (Y3); “I’m not afraid to let them know my disability…that I have all these other issues, because…they have that information in hand, they might get you help quicker” (Y8); “It makes me feel a little bit better, because if I’m having trouble, at least I can go to that person and talk to them about it” (Y2).

**Anticipated Outcomes**

Professionals and young adults shared both positive and negative anticipated outcomes of disclosure that influenced professionals’ advice and young adults’ decision-making. Positive anticipated outcomes included provision of accommodations (described above), greater understanding, the opportunity to “take the temperature” of the workplace, and social supports. Negative anticipated outcomes included being bullied/treated poorly and not being hired/being fired.

In some cases, young adults described how their employers’ experiences with people with disabilities led them to anticipate (or report experiences of) positive outcomes. Young adults shared: “they work with people with intellectual and developmental disabilities, and I felt no shame since they work with people [with disabilities], then they’ll probably be easy to work with me” (Y5); “it made me feel better [that they regularly employee people with disabilities], because they might have understood me a little better” (Y2). Professionals shared similar perspectives, as one career counselor stated, “let’s say you find a store manager who was like,’ oh my sister…has a disability,’ I would be all for [disclosure]” (P16). Another professional similarly shared, “usually find somebody in one of our job sites that…they either have a family member, or they know somebody, or they’re familiar with the disability…we can have that person that can kind of be the go-to and understand the disability and understand what helps that individual” (P13). One young adult said that she evaluates a workplace’s familiarity with people with disabilities to guide future disclosure decisions: “kind of see, who are the other coworkers…did they disclose? Or is there awareness of accommodations? “(Y10). These quotes suggest young adults and professionals were keenly aware of how employers’ familiarity with disabilities may influence outcomes of disclosure.

**Positive Anticipated Outcomes**

*Take the temperature.* Some professionals described disclosure during the application process as an opportunity to “take the temperature” of a workplace, noting that the employer’s reaction—positive or negative—would provide important information about how accepting the workplace may be of individuals with disabilities. For example, one professional said: if they’re [employers] discriminating, that’s not the place for them to be anyhow. So, it’s almost better to just be upfront…because if they're going to work with a business or people, they want to be accepted for everything…[if employers] aren’t willing to accept those needs … then that's probably not the right place, and it's not going to be successful
for anyone (P9).

Similarly, another professional commented:

sort of taking the temperature of the workplace environment….It is sort of a test to see...how the manager will react to learning of a mental health condition…So if they did reject them…they would say, “I’m better off…it might not have been a good for me anyway.” (P20)

One young adult agreed, sharing, “Do it [disclose], because you never know. The best thing…if you do it, and they don't accept you, get up and leave…If they don’t support you, it's not the job for you” (Y13). Thus, disclosure during the job application process was perceived by some to be an important opportunity to learn about potential employers and make an informed choice about the job.

**Understanding.** Both groups also emphasized that disclosure may lead to more understanding in the workplace. Professionals discussed employers being more understanding of the need for supports, or potentially time off, while young adults spoke more generally about being understood in a more holistic sense and how disclosing may help explain their behaviors at work. For example, one young adult with anxiety shared, “I was going to [disclose]…I figured I might look like a bad employee for certain things if I didn’t mention that I had some issues.” She felt, “disclosing, you get a little bit more, not leeway, but understanding” (Y1). This sentiment was shared by another young adult, who disclosed, “what’s going on with me and stuff like that,” with the expectation that consequently, “they’ll understand. Some workers will be understanding, some won’t” (Y9). Herein, young adults seek understanding of their personalities, symptoms and behaviors, and needs through disclosure. Professionals agreed that disclosure may lead to greater understanding; one professional shared an experience in which a young adult had a “more positive outcome, because the employer knew. And they have more patience. It wasn't somebody that was trying to goof off on the job, or do task avoidance, it really, they were just overwhelmed and didn't know what steps to take” (P11). Another professional noted that disclosure could lead to employers being “hav[ing] more consideration” (P19).

**Social supports.** Professionals often spoke about establishment of natural supports or a co-worker “mentor” in the workplace, but that this may not always require mental health disclosure. However, young adults who felt they had a positive work environment felt that disclosing their mental health condition had led to coworker support, which made them feel more open to disclosing in the future. One young adult described, how “we all just helped each other,” and how her coworkers support her mental health through “hugs, talking to me…coming in and covering for me for on the spot, so I can go take a little mental health break, get in the right headspace. (Y10). Often coworker support was garnered when they felt they had at least one coworker to whom they could relate. For example, “[Disclosing] made it easier to talk to them…one of my workers talked about mental health. ‘Like I feel you on that, I’m taking the same medication…I’m like, ‘wow, we’re actually bonding over something that we’re struggling with.’ So, it felt really good, because it’s not just me” (Y5).

**Negative Anticipated Outcomes**

**Being treated poorly.** Young adults readily shared stories of being discriminated against for their disabilities, though often, these stories centered on their developmental disability. However, they often expressed concern about disclosing mental health conditions, largely due to
stigma. For example, one young adult shared, “I didn’t want to look like I’m a psychopath” (Y3) and another anticipated being treated differently: “I just didn’t think everybody should know about my disorders…they will probably say, ‘well she’ll get mad easily or she’ll do this.’ People will judge you for the bipolar and depression” (Y9). Accordingly, both professionals and young adults reported more comfort disclosing their developmental disability, in part because there is less societal stigma associated with these disabilities (e.g., “If someone judges me for being autistic, then they’re just being a jerk…I can more easily reject that. Whereas with PTSD, I guess I feel more vulnerable to judgment by people on it and feeling like they might look down on me” (Y10)).

Professionals shared that they had also observed fear of poor treatment leading to the decision not to disclose: “I’ve heard from a lot of my individuals especially if it’s their first job, that they’re afraid people will either be mean to them or treat them differently because of their disability” (P7). They also noted how previous experiences of poor treatment could be a deterrent from future disclosure, as one professional shared, “some folks who have had some really bad experiences with prior positions that they have disclos[ed]…they absolutely do not want to disclose” (P18). Professionals often advised young adults to avoid disclosure to coworkers, feeling that coworkers, rather than supervisors would treat them poorly: “you tell one coworker, they spread it around, and then you get [the] target of bullying” (P13).

**Lack of employment.** Some young adults expressed concerns that they would not be hired if they disclosed their mental health condition, stating, “I might not get the job if I have mental health problems” (Y6), and “I don’t really talk about my two disorders. I really don’t. Because…they probably won’t hire you again” (Y9). Professionals expressed some similar concerns, leading to their advice to only disclose relevant information and/or to wait until after young adults have been hired (see below): “There’s no point in jeopardizing her job by disclosing these things when they’re not relevant at the time” (P3).

**Honesty**

While young adults did weigh needs and anticipated outcomes, four young adults felt that it was their responsibility to disclose their mental health condition and developmental disability, even while acknowledging their rights. For example, one young adult shared, “some people say they [employers] do not have the right to know, but if they’re hiring you and they’re paying you, yes, I think that have somewhat of a right to know” (Y8). Another young adult felt, “it’s important to tell the truth” (Y12) about their mental health support needs. One young adult who frequently works with kids shared, “because they need to know [about mental health challenges] if I’m going to be around the kid” (Y2), suggesting the “right” of employers and consumers to have information about them. Herein, a sense of responsibility to the employer drove some young adults to disclose, regardless of anticipated outcomes.

**Timing of Disclosure (“When” to Disclose)**

Advice and young adults’ experiences regarding timing of disclosure reflected the described balance of perceived needs and anticipated outcomes. Most individuals spoke about disclosing either at the interview or soon after receiving the job, *if* their mental health symptoms were perceived as relevant to their work performance and created a need for accommodations. Some young adults disclosed before or at the interview. Rationales provided for disclosing at the interview centered on reducing anxiety about being treated differently and young adults’ desire to “be up front” (described below). Professionals discussed disclosure
before or at the interview when individuals’ anxiety and/or other symptoms may lead them to have challenges during the interview and/or necessitate support for the interview. For example, one professional described working with a young adult who said, “I don’t think I can make it to the interview without telling this person” (P18). Another professional shared:

I worked with a girl who…had extreme anxiety…her anxiety was so crippling that her interviews were awful. So, she wasn’t getting anywhere, because she’d go into these interviews and just fall apart…So, it took me a long time to convince her, but I did suggest that she start disclosing at the beginning of the interview, and also tell them that she was extremely nervous, just so they understood where she was coming from. (P2)

In situations like this, disclosure at the interview was perceived as a way to support interview performance. However, others asserted that after the interview was more advisable, given the potential for discrimination (discussed above): “I always say, don’t bring it up in the interview, you need to wait ‘til the job offer is made” (P14); “I always give the advice that they shouldn’t disclose it during an interview, they should get the job first” (P18). Young adults expressed the desire to disclose early (at the interview or immediately after being hired) to enhance understanding and receive accommodations, as described in the “work place support needs” section, above.

Both groups shared examples of waiting to disclose until their mental health became relevant to work. For many young adults, their mental health condition did not have consistent impacts on their work. Thus, they only disclosed and/or were only advised to disclose when they experienced mental health-related challenges at work and needed accommodations. Some professionals noted the cyclical nature of mental health conditions, stating, some of them could be in a really great place, so they might not need to disclose their disability. Again, if they’re cycling, and they’re in a situation where they would have to…it’s all depending on how they’re feeling at that particular moment in time. (P1)

Two young adults described waiting to disclose their mental health conditions until they had exacerbations in depression or anxiety due to life events. Another young adult shared that she did not disclose her PTSD until she “was triggered at work” and had “a meltdown” (Y10), leading her to describe additional support needs to her supervisor.

Interestingly, both young adults and professionals identified situations in which the decision to disclose was not available to young adults, given the involvement of vocational services/agencies in the job application process (e.g., “they’re going out with a provider, or they’re going out with a job coach, so I kind of think it’s almost taken away that decision to disclose” (P9); “us being there…that doesn’t even give them the opportunity to choose” (P3)). Young adults agreed that the presence of others served as implicit disclosure at, or prior to the interview: “I had my job coach person that was with me…So, they’ve worked with people with disabilities in the past…it wasn’t like they didn’t know that I had a disability” (Y2); “I honestly felt like they knew…having a job coach that sort of sets off red flags” (Y5). Other young adults were employed by people or through agencies whom they had known them for a long time; thus, the disclosure was, in effect, not optional.

Mental Health as a Private Matter (“What” and “To Whom” to Disclose)

Professionals and young adults described mental health conditions primarily as a private matter, as evidenced by the emphasis on disclosing only information relevant to work and constraining the disclosure to supervisors and/or human resources. When disclosing how mental health impacts work performance, both groups felt impacts should be followed by solutions to
ensure success and with a focus on strengths. They emphasized that personal history and past impacts did not need to be shared. To stay focused on impacts directly relevant to work, professionals emphasized that it was important to be “short and sweet.”

**What to disclose.**

**Only what is relevant.** Professionals consistently shared that they “advise, you only need to disclose the things that impact your job” (P11). They shared that sometimes young adults want to share past challenges, but that if those challenges have “been under control for several years. There’s no point in [young adults] jeopardizing [their] job by disclosing these things when they’re not relevant at the time” (P3). They felt that the most relevant information was “what needs to be shared to be successful in the workplace” (P20) or may cause challenges. To stay focused, professionals recommended that disclosure be “short and sweet” (P20; P18)” or “keep it simple and keep it short,” as employers, “need to know what they need to know. They don’t need to know everything” (P15).

Several young adults shared this perspective, as they described selecting which condition(s) to disclose. One young adult stated, “They don’t need to know that I have depression, but they do need to know I have anxiety and that I have OCD, because both of those will impact my job at least for me more than depression would and autism” (Y1); this was echoed by another young adult who shared, “The depression parts usually weren’t a problem, so I never mentioned that” (Y14). Young adults said that relevant information they shared included behaviors (e.g., “If [I] raise my fist, it’s just that [I’m] angry…it would be at anyone or on purpose” (Y6)), and mental health impacts (e.g., “I just basically told them it takes me out of commission for a while…so I try to stay home” (Y13)).

**Focus on solutions and strengths.** Professionals felt young adults should identify solutions for their mental health challenges to ensure employers would view them positively and be more understanding of the need for accommodations. One professional’s advice was,

> Once you tell them you have trouble with something, I’m like ‘have a solution and say, but when this problem occurs, this is what I found that helps me out.’ So the employer knows, okay, this is the accommodation you need right away. If we get that in place, right now, we shouldn’t have any issues. (P3)

They felt that having solutions helped to “put it in a positive light,” stating, “this is what I need help with, this is what helps me’…‘this is what I need in the workplace to be successful,’ has been kind of the best approach I’ve seen” (P4). In general, professionals felt young adults’ ideas for solutions are well-received, because, “I think [employers] want to know that the job is going to get done and it’s going to get done right. So, they’re happy that if [young adults are] making a suggestion to make sure that they’re successful” (P9). Providing solutions was not discussed by young adults.

Young adults and professionals both shared the importance of sharing strengths during disclosure. For example, asserting the importance of, “highlighting their strengths” (P20), and “always accentuating the positive” (P9). Notably, three participants (one professional, two young adults) specifically associated OCD with cleanliness and attention to detail desired by many workplaces. For example, “I would usually mention OCD as a kind of selling point, because if I see something that’s placed on a shelf, or if something’s not cleaned in a specific way, I’ll end up doing it myself” (Y14); “it could be an advantage to your attention to detail, if that’s part of your, ‘OCDness’” (P14).
To Whom to Disclose

Both professionals and young adults spoke about making an initial disclosure to a supervisor or boss. Professionals added that in some work contexts, disclosing to human resources was also helpful. They described that in organizations with robust human resources, these workers, more so than supervisors, may “have the knowledge of what accommodations can be put in place” (P7) and be responsible for implementing them. Therefore, when the opportunity existed, human resources was considered a good starting point. Disclosure to young adults’ direct supervisor or HR was considered “helpful to get the needed accommodations” (P4) and because “they are the only ones that are going to address the situation [challenges] if it comes up” (P3).

Young adults felt disclosing to their manager was important for a range of reasons, including: the supervisor’s status (e.g., “because they were my manager” (Y6); “because they were the person in charge” (Y14)), comfort with their supervisor (e.g., “in my interview, I just felt really connected to [my manager]. And anytime I was around him, I just felt really calm and happy. And so, I felt safe going to him” (Y10); “because he’s really friendly…I trust him more” (Y13)), and because their manager was evaluating them (e.g., “mostly to the people who were evaluating how I was doing the job” (Y1)), and because “[the supervisor]’s the one that actually has to…make sure that accommodations are met” (Y8).

As mentioned above, professionals actively discouraged disclosure to coworkers, and shared stories of how this had led to bullying and/or sharing of private information. Young adults had varying opinions, with some sharing that the support of their coworkers was invaluable and others confirming that disclosure to coworkers had led to negative outcomes (e.g., “they’ll just use it to…pick on people with disabilities (Y8)) or had concerns that they “don’t know what other people could do with [their] private information” (Y6). Many young adults who disclosed to coworkers reported that they had developed friendly relationships with their coworkers, and suggested that disclosure felt natural (e.g., “it would get brought up casually, like ‘hey do you guys ever have issues with this?’” Y1). Other young adults had coworkers also had disabilities, and this helped them feel comfortable disclosing (e.g., “usually [I disclose to] the people in the back that had the same disability that I have” (Y2)) and/or feel comfortable seeking additional supports after they had disclosed (e.g., “And turned out, she’s also autistic. So you’re able to support each other that way too” (Y10)). Herein, young adults described disclosing only once they had determined their coworkers would be trustworthy and understanding.

Discussion

Young adults with intellectual/developmental disabilities and co-occurring mental health conditions and professionals who support them in attaining and maintaining employment described mental health challenges as a private matter, and the decision to disclose as a balance between perceived needs and anticipated outcomes. These findings echo previous research with related groups (e.g., young with a range of physical and sensory disabilities; Lindsay et al., 2019; individuals with mental health conditions without intellectual/developmental disability; e.g., Brouwers et al., 2020), as previous studies have noted that the need for accommodations and understanding are typically perceived as reasons to disclose while stigma and poor treatment were negative anticipated outcomes (Lindsay et al., 2018, 2019a; MacDonald-Wilson et al., 2010; Romualdez et al., 2021; Von Schrader et al., 2014). Additionally, the alignment of perceived needs and timing of disclosure and the pattern of initial disclosure to supervisors,
followed by potential disclosure to coworkers whom employees relate to and/or trust is concordant with previous research with other groups (e.g., Lindsay et al., 2019a). As disclosure is required for workers to receive accommodations, the remainder of the discussion operates under the assumption that disclosure is positive and proposes ways to facilitate disclosure for young adults with intellectual/developmental disabilities and co-occurring mental health conditions. However, we acknowledge that there may be circumstances, where due to societal stigma and ableism, disclosure may not be beneficial (e.g., Brouwers et al., 2020; Romualdez et al., 2021; Von Schrader et al., 2014).

Some young adults in this study discussed the importance of social support (including natural social supports) in the workplace. In some cases, young adults felt more comfortable disclosing when they were aware of others having disabilities in the workplace. In other cases, young adults may not have known about coworkers’ shared identities/experiences at the time of disclosure, but learning about them helped them feel more comfortable seeking supports. Herein, knowledge of coworkers’ disabilities supported disclosure and feelings of support in the workplace. Workplaces may consider setting up formal mentoring programs or affinity groups to facilitate these connections (e.g., Harris & Davis, 2018; Hayes & Balcazar, 2008).

Young adults and professionals shared that perceived employer familiarity with disabilities may influence disclosure. This is an important feature of the workplace environment that may not be easily appraised by prospective employees, especially in absence of vocational supports. Workplace culture and inclusion is often noted as an important factor when making disclosure decisions (e.g., Lindsay et al., 2019a; Von Schrader et al., 2014). Employers may signal their inclusiveness and familiarity with disabilities by developing job postings stating that reasonable accommodations can be provided, advertising job openings in venues specifically for young adults with disabilities, referring to flexible workplace practices, and providing accommodations during the job application process (Lindsay et al., 2019b).

Using CAT as a framework to studying young adults with disabilities without mental health conditions, Lindsay’s team (2019) suggested that increased understanding and familiarity with people with disabilities may lead to shifts in non-disabled employers’ interactions. CAT also postulates that there is a tension between group identity (e.g., identity as a person with a mental health condition) and the desire to accommodate, or attain in-group status with a dominant group (i.e., employers presumed to be non-disabled) (Gallios et al., 2005). If young adults have a strong identity as a person with a mental health condition, they may be more likely to disclose than those young adults who have a weaker identity as a person with a mental health condition who may seek to attain ingroup status with their employer. Therefore, helping young adults establish empowered identities as people with intellectual/developmental disabilities and co-occurring mental health conditions may lead to greater confidence disclosing. Alternatively, employers can focus their communication on topics that privilege young adults’ identities as employees (or prospective employees) to help establish ingroup status.

For those young adults who do not strongly identify with their mental health condition, as was the case for most young adults in this sample, CAT suggests that communication partners can use “accommodation strategies” to facilitate feelings of being an ingroup member for the person with the subordinate identity (i.e., young adults with intellectual/developmental disabilities and co-occurring mental health conditions) (Gallios et al., 2005). Examples of accommodation strategies include adopting the language used by young adults and anticipating their perspective and knowledge base; doing so may cultivate a shared understanding of the young adult as an ingroup member. Notably, employers should be wary of
“overaccommodation,” in which they presume a lack of knowledge or breadth of vocabulary, as these overaccommodation strategies can further serve to distance the young adult from the employer (Coupland et al., 1988; Gallios et al., 2005). Additionally, if the supervisor is a person with a disability, sharing their identity may help facilitate a shift in perceived social relations, leading to different communication strategies, and also increasing the likelihood of disclosure (i.e., communication content).

Finally, in this study, and others (e.g., MacDonald-Wilson et al., 2010), individuals with disabilities sometimes did not have the opportunity to make their own decisions about disclosure due to the involvement of support providers (e.g., vocational rehabilitation, job coaches, etc.). In keeping with the value of self-determination, it is important to explore ways in which support providers can do their job without disclosing their clients’ disability. This may include shifting the timing of professionals’ interactions with employers or establishing connections confidentially with HR or hiring managers, rather than directly with supervisors. Future work is needed in this area to identify innovative practices that can both facilitate effective disclosure while maintaining the employee’s self-determination and privacy in this process.

**Implications for the Social Security Administration**

The Social Security Administration has committed significant resources to promote employment among individuals with disabilities. Initiatives such as the Ticket to Work, work demonstration projects and work incentives have been implemented to facilitate engagement in the workforce among individuals who are receiving disability benefits. For many individuals with disabilities, reasonable accommodations are critical for performance of essential job functions, and thus to maintain employment. This study suggests that young adults with intellectual/developmental disabilities who have co-occurring mental health conditions may be more likely to disclose (a requirement to establish accommodations) when they anticipate a positive outcome. In addition to receiving accommodations, these positive outcomes include an understanding of their condition, symptoms and workplace challenges, as well as natural supports. Young adults and professionals in this study suggest that these positive outcomes are more likely to occur in environments familiar with people with disabilities, including their strengths. In addition, previous research suggests that “employability” may increase with employers’ knowledge about employees’ disabilities (e.g., McMahon et al., 2020). Therefore, interventions targeted at employer knowledge about co-occurring intellectual/developmental disabilities and mental health conditions could be a first step towards developing inclusive practices that foster environments in which employees perceive that it is safe to disclose. Employer-level interventions could include refining recruitment materials to demonstrate awareness of and inclusion of disability and strategies for incorporating accommodations strategies during communications with prospective employees. Therefore, these findings, in combination with previous research, suggest potential employer-level targets for future Social Security Administration initiatives, in contrast to targeting individual-level factors and transition services (Fraker & Rangarajan, 2009).

**Limitations and Future Research**

This study included a small sample of young adults, a majority of whom have autism. Future research should include a larger and more heterogenous sample. The individuals in this
study had a range of experiences with vocational rehabilitation, and this made it difficult to draw conclusions about the extent to which the advice of professionals was integrated into their decision-making process. Findings from this study raise several areas of future research, including the differences in perspectives on disclosing a developmental disability compared to a mental health condition. Additionally, in the present and previous studies (Brouwers et al., 2020; Lindsay et al., 2019a; MacDonald-Wilson et al., 2010; Von Schrader et al., 2014), the workplace environment was noted as having an influence on disclosure decisions and the nature of disclosure; more research is needed to characterize supportive work environments for young adults with intellectual/developmental disabilities and co-occurring mental health conditions. Analysis of communication strategies utilized in initial interviews and onboarding interactions may provide further insights to ways in which employers facilitate the development of employee (i.e., “ingroup”) identities. In this sample, some young adults discussed how previous negative workplace experiences both led to and deterred future disclosure. Future research should explore the impact of previous experiences on subsequent disclosure decisions and approaches in a larger and more diverse sample of young adults.

Conclusions

Young adults with intellectual disabilities and co-occurring mental health conditions and professionals who support them to acquire and maintain work described disclosure decisions as largely influenced by perceived needs (i.e., for workplace accommodations) and anticipated outcomes. The professionals and young adults queried in this study largely agreed about the logistics and strategies of disclosure. When individuals disclosed their mental health condition, they largely constrained disclosure to work-relevant content. Many young adults disclosed to coworkers with whom they were comfortable, though both young adults and professionals agreed that initial disclosure should be limited to supervisors and/or human resources. Future research should explore differences in disclosure decisions related to different diagnoses, especially for individuals with co-occurring diagnoses.
References


<table>
<thead>
<tr>
<th><strong>Table 1. Interview participants (n=12)</strong></th>
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<tbody>
<tr>
<td><strong>n (%)</strong></td>
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<tr>
<td><em>Age (mean, sd)</em></td>
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<td>Female</td>
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<td>Internship</td>
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<tr>
<td>Support from a job coach</td>
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<tr>
<td>Support from a Center for Independent Living</td>
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<td>Other supports</td>
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*aParticipants could select multiple categories
bData missing for 1 participant
cSupport from a parent, youth transition program, and self-advocacy organization
Table 2. Focus group participants (n=17)

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<td>Transition specialist</td>
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\(^a\)Includes: Program manager, Career Counselor, Job developer/trainer, Vocational counselor