



National Disability Coordination Officer Program

Considering higher education?

A planning guide for people with disabilities or medical conditions

TELL OR NOT TO TELL...

Disclosing a disability or medical condition in the education setting

Introduction

The information presented here is intended to help students with disabilities (and others who interact with them) by offering a resource about the issues of disclosure and medical conditions. The information will also help students with disabilities to make informed decisions about whether or not to disclose.

Background

There is much information about disclosure in current literature for and about students with disabilities. There has been research about disclosure of mental health disorders and information about disclosing to employers. This information consolidates these references and provides general information to students about this very important decision.

Disclaimer

The authors have taken considerable care to present this information in a balanced way, citing the possible positive and negative consequences and also providing information about making the decision to disclose. The questions or issues that arise for you from this information may well be useful discussion starters with university disability contact staff at your institution. Every effort has been made to attribute the correct sources of information.

Acknowledgments

Information used in this site is directly drawn from and based on a number of existing publications. They are listed on the References page.

Disability legislation

Based on the Disability Discrimination Act 1992 (Cwlth)—a disability can mean

- an intellectual disability
- a neurological or learning disability
- a physical disfigurement
- a physical disability
- the presence in the body of disease-causing organism (eg HIV virus)
- a psychiatric disability
- a sensory disability.

The DDA covers a disability which people

- have now
- had in the past (eg back injury, episode of mental illness)
- may have in the future (eg a genetic illness such as Parkinson's disease, heart disease, HIV positive status)
- are believed to have (eg assumption that someone living with someone with an infectious disease also has that disease, AIDS for example).

The areas covered are

- education
- employment
- access to premises
- accommodation
- buying or selling of land
- activities of clubs, sport, administration of commonwealth laws and programs
- provision of goods and services and facilities.

What is a disability?

- Loss of physical or mental functions ie person who has quadriplegia, person who has a brain injury, epilepsy or a vision and hearing impairment.
- Loss of part of the body (eg amputation).
- Infectious and non-infectious diseases and illnesses (eg AIDS, hepatitis or TB, allergies, typhoid bacteria).
- Malfunction, malformation or disfigurement of a part of a person's body (eg diabetes, asthma, birth marks or scars).
- A condition, which means a person, learns differently from other people (eg autism, dyslexia, intellectual disability).
- Any condition, which affects a person's thought process, understanding of reality, emotions or judgement or which results in disturbed behaviour (eg mental illness, depression, neurosis, personality disorder).

What is disclosure?

Disclosing a disability or medical condition can be a life long process. Every time you enter a new work or study setting or meet new people you may need to make decisions about disclosing personal information.

Disclosure in a university setting may be about ensuring that you can access supports that the university offers students with a disability or medical condition. It may also be about deciding whether to tell other students as you find yourself making friendships or working with others.

Disclosure could be

- telling someone you have a disability or medical condition
- telling someone about aspects of your disability or medical condition.

At university disclosure may mean

- educating someone about your disability or medical condition
- telling someone about the impact of your disability or medical condition on study and how you do things successfully
- telling someone about your learning style
- providing documentation about your disability or medical condition
- talking to another student about your disability or medical condition.

'With a hidden disability you get very good at being able to camouflage. However when you try to hide the disability those who you need support from may not believe you' (UniAbility 2000, p19).

Considering disclosing

The decision to disclose is a difficult one. The choice will be different for everyone because they have different experiences and different needs. Disclosing is a personal decision—you are the only one who can make it. Don't give in to pressure to disclose for the sake of other people, you are the one who will live with the positive and negative outcomes. The following questions may help you make a decision.

Who may need to know and why?

Disability liaison officers—so that they can arrange the support that you need and advocate on your behalf if necessary.

Lecturers and tutors—to make appropriate accommodations to their teaching style and to the assessment process as required.

Other students—so that they understand why you are receiving accommodations for your study and so that they can support you.

Administrative staff—to assist you with processing information or applications, such as parking permits, keys for access to certain areas.

Equity staff—these people will assist you if you are being discriminated against or you are not receiving the support to which you are entitled, or you are not sure of what support you are entitled to.

What do I need to consider?

- Will telling someone assist me in some way/will I be better supported?
- Do I trust the person I would tell?
- What could be the repercussions from disclosing?
(Queensland 1997 and Commonwealth 1999).

When would I tell them?

Before you start studying

- on your QTAC application
- on your enrolment form
- on any course or topic questionnaires.

When you have started attending lectures and tutorials.

When you require some reasonable adjustment for teaching methods or assessment (Speaking up 2000).

Duty of care

If disclosure of a disability becomes an issue of duty of care, your safety or others (this is rarely the case), then people who need to know may be informed.

What if you are not in a position to speak for yourself? Do you carry appropriate information, such as a medic alert bracelet or similar?

Equity officers and counsellors have a duty of care to respect your confidence.

Confidentiality

An important consideration for you may be confidentiality, for example: 'If I disclose, then what will happen with this personal information?'

If disclosing to a friend or another student you may want to ensure that they understand if you want to keep information private. You will need to make a decision about trust in the relationship.

Disclosing for academic or support purposes may mean that there are confidentiality policies in the university which support your right to make decisions about what happens to personal information. You may want to find out about these policies before you decide to disclose.

Relationships

You may want to consider how disclosing may impact on your relationship with the person to whom you disclose, for example a lecturer, friend, or other student. Do you trust the person? How do you know you can trust them? What are their beliefs?

'I did not disclose lightly. I watched people over a period of time; I talked with them and got to know them. Let your conscience be your guide and follow your instinct. If you believe that someone is trustworthy then disclose' (UniAbility 2000, p19).

Benefits of disclosing

Benefits may include

- better support
- staff may feel more empathy when disclosure occurs at enrolment or when the disability occurs because this allows time to make adjustments
- adjustments can be negotiated and implemented
- if staff respond positively you may feel more confident about your studies. You may meet other people with similar experiences through disclosure
- if people you trust know more about who you are you may have better relationships with them
- making your needs known will help ensure that the university is responsive to the needs of other students with disabilities.

Advantages of disclosing a condition include

- obtaining access to services such as accommodations, adjustments to courses, facilities and services
- being better understood and accepted getting more emotional support - obtaining greater interest, care and follow-up from staff receiving appropriate actions in difficult situations from staff receiving clear rights of non-discrimination
- not being seen as a difficult student
- receiving advice on advocacy (Victoria 1998, p2).

Students who have chosen to disclose give reasons such as:

'...I want people to understand when I'm not myself...'

'...I'd rather be open...'

'...Sharing the problem relieves my anxiety...'

'...I think it's a way to help people understand mental illness...'

'...I want to pass and I see this as a fall back position...'
'...If anything goes wrong, staff need to know who to contact...'
(Victoria 1998, p2).

It is a far from perfect world, however; and colleges are in many ways microcosms of the societies of which they are part. Disclosure has not always resulted in increased understanding, nor have students always received the support to which they felt entitled. Despite the potential problems, many students still opt to disclose in order to obtain additional support' (Victoria 1998, p2).

'My biggest fear was what if I have to go to hospital? In my third year at uni I did. I was there for over two months. People I studied with would bring the lecture notes to me, and I managed to keep up with my assignments' (Queensland 1997, p6).

Disadvantages of disclosing

Some disadvantages of disclosing may be

- apprehension about there being less support
- others may feel threatened, due to ignorance and personal experience
- the burden of having to explain disability
- the fear of discrimination
- feelings of rejection
- the fear of being singled out in class
- misunderstanding by others of the disability's impact.

'Disclosure may indicate that the person is ready to talk about their illness and feel comfortable about it. If this is not the case, then it is wise not to disclose' (UniAbility 2000, p19).

Please note:

If you consider you have been discriminated against because of disclosing your disability you have the legal right to object. Please refer to

- the disability liaison officer at your institution
- the equity representative for your organisation
- the Student union
- the institution's grievance procedures
- the Equal Opportunity Commission
- the Human Rights and Equal Opportunity Commission.

So, when do you tell?

There are a number of times during your study that you are presented with an opportunity to disclose. Because each university's systems may be different, it may be useful to ask about how this information will be used.

Admission—you may be given the opportunity to disclose on forms you complete to gain acceptance into courses. This information is used only for statistical purposes. In Queensland, an opportunity may also be given to declare educational disadvantage and request special consideration. Once again this presents an opportunity to disclose a disability/medical condition and the impact it has had on previous study. It is unlawful for this information to be used to discriminate against

you, and its aim is to provide an opportunity to redress the past disadvantage you may have experienced.

Enrolment—most institutions ask students to indicate if they have a disability or medical condition. In many circumstances this information is used primarily for statistical purposes and is also the basis on which funding is provided to universities for equity programs to provide support services to you. Some universities will also use this information to write to students about the services available to them. If you want more information about how this information is stored and who has access to it, contact the disability liaison officer at your institution.

Course work—when you begin attending lectures and tutorials, and often in the statement of assessment methods or outcomes for that topic or course, an opportunity is given to talk to the topic or course coordinator about any factors of which they may need to be aware.

Assessment—at the point at which you are completing or handing in work there may be a reason to disclose your disability if you require reasonable adjustments.

‘...I wandered round for a week trying to avoid everyone because I hadn't handed in my assignment. When I saw the lecturer walking towards me I hid in the toilets. I felt a bit silly later because he had been trying to contact me to give me an extension’ (Victoria 1998, p11).

Course or topic questionnaires—often to evaluate a topic or course, a questionnaire is given or sent to students asking them to comment on the content or teaching in the topic or course. These forms may ask you to indicate whether you have a disability or medical condition.

Other times you may choose to disclose

- when you meet new people at the beginning of your study or a new course
- you may want to tell other students you meet or work with
- when you first join clubs or groups at the university
- when making new friends
- when working in groups with other students.

There are many opportunities within your study career to disclose. However it is your decision as to when is the right time, who is the right person, and how much information you need or want to tell.

‘Generally speaking I have only disclosed on a "need to know" basis, for example when I need to explain long absences, or get additional assistance, or when untrue rumours start to be passed around about why I am absent (Bathurst, L and Grove, J 2000, p5).

How do you tell?

What can you do to prepare?

- know yourself and your disability or medical condition
- identify your strengths
- identify areas you may need assistance

- plan ahead and practice what you might say
- know the resources available to you
- discuss what you will say with a disability liaison officer or counsellor
- become familiar with the equity policies and procedures of the university
- consider possible attitudes you may encounter and how to deal with them
- be prepared to deal with insensitive questions
(adapted from Queensland 1997, p4–5).

How do you tell when disclosing for academic purposes?

- be brief
- be study specific
- be assertive and enthusiastic
- be familiar with topic and course requirements
- describe the way you learn the most effectively
- discuss the reasonable adjustments you are requesting on the basis of your disability or medical condition
- describe how you overcome difficulties they may see as problems
- be prepared to deal with insensitive questions
(adapted from PSEDN 1998, p37).

What do you need to know

- what will the person do with the information you have shared with them
- if there are other things they need to know, things they need to ask you rather than to assume (and understanding that you may not want to answer more personal questions).

You may want to let the lecturers know that they can come back to you for further clarification if need be.

Where do you tell?

Bear in mind that there are good times and places to discuss these issues with staff that respect both your right to privacy and be listened to appropriately and their rights to devote a reasonable time and attention to discussing this with you. Some useful ways (depending on your preference) may be to

- visit staff at their student consulting times
- phone them
- e-mail them
- write a brief letter.

Less effective times and places might be

- after lectures with other students listening
- in the cafeteria in a corridor.

'I found it really useful when lecturers knew they could ask me about my disability and not make assumptions' (Knight 2001).

Outcomes - student experiences

'I was really amazed at how supportive the lecturers were when I finally disclosed' (Herbert 2000).

'I have decided not to disclose next year. The attitudes towards disabilities of any kind are still Stone Age and mental illness is very misunderstood. People with mental illness are seen as crazy, dangerous, nuts, stupid and the list goes on. I know that by not disclosing, a drop in the standard of my work or the need for extensions may be mistaken as laziness. If the fact that I am not going to disclose means that I will lose the support from the disabilities unit and the special exam conditions then I am just going to have to accept that' (Bathurst and Grove 2000, p3).

'Another reason why I haven't disclosed to my current coursework educator—to do well academically when you have a mental illness is a great self esteem boost' (Bathurst and Grove 2000, p6).

'Some people can be quite ignorant of mental illness and I did not want to expose myself to this ignorance. When I did disclose I was surprised at the level of support I was given' (UniAbility 2000, p20).

'...I could say nothing about my illness, but that doesn't help me, because I need some conditions in the course modified, and asking for that without disclosure is more difficult; otherwise teachers see it as privileges' (Victoria 1998, p24).

'I found it really useful to make a plan and jot down ideas before I went to disclose, that way I was much less frightened and did not get off the track' (Knight 2001).

If someone discloses to you (information for staff, friends and others)

What if someone discloses to you?

Students make disclosure so their educational needs can be addressed, so the purpose of disclosure is to assist you support them in their learning. Have a direct discussion about the student's educational needs.

'Self disclosure has always been a sensitive issue for me. I want to be open, yet not judged by others. It's a risk I take, to be or not to be accepted' (Bathurst and Grove 2000, p7).

What should you do?

- Believe the student.
- Respect that the student has told you something personal.
- Discuss confidentiality with the student, agree on what you will and won't do with the information.
- Address the educational need.
- Provide for the student so that the normal workload can be completed.
- Accept alternative methods of reporting and assessment if necessary.
- Ensure the student demonstrates the skills required for the certification granted (adapted from McCulloch 1998).
- Check whether the student knows about the disability liaison officer and is aware of that person's role.

What shouldn't you do

- Demand to see written proof.
- Talk about this personal issue to others break the confidentiality agreed between you and the student by telling others.
- Assume that the student cannot complete the course (due to their disability).

'I let all the teaching staff know of my condition. I showed them my "Headway" card and was consequently given all the help I required. People with a brain injury are usually reticent about telling others of their condition. I used to be like this but have come to realise, if you don't ask, you don't get. Anyway, what are they going to do? Sack me? All my lecturers were pleased I was making the effort and were more than willing to help (Victoria 1998, p23).

What would your response be to a student's disclosure? (adapted Mc Culloch 1998)

'Early days in the course I was asked by the lecturer (who I had told), to share my experience of the loony bin with the class for their learning. I wouldn't do it again. It made for a very lonely way through' (Bathurst, and Grove 2000, p2).

· What experience or understanding do you have of various disabilities or medical conditions—do you need to do some research?

'Disclosure involves a risk that academic staff members may not be able to cope with the knowledge, due to a lack of understanding of the illness' (UniAbility 2000, p20).

· Confidentiality—what you will do/won't do with the information.

· Where in the university could you refer the student if you felt unable to fully assist? What could you ask the student?

· Examine your own attitude/behaviour.

· What policies and procedures does the university have about students with disabilities or medical conditions.

· Who can provide you with more information about these issues.

Confidentiality

It is important to discuss what you and the student mean by confidentiality. It may be necessary to notify tutors of the arrangements you have made with the student.

In most circumstances, it is best practice to gain the permission of the student to pass the information to other staff. You may like to discuss whether the student feels comfortable with their tutors knowing about their disability or medical condition. However there may be times where this is not necessary, and all that needs to be communicated to other staff is the reasonable adjustments that need to be made.

There are a small number of situations where you may need to tell other staff. If you believe that the person may harm themselves or others it is appropriate to contact the health or counselling staff at your institution to discuss whether referral may be

appropriate. Remember also, that staff are available to discuss situations on a hypothetical basis.

Other useful resources

On campus

- Disability liaison officer
- Counsellors—self confidence and esteem, talking about yourself and your learning needs, assertive communication
- Disability Contact Officers—for the program/course/unit or schools/departments
- Discrimination advisers

Web sites

Support groups for your particular disability or medical condition see the Disability Information and Resource Centre's website <http://www.dircsa.org.au/>

NCET <http://www.tedca.org/ncet/>

Reasonable Accommodations: Strategies for Teaching University Students with Disabilities <http://www.anu.edu.au/disabilities/reaacc.html>

Towards Success in Tertiary Study series
<http://www.services.unimelb.edu.au/towardssuccess/>

- discovering your learning style
- with acquired brain injury
- with Aspergers syndrome
- with deafness
- with learning disabilities
- with ongoing medical conditions
- with psychiatric conditions
- with vision impairment.

Teaching Students with a Disability, University of Adelaide, UniAbility
<http://www.unisa.edu.au/eqo/pubs/uasheets.htm>

DRC Information booklet <http://www.deakin.edu.au/css/ss/DRC/booklet.htm>

Ozadvocacy: information dissemination and discussion list for people interested in disability rights in Australia. To subscribe send a message to listserv@maelstrom.stjohns.edu

Know your rights: Human Rights and Equal Opportunity Commission (HREOC)
http://www.hreoc.gov.au/disability_rights/index.html

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