

Disclosure at University: The Art of Sharing Information about your Disability

This thought piece is for neurodiverse students who are considering going to universityⁱ, or those who are already attending. It has been written in collaboration with autisticⁱⁱ people. This piece will discuss the aspects of disclosing your diagnosis at university.

“Disclosure means sharing information”

Disclosure means sharing key information about your disability with certain people in your immediate environment. Making the decision to share your private information is inevitably your choice. Thus, the objective of this thought piece is not to enforce or demand of you, but rather, to raise awareness of some key reasons which may help you make the right choice for your situation.

Extensive research shows that disability populations consistently reported a fear of discrimination as the major reason why they do not disclose their disability status to those around them (Erikson et al., 2014; Von Schrader et al., 2014; Jammaers et al., 2016).

No-one should experience discrimination. With this in mind, we provide information on the general policies of universities regarding disability law, confidentiality, adjustment processes, accommodations and opportunities.

Confidentiality First

Universities respect the confidentiality of their students, particularly in reference to disclosures of a personal nature. Within Australia, universities operate as private entities which are legally required to comply with the Privacy Act (1988). In the US, Federal law protects student's privacy.

As such, each university has a set procedure for handling your disability disclosure process, and this is managed in an ethical and reassuring way. If you wish to disclose your disability, the first step is to speak to someone within your university who can give you relevant, timely and proper support. It is best to reach out to one of the following offices/ resource teams:

- The Office of Student Services
- The Disability/ Accessibility Unit
- Student Counseling Services

These administrative bodies will listen to you and work with you to determine how to best support your needs, whilst also protecting your personal details. They will keep

your private information confidential. This means they will not disclose your condition to anyone else unless you give them express permission to do so.

Disclosing your disability to your university does not mean you are disclosing every aspect of your condition to everyone, including your lecturers and peers.

When you tell your university about your disability, the only people who will know are a small group of staff who are bound by legal, ethical and social requirements to protect your information. These offices and teams are part of the university to support *all* students in the best way possible, so that they can flourish in their studies.

The office/ resource team you disclosed to may suggest you speak directly to a Disability/ Accessibility Coordinator within your University or direct you to another faculty member/office who could help you further. It is important to remember, when administrative bodies offer you a second person/ office to speak to regarding your lived experience, they are doing this because they want to ensure you receive the best assistance possible. It is also worthy to note, in each university, your process of disclosure will differ; the people you speak to and how you become linked with services may vary – there is no “one way”. The result, however, is the same: you will be registered with the Disability/ Accessibility Support Unit at your university and will likely be eligible for the benefits and accommodations offered by this Unit.

Equal Rights for All

Universities want to see *all* their students succeed and complete their courses. As a neurodiverse individual, your experience of the world is quite different, and when attending university, you may find certain aspects challenging. While accessibility practices are growing within universities around the world, *your* lived experience may require additional support to navigate this new environment. Universities are willing to help. If you need more resources or supports to enable you to work more effectively, universities will do their best to accommodate you. The Disability/ Accessibility Support Unit is committed to supporting students by giving them access to a co-operatively developed and tailored structure that works *for* the student and provides the opportunity for the student to use their skills, capabilities, and strengths to an advantage.

In Australia, the *Disability Discrimination Act (1992)* states that it is unlawful to discriminate based on disability and promotes equal rights, equal opportunity and equal access for people with disabilities. The Act defines a disability with a broad definition, including affects caused by trauma, disease, disorder, life experience and medical difficulties. Disability may be temporary or permanent, total or partial, lifelong or acquiredⁱⁱⁱ. The Act also explains that those who identify with a disability are entitled to 'reasonable adjustments' at their workplace, university, or community environment.

In the United States, the Americans with Disabilities Act (Title II, 1990) and the Rehabilitation Act (s.504, 1973) protects students with disabilities from discrimination, in both secondary and postsecondary school.

Pathways for Success

Reasonable adjustments and accommodations are the changes the university makes to the learning environment which benefits and supports their students. A few examples of reasonable adjustments may include providing a note taker, increased accessibility of information (e.g. visual aids, audio files, large text, etc.), permission to take short breaks during classes, access to video recordings of lectures/ classes, and so on. Alternative assessment arrangements or special conditions may also be available when you disclose a disability to the university. Common alternatives include extra time, a special venue or specialized equipment. You should be aware that disclosure at university requires documentation of your diagnosis in order to receive reasonable adjustments and accommodations.

“If the university understands your needs, they will be able to provide more
tailored support”

Registering your condition with the Disability/ Accessibility Services at your university will also provide the opportunity for a confidential discussion with a Disability/ Accessibility Coordinator. This is a person who has experience in student advocacy, education and working with diverse populations. They are someone who can better identify your needs

at university and working with you to find potential solutions to accessibility problems as a result of your disability. As such, if the university understands your needs, they will be able to provide more tailored support. By having this conversation, you may also learn how to make the most of your autistic or neurodiverse strengths. It is beneficial to be proactive in disclosing. Remember to register with your university's support services before problems arise. This will ensure you receive the accommodations you are entitled to from the beginning and get off to a great start.

In addition, registering your disability at your university may provide opportunities to participate in specific internships, work-ready programs or work experience engagements. These types of opportunities are becoming increasingly prevalent at universities and more are being designed with neurodiverse students in mind. This action demonstrates the willingness of universities to accept, respect and support the neurodiverse population.

Some other programs and opportunities that could be offered at your university include:

- life skills workshops/ resources
- academic/ study skills support
- career preparation workshops/ resources
- peer coaching/ mentoring
- industry mentoring
- job shadowing and field visit opportunities with companies that currently have, or who are developing, neurodiverse employment programs.

In sum, reasonable adjustments and accommodations can help you thrive and do your best at university.

Know Yourself

When deciding whether to disclose your disability, you may like to consider how much your disability affects your ability to perform. If you feel your disability has no bearing on the productivity of your studies or your ability to be a good student, you may feel it is unnecessary to address the matter. Nonetheless, it can be helpful to know that the university is always ready to help if you change your mind, and whenever it is that you decide you to disclose.

Below is a personal account by an autistic male (early-20s) who describes his experience and difficulties transitioning to university from high school:

“In secondary school mostly everything academic is supervised and planned. Studying wasn’t an independent issue... [however] university is an entirely different affair. You are expected to receive less instruction and have more flexibility with your time, which I relished at first because it gave me a sense of newfound freedom. [At university] I struggled to navigate the open-ended requirements and meet deadlines that seem to stack onto each other relentlessly... After much deliberation, in my 2nd year, I finally shared my autistic diagnosis...and with knowledge [the university] understand that I may need more time to meet assignment deadlines and more detailed guidance to studying.”

Another perspective from an autistic woman (late-30s):

“In my first degree, I did not know I had a disability. I really struggled at Uni to figure out how to do assignments and meet the deadlines. I failed a few subjects but -by sheer determination- I did end up completing that degree. Then many years later, after I got my diagnosis I returned to Uni and started postgraduate studies. I disclosed my autism, learning difficulties and co-existing conditions on the entry form to the course, so that the administration and disability services would be able to help me from the very start. I have been so impressed with the amazing support provided to me and the opportunities that have opened up since disclosing. It was definitely scary to disclose, but this time around I didn’t want to struggle alone.”

These two accounts capture very different experiences of disclosing a diagnosis and of being at university. Your lived experience will certainly impact your decision-making process. Take time to think about what disclosure will mean for you.

Understanding Fears

It is okay to have apprehensions about disclosure. This is private information; it is your identity and who you are. We also understand societal pressures and feelings of uncertainty may surround your decision-making process.

The portrayal of neurodiverse and autistic people in the media tends to take a misinformed stance by showing disability as “bad,” “not fitting in,” and/or extreme in some way.

However, as you may know in your own lived experience, neurodiversity and autism present in many different forms, often far from the way in which it is portrayed in the media.

Disclosing *your* experience and sharing *your* world view may further allow you to educate others who do not understand (or who have misinterpreted your population based on media portrayals), as well as to demonstrate a different perspective of your experience—a sense of “ability”, in place of “disability”. As mentioned earlier in this piece, the decision whether to share information about your experience to your university is inevitably your choice.

Taking the Leap

Commencing study at university is a great achievement and an exciting time. As a neurodiverse student, you may feel at a disadvantage. When you first arrive on campus, whether a new student or a returning student, there are new things to discover: new processes, new policies, different locations to find, new ways to travel there, new people to meet, and new ways to learn how to ‘be’ at university.

At this time, you may want to immediately find a person to disclose your disability to (in order to remedy any current or future accessibility issues), or you may simply want to feel more comfortable in the new environment you find yourself in.

In the first instance (a wish for disclosure), we recommend you find the Disability and Accessibility Support Unit and arrange a meeting with a Disability/ Accessibility Coordinator to discuss your needs.

In the second instance (a wish for groundedness), we recommend you continue reading the Neurodiversity Hub Resources section for [Students](#), and seek out the material on “Transition to University.”

Quick reference guide:

- [“Transition to University”](#): To learn more about the differences between secondary and tertiary school and explore examples of reasonable adjustments and accommodations.
- [“Lost on Campus”](#): This is a smart phone App that has maps/ layouts of Australian universities, enabling easier navigation on campus (with directions to lecture rooms, cafes, libraries, etc., and chat options to connect with fellow students regarding the facilities on campus). Check to see if your university is on the App.
- [Students with Disabilities Preparing for Postsecondary Education - Know Your Rights and Responsibilities](#): To learn more about Federal Legislation in the United States.

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ⁱ We use ‘university’ as a generic term referring to tertiary providers including universities, colleges and vocational training providers (and, per Australia: TAFEs).

ⁱⁱ Please note that within the autism movement there are predominately two approaches to addressing those with a disability. One approach is to refer to people using ‘person first’ language, which describes the disability as a character or feature of the person (Dunn & Andrews, 2015), such as to say “a person *with autism*”, “a person *hard of hearing*”, or “a person *who suffers from schizophrenia*”, etc. The other approach is to address people using the ‘identity first’ language, a style which is often advocated by the disability community themselves (see more: Moran, 2006; Murugami, 2009; Sinclair, 2013). Identity-first language views the disability as an integral part of the human-being, and it places the disability first, per “an autistic person”, “a deaf person”, “a schizophrenic individual”, etc. While both linguistic styles have positives and negatives to usage, it is ultimately up to person how they would like to be addressed, and others should respect whichever approach they choose. This paper will use ‘identity first’ language to highlight neurodiversity as a positive part of a person’s identity.

ⁱⁱⁱ The Disability Discrimination Act (1992) defines disability as: “a condition which is caused by a “total or partial loss of the person’s bodily or mental functions; presence of disease or illness; malfunction, malformation or disfigurement of a part of the person’s body; a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or a disorder, illness or disease that affects a person’s thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour” (s4, ‘Interpretation’).