Holland Blcorview Kids Rehabilitation Hospital

**Blcorview** RESEARCH INSTITUTE

# DISCLOSURE

DO I START THE CONVERSATION AND LET ON, SPEAK UP AND REVEAL?

Learning More and the Practical Considerations

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# Your Workplace Needs and Strengths

When deciding if and how to disclose, it is also important to consider some of your own **workplace needs** and **strengths!** 

Autistic employees, just like anyone, might have needs in the workplace depending on their job role and the work environment. For example, some people on the autism spectrum have difficulties with remembering workplace tasks, working under strict schedules and deadlines, social tasks, self-management skills, noisy environments, bright lights, getting tasks started, and managing large projects / tasks.<sup>13,15,17,18,23-27</sup>

To address some of these needs, **workplace adjustments or accommodations may be needed**. Here are some examples:

- Flexible working hours<sup>19,28</sup>
- Changes to how you are interviewed for the job<sup>18,19,26,28</sup>
- Modifying lighting and noise levels<sup>18,25,26,28</sup>
- No customer-facing tasks and providing communication/social skills training<sup>13,18,19,24</sup>
- Providing planners, organizers, reminders, etc.<sup>18,26</sup>
- Adjustments to physical setting (e.g., having a standing desk)<sup>18,26,28</sup>
- Technology supports (e.g., digital assistants, text-to-speech software)<sup>25,26</sup>



Sometimes you might need multiple accommodations or adjustments to address your needs. Or, sometimes one accommodation or adjustment might help to address a few of your needs. Also, remember that your needs may change depending on your job role and workplace environment.



#### Let's hear from the autistic youth and young adult advisors who helped develop this tool about their workplace needs!

My workplace needs are very minimal. As long as I have one other person that I can ask questions to and I can access important information after it's been communicated to me should I need to remind myself, I'm good. Having concise directions given to me either verbally or written always helps as well. I also tend to write instructions and notes down.

(Woman, age 29)

I remember starting out at a sushi store in 2016. I was in my Junior year (third year) in College and I was still under the training phase of my new sushi chef job. My impressions were that the job was fast paced and demanding. I sat down with my manager and HR manager to disclose my autism, the need for accommodation, and balancing this job and college studies. As a result, I got reduced work hours and workload. So, I became responsible for cooking customers traditional Japanese meals such as Teriyaki or Ramen Soup, customer service, and cleaning the workspace. (Man, age 26)





**TIP:** If you're not sure about what you might need or are having challenges with at work, you can ask the people you work with. For example, you can ask your direct manager or coworkers for feedback on your work to see where you can improve.

It is also important to think about and highlight **your unique workplace strengths** and **what you bring to your workplace**! Some examples of strengths (both unrelated and related to autism), include honesty, good memory, kindness, analytical skills, detail-oriented, quick learner, strong work ethic, and not easily distracted.<sup>13,29-32</sup> If you are considering disclosing, you may want to think about also sharing some of your strengths.



Let's hear from one of the the autistic youth and young adult advisors who helped develop this tool about the importance of autistic strengths!

I believe employers should hire job seekers with autism because they have a strong work ethic, which results in high productivity. Also, autistic people can be more tactful or reliable for an employer or company because they tend to "stick to the rules" a little bit more than neurotypical people.

(Man, age 26)

# **Identity & Personal Values**

It is important to think about your **personal values and what's important to you**. Personal values shape the choices that you make. For example, if honesty is extremely important to you, maybe you are thinking about disclosing because you want to be honest about your autism. Everyone has different values. These different values might influence your disclosure choices. Other examples of values can include kindness, loyalty, and independence.<sup>33</sup>



#### Let's hear from one of the the autistic youth and young adult advisors who helped develop this tool about their personal values!

The personal value that has probably been the most instrumental in whether I disclose my autism is independence. Independence in the sense that I have, and expand on, marketable skills that can guarantee that I will have fulfilling work no matter what and do not have to depend on mentioning my diagnosis to get an income.

(Woman, age 29)



Did you also know that **different parts of your identity can influence disclosure**? For example, is autism a big part of your identity? Does it shape who you are in everyday life and at work? There are also other identities that might shape who you are and may influence disclosure.<sup>13</sup> For example, your gender, sexual orientation, other disabilities, race, cultural beliefs, and/or ethnicity. In fact, there is a term used to describe this – **intersectionality**. Intersectionality is how these different identities interact to influence how you experience everyday life (e.g., at work, friendships, etc.).<sup>34-36</sup>

It is important to consider these other identities and how they might influence your choice to disclose your autism.<sup>13</sup> For instance, did you know that women are often more likely to "mask" or hide their autism rather than disclose compared to autistic men?<sup>37,38</sup>



#### Let's hear from one of the the autistic youth and young adult advisors who helped develop this tool about her thoughts on her autistic identity!

Autism is a big part of my identity. It's what the bulk of what my current work is in. However, I do not want my diagnosis to override everything else about me so I'm selective in disclosing at work and in everyday interactions...I want to be respected and taken seriously for my work because I'm good at it, not because I have an Asperger's diagnosis.

#### (Woman, age 29)

# **Disclosure in Action**

#### The When, Who, Where, How, and What of Disclosure

#### When to disclose?7,8,13,18

Job application or cover letter *Why*?

- EXAMPLE 1: Your employer is looking for neurodivergent candidates or has specific neurodivergent job programs (e.g., Microsoft).
- EXAMPLE 2: Autism is an important part of your identity, so you want to disclose right away.

#### During the interview

Why?

• EXAMPLE: You need accommodations during the interview and for the job you're applying for, so you feel that it is a good time to share your needs.

#### After getting hired (e.g., a few weeks, months, or years)

Why?

• EXAMPLE: You may prefer to disclose after getting to know your team, your job expectations, and daily tasks.

#### Who to disclose to?<sup>1,13</sup>

Your manager, boss, and/or human resources *Why*?

• EXAMPLE: You require specific workplace supports or accommodations and/or you value honesty and want to be your authentic self.

#### Coworkers

Why?

• EXAMPLE: You want to explain some of your autistic behaviours, you want to improve workplace friendships, and/or you want to be honest.



**TIP:** Some autistic youth and young adults have identified "testing the waters" before disclosing. This might include bringing up autism in casual conversations or disclosing another disability to see how people react first.<sup>13</sup>

#### Where to disclose?

It is important to think about where you might disclose. Think about the setting where you feel most comfortable so that you can control the conversation and who has access to the information that you're sharing.

#### Private office (in-person)

Why?

• You may be disclosing to your direct boss, manager, and/or human resources and want to control who can hear this conversation to keep it private.

#### Common break room (in-person)

Why?

- You might be disclosing to a specific person, but you're not opposed to coworkers hearing your disclosure conversation.
- You might be disclosing to more than one person and do not care if other coworkers hear the conversation.

### Virtual mediums (e.g., email, web-conferencing meeting) *Why?*

• To feel the most comfortable, you might prefer a virtual setting. This might also be an option if you want to have an electronic record of the conversation.

#### How to disclose?

Formal meetings (often requires planning)

• EXAMPLE: with your manager, to keep your disclosure private

#### Casual conversations (sometimes requires planning)

• EXAMPLE: with coworkers on your direct team and/or your manager

#### Verbal versus written communication

• EXAMPLE: on applications, resumes, or email versus verbal conversations

#### **Unplanned scenarios and conversations**

• EXAMPLE: another colleague shares that they're on the autism spectrum while you and a few coworkers are having lunch, you might then feel comfortable sharing your autism too.

#### What should I say when I disclose?

This will depend on your goals of disclosure, for example, if you're disclosing to receive workplace accommodations, you might share your specific job needs (e.g., you need help staying organized) and the accommodations that you are requesting (e.g., organizational tools, to-do lists, check-ins, etc.). Other strategies by youth with different disabilities include using humour, tailoring the message to the person you're disclosing to, highlighting what you're good at, using reassuring words, giving them information about your disability (e.g., describe how you experience your autism), and telling them about what you need to do your best at work.<sup>9,39,40</sup> Remember that you do not have to disclose your autism diagnosis.



**TIP:** Unfortunately, not everyone is educated about autism. If you decide to disclose, you may need to share information about what autism is and how you experience autism. Remember to give the person who you disclose to time to process, reflect, and ask you questions. You can also ask them questions!





Let's hear from one of the the autistic youth and young adult advisors who helped develop this tool about their disclosure strategy!

"I learned "solution-focused" accommodation requests over "problem-based" accommodations. It can be helpful to subtly change your wording from "I struggle/can't..." to "I work best with..." (Man, age 19)

#### Should I plan for disclosure?

In some situations, you might not be able to plan for disclosure, which is okay. However, research shows that when possible, it's important to plan for and practice disclosing.<sup>21,41</sup>

#### What if disclosure doesn't go as planned?

Sometimes, disclosure conversations may not go as you had planned. Below, we outline some examples of when this may happen. The autistic youth and young adult advisors who helped develop this tool offer some tips for how they might approach these scenarios. These are just suggestions, and remember to always do what's best for you and to talk to someone you trust if you need support or have questions.

**EXAMPLE 1**: You ask your manager for access to the quiet office space on your floor instead of working in the open workspace. You say this is because you have challenges with the noise and bright lights. Your manager continues to ask you why you have those challenges and are requesting this support when everyone else is fine working in the open workspace.

Remember your workplace rights. You do not have to share your diagnosis if you're not comfortable doing so. If possible, use solution-based language when making your requests. Explain why having these supports will make you more productive at work.

**EXAMPLE 2:** After disclosing, your manager remains quiet and doesn't ask you any follow-up questions. You are unsure if your manager understands your request and will provide you with the supports you need.

One way to approach this could be attempting different communication styles. You could try email, a virtual meeting, or in-person, depending on how you first disclosed. You may also want to write a script for any future conversations you have. You can also express that you're prepared to answer questions if they have any (but this means you need to be open to answering those questions)!



**TIP:** When disclosing, if possible, try to take detailed notes about how these meetings went for your own reference and record. This is also helpful if you need to refer back to what was discussed.



# DISCLOSURE CASE EXAMPLES

Here are two examples of **disclosure in action** that were created with the autistic youth and young adult advisors who helped design this tool. Parts of these examples are based on their own experiences with employment and disclosure. No real names are used in these scenarios.



Miguel has just started a summer job working as an entry level data analyst. While Miguel is on the autism spectrum, he feels that it isn't a big part of who he is or how he experiences life, and so, not many people know that he is autistic besides his family and very close friends. However, because of his autism, he has experienced some challenges that have impacted jobs. For example, Miguel has difficulties with organizational and time management skills. Miguel decided that he may need to have a conversation with someone at work to discuss his needs.

He decides to speak with the direct manager he reports to as well as a representative from human resources. Miguel also knows that he does not want to disclose his diagnosis. To prepare for sharing his needs and accommodation requests, Miguel wrote everything down to share with his manager and human resources. During the meeting, Miguel discussed his needs and asked for more frequent check-ins with his manager, and organizational tools (e.g., checklists, weekly to-do lists). He did not disclose his autism diagnosis.

Miguel created a document that outlined what he needed to do his best at work to give to his manager and human resources. For example, he wrote that he needs help organizing his job tasks and priorities due to executive functioning difficulties, and so checklists and to-do lists would be helpful to break down and organize job tasks.

### Meet Anisa (22-years-old)

Four months into her first job after university, Anisa received her autism diagnosis. After the introduction of remote work due to the COVID-19 pandemic, Anisa was finding the transition to her job more difficult and was struggling to focus. She decided that she needed to ask for an accommodation that would allow her to go into the office to work, which she believed would help with her executive functioning skills. She knew that this would be a difficult accommodation to receive as her entire team worked remotely. So, Anisa decided that she would disclose her autism to her manager during a regular check-in. Before the meeting she prepared a few talking points – for example, what she was struggling with, why she believed having a dedicated workspace would help her, and information about her rights to reasonable accommodations. Her manager was very understanding and provided Anisa with the accommodation.

A few months later Anisa learned that her work was hosting an event celebrating neurodiversity and hosting a panel discussion with neurodivergent team members. Since her decision to disclose with her manager, Anisa had become much more comfortable with her autistic identity. Anisa decided that this was a great opportunity not only to educate her coworkers about autism, but to bring her entire self to work. She decided to volunteer for the panel to talk about her experience. The event went well and afterwards, Anisa not only felt more comfortable at work, but also was introduced to a group of neurodivergent coworkers she could connect with.



# **Non-Disclosure**

Maybe disclosure isn't right for you or relevant right now, and that's okay! It is a personal decision that varies from person to person. There are many reasons why someone might choose not to disclose.

#### Some reasons might be external:

- You don't feel comfortable or safe disclosing at your job because of the people at your job or the work culture.
- The policies at your workplace don't seem supportive of persons with disabilities.
- Your workplace already has a lot of flexible supports (e.g., you can work from home, you have flexible hours), so you have all of the supports you need and don't need to disclose.

#### Some reasons might be internal:

- You can manage at your job on your own and don't need any accommodations or supports.
- You don't want to disclose and don't think it's important.
- You are feeling self-conscious about your autism.

If you're still unsure about if you want to disclose, remember that you don't have to disclose your autism diagnosis. You can always selectively disclose (refer to Part 1 of the tool on page 1 for definition).

#### Example phrases to support selective disclosure:

"To do my best with this role, I need certain supports \_\_\_\_\_ (e.g., a standing desk, access to noise cancelling headphones, having daily feedback on your work performance, etc.). This is because I have some challenges with \_\_\_\_\_ (e.g., sitting for long periods of time, noise, prioritizing tasks and knowing how I'm doing with my work)." Having these supports will help me to be the most productive."

"I usually use this support \_\_\_\_\_ (e.g., planner on my smartphone, kneeling chair, take 5 minute breaks every one hour) when I work at home to help me stay focused and be productive. I was hoping that I can use these at my workstation / desk to help me do my best with this job."



If you decide not to disclose, make sure to monitor your own mental, emotional, and physical needs.



- How is my physical energy today?
  - Am I feeling tired, drained, burnt out?
  - Am I feeling energized, well-rested, mentally sharp?
- How is my emotional energy?
  - Am I feeling sad, confused, anxious?
  - Am I feeling happy, calm, neutral?
- What can I do that might make me feel better?
  - Think about some activities that fill you up! For example, going for a walk, cuddling with an animal, watching your favourite television show, calling a friend, writing down your thoughts in a journal, etc.

If you are having a hard time, always remember to talk to someone you trust and who cares about you!

NON-DISCLOSURE CASE EXAMPLES

Here are two examples of **non-disclosure** that were created with the autistic youth and young adult advisors who helped design this tool. Parts of these examples are based on their own experiences with employment and non-disclosure. No real names are used in these scenarios.



#### Meet Philip (20-years-old)

In summer 2021, Philip worked at an organization creating educational/financial literacy content for newcomers and low-income groups. This all occurred during COVID-19, so the work was 100% virtual. In his position, situated fully at home, he made documents and slide decks/presentations according to what his manager assigned him at the start of each day. Philip was basically in charge of setting his own schedule as long as he completed his work on time. One accommodation he usually needs is a stand-up desk to enable him to move around throughout the day. This was personal furniture in his own home, so he did not need to bring its use up with his manager. Another accommodation he requests is written instructions to give him clear deliverables. Most of the time, his manager's requests were expressed verbally during their virtual meetings, but this was enough for him, as he could quickly type notes about what his manager was asking of him. For the above reasons, he felt no need to explain his medical history at his work-from-home job. Philip felt that non-disclosure was the right decision for him.



#### Meet Sandra (16-years-old)

At her high school job, Sandra did a newspaper route. She did not disclose while getting the job and once she got it, it was a job where everything was almost all by herself. Her main tasks involved putting flyers in the newspapers, and delivering the newspapers to the correct addresses at any time she wanted, as long as it was done by the end of the week. Since the only interactions Sandra had were occasional conversations with neighbours while delivering the newspapers, and she always delivered the newspapers with the flyers on time, there was never a need to disclose. Sandra felt that non-disclosure was the right choice for her.





Use the space and prompts below to write down some of your main takeaways after going through this part of the tool.

One thing that I learned that I didn't know before is:

One thing that is the most interesting to me is:

One thing that I still wonder about is:



Please take a break before moving on to Part 3 of the tool if you need to.

When you're ready, download the PDF of Part 3 of the tool and watch the introductory video on the tool webpage.

Part 3 of the tool is optional.

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